

**May 2009**

**Self-Directed Community Aged Care for  
People with Complex Needs:  
A Literature Review**

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## Aims of the Review:

The key objective of this review is to evaluate and present research providing information as to what works, for whom, and under what conditions, in the field of self-directed aged care and to derive evidence-based recommendations for the implementation of such a program in Australia. It seeks to:

- Identify and describe evaluated SDC programs
- Appraise context
- Appraise the quality of evidence
- Identify promising innovative initiatives
- Combine a 'best available-evidence approach' including multi-method, qualitative, and quantitative studies
- Derive recommendations for practitioners and policy makers

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ISBN forthcoming

Additional copies can be downloaded from:

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Suggested Citation:

Ottmann, G., Allen, J., Feldman, P. (2009) Self-Directed Community Aged Care for People with Complex Needs: A Literature Review. UCCO/Deakin University QRN, Melbourne.



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## EXECUTIVE SUMMARY AND RECOMMENDATIONS

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This report critically reviews the literature focusing on studies of older care recipient-directed care arrangements in the United States, United Kingdom, and Australia. It highlights the importance to distinguish between **Cash-for-Care** and **Self-Directed Care** schemes. Cash-for-Care schemes typically involve the handing out of cash payments or vouchers to enable care recipients to purchase their own care instead of receiving in-kind help at home (Timonen et al., 2006 in Arksey 2008). Ideally, Self-Directed Care programs, on the other hand, are more holistic, care outcome focused and allow participants to choose among a continuum of care ranging from traditional case management approaches to cash options. Whereas the former tends to place a lot of emphasis on budgeting and regards the marketisation of care arrangements as key to more choice, the latter focuses on increasing care recipients' control over care arrangements. This may or may not involve the marketisation of care packages.

Most of the reviewed literature focuses on Cash-for-Care schemes. However, as the more recent research suggests, Cash-for-Care programs may not provide the kind of choice that resonates with the preferences of many older people. Indeed, with the exception of Cash-for-Care schemes in California and Washington, programs were primarily aimed at and designed for people with disabilities. Perhaps unsurprisingly, there tends to be a rather large gap between older people's expressed interest in Cash-for-Care projects and those actually taking up the option. For instance, whereas around 35% of surveyed older US citizens expressed interest in cash-for-care schemes, less than 10% actually enrol in such programs (Foster et al., 2005b, Mahoney et al., 2002). Yet, while some of the Individual Budgets pilots implemented in the UK allow for more choice and appear more in tune with the preferences of older people (Care Services Improvement Partnership, 2007), Self-Directed Care programs for older people have been poorly explored.

Those who do enroll in Cash-for-Care schemes tend to be generally satisfied with care outcomes. Most research indicates that Cash-for-Care programs generate either similar or

better outcomes, especially in the domains of service satisfaction and self-determination, with marginal detectable increase in risk, when compared with traditional agency-directed services. Yet, the research also indicates that positive outcomes are directly linked to appropriate user supports.

Care recipients who hire family members as carers derive extra benefit in terms of safety and service satisfaction. However, it is not clear how these arrangements influence the wellbeing of the paid family members, apart from providing extra income.

Moreover, consumer-directed care has some positive impacts for informal carers. However, it is important to point out that Cash-for-Care schemes do not automatically reduce the overall caregiver burden. Carer burden is, among other things, related to available hours of paid care assistance. Only adequate levels funding and better incentives for paid carers to enter the labour market in conjunction with other programmatic and structural changes can ensure better outcomes for care recipients and carers.

The relative expense of running a Cash-for-Care program compared with the traditional agency-directed approach, albeit dependent on a range of contextual factors, appears to be cost neutral.

## **Key Recommendations:**

Self-directed care programs should be more than simply a potential cost saving for administrations. They should to be tailored to the needs and preferences of older people and their carers.

### **1. Program Implementation:**

It is recommended that:

- Self-Directed Care programs should have a system-wide focus and address systemic, educational, and cultural concerns as well as community involvement issues. The successful implementation of Self-Directed Care hinges on:
  - Well-designed and clear policies on risk management, duty of care, and client review procedures that balance agency and worker responsibilities with the self-determination aspirations of their program and its participants;
  - Extensive and thorough staff training and organisational change management prior to implementation addressing ageism in professional culture and concerns of aged care professionals around abuse, neglect, fraud, exploitation, contractual agreements, as well as the capacity of older people; and realistic workload assessments.
- A programmatic review and continuous improvement process should be in place to improve care outcomes.

## 2. Case Management Approach:

It is recommended that:

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

## 3. Program Design:

Although older people do want to have a say over their care arrangement many do not want to take on the added responsibility and paperwork of budgeting and procuring service.

It is recommended that:

- The overall program structure is simple and comprehensive requiring a minimum of paper work.
- Eligibility criteria should include and enable older people rather than exclude them from Self-Directed Care.
  - Age and mental health status are not in themselves sufficient criteria for inclusion or exclusion from self-direction.
  - Eligibility should be regarded as a process during which program participants aided by social care professionals construct the necessary safeguards and support structures that enable them to direct their own care arrangements.
- Self-direction should not be offered during times of crisis. In recognition of their fluctuating health conditions and changing circumstances, older people:
  - Should be able to move between self-direction and full case management as needed and
  - Require shorter review cycles than those used for younger adults with disabilities.
- Older people should be able to pick and choose from a menu of service options ranging from traditional agency-led services and a Cash-for-Care option.
- Case managers should discover and explore the interests and perspectives of potential participants encouraging older people to set goals and priorities and translate them, where appropriate, into self-direction.
- Participants receive simple, clear informational aids to help them understand their program options and responsibilities and to help them develop and implement their care plan.
  - Agency staff should use applied examples when providing information. Case managers should check, not assume, that information has been understood.



- Where participants are to take over care coordination functions, or contractual and financial responsibilities, they must receive full training and support in these activities, with regular monitoring.
- Older people and especially more frail, socially isolated elders should have access to adequate safeguards. Potential risk factors for abuse, neglect, and greater levels of anxiety include:
  - The need for more paramedical help,
  - More complex needs,
  - Less stable provider relationships, and
  - Lack of support from family and friends.

An enabling risk management process may be necessary to balance client's risk and protective factors and determine appropriate social supports.

- A 'circle of support' program as well as peer and volunteer support should be considered when care recipients prefer less agency involvement.

Peer groups and volunteer programs need ongoing support and resourcing to be effective and sustainable over the longer term.

#### **4. Service Provider Context:**

It is recommended that:

- Governments and provider agencies purposefully develop and regulate care services markets to enable greater choice of providers.
- Governments and program providers need to work out incentive-based solutions to address the shortage of skilled formal carers.

#### **5. Policy Context:**

It is recommended that:

- State and Federal governments pool existing aged care packages and develop a new, comprehensive Resource Allocation System that is more responsive to the needs of care recipients and generates productivity gains by cutting unnecessary red tape.

## 6. Further Research:

It is recommended that:

- Further research is being conducted into the
  - Preferences of older people regarding self-directed care;
  - Domains of decision-making that matter most to older people seeking to retain autonomy and independence;
  - Integration of health care and, in particular, restorative approaches within an Self-Directed Care context;
  - Effectiveness of programmatic safeguards; and
  - Effects of Self-Directed Care on the mental and physical health of care recipients and carers in the medium and long term.

## INTRODUCTION

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This review provides a methodical integrative assessment of the outcomes of interventions designed to place the control over home-based aged care in the hands of users enabling them to self-direct care services. Its aim is to derive a set of evidence-based recommendations from this literature that can guide the development and implementation of self-directed care models for older people with more complex needs in Australia. It focuses on examples from settings in which community-based aged care is seen as part of social care and, as such, as part of the wider state-funded welfare system in which state agencies and/or subcontractors play an active role as service providers. The review includes studies from the United Kingdom (UK), the United States of America (US) and Australia that report on research focusing on user preferences, program implementation issues, and program outcomes. In Australia, bureaucratic institutions and the social care context have been significantly shaped by an English colonial history and, more recently, by the wholesale importation of UK and US models and approaches. Hence, studies from the UK and US were deemed particularly relevant. A wider than usual range of studies, including mixed methods, quantitative, qualitative, research-based expert opinions, and policy statement were included in order to adequately capture the contextual background of interventions.

This review excludes models of care recipient-direction that emerged within welfare frameworks that are more explicitly consumer-financed, say through social insurance schemes, or models in which state-funded social care is seen as an income supplement that can be disposed of freely, such as in Germany, Austria, and Italy. Moreover, the review excludes initiatives as they have developed in many central European countries such as the Netherlands, France, and Sweden. While self-direction is generally popular among older people in these countries (Wiener et al., 2003) the administrative, socio-political, and legislative contexts of these programs are too different to meaningfully inform the development of a model suitable for Australia.

Studies included in this review focus predominantly on Cash-for-Care schemes. Cash-for-Care schemes typically involve the handing out of cash payments or vouchers to enable care recipients to purchase their own care instead of receiving in-kind help at home (Timonen et al., 2006 in Arksey 2008). This review highlights the need to develop a more holistic approach to self direction. Self-Directed Care programs should be more holistic, care outcome focused and allow participants to choose among a continuum of care ranging from traditional case management approaches to cash options. Whereas Cash-for-Care tends to place a lot of emphasis on budgeting and regards the marketisation of care arrangements as key to more choice, Self-Directed Care focuses on increasing care recipients' control over care arrangements. This may or may not involve the marketisation of care packages.<sup>1</sup>

## Key issues guiding the review

### Evidence-Informed Social Policy

Social policies and their associated programs generally operate in dynamic environments that are inherently 'open' and are subject to a multiplicity of variables that are often difficult to control (Pawson and Tilley, 1997, Judge and Bauld, 2006). Social policies work across multiple dimensions simultaneously - physical, social, economic and political and they aim for change at different societal levels – individual, family, local community, and administrative/service systems (Kubisch et al., 1998). These contexts differ sharply between countries, states, and even municipalities. For instance, the below-featured Cash and Counseling program implemented in Arkansas, Florida, and New Jersey, although similar in intention and content, displays upon a more close examination significant dissimilarities. Factors, such as demographics, social conditions, the state of the local economy, and differences in legislation all contribute to distinct settings that influence program outcomes in their own right.

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<sup>1</sup> In the US, 'Cash for Care', 'Consumer Directed Care' and 'Self Directed Care' are often used synonymously. In this review, we reject this rather simplistic conflation of concepts that equate self direction and choice with the ideal of cash payments and the procurement of services in a de-regulated market place. Although cash payment may form part of a SDC suite of options, SDC for older people should encompass a wide range of flexible options that are not necessarily market based.

Moreover, changes in legislation and unexpected enrolment outcomes are likely to have shaped the research in each site. The causal relationships between these contextual variables are often difficult to discern and, hence, difficult to control for. More importantly still, the views of multiple stakeholders need to be assessed to capture effectiveness and appropriateness of a model for different target groups/stakeholders.

The complex and multilayered terrain of social policy models has important implications for the design of evaluation studies as well as the methodology of research reviews. Given the multiplicity of viewpoints, factors and variables intertwined in often unclear causal relationships, uni-dimensional research designs are rarely sufficient for evaluating social interventions (American Evaluation Association, 2003, Lincoln and Guba, 1989). What can be gleaned from such research is often patchy and, in isolation, fails to provide the breadth and depth of information that would allow practitioner to successfully replicate a 'model'. It is for this reason that a consensus is emerging among program evaluators endorsing a pragmatic approach to the evaluation of social programs and models of care. This means that the most feasible and causally illuminating design appropriate to the task should be chosen, on a case by case basis. Put differently, it is the research problem at hand that should determine the methodological approach, rather than a rigid set of preconceived procedures, techniques, and taxonomies. Hence in practice, custom-built mixed method designs that bring together quantitative and qualitative research in a mutually supportive fashion are the norm rather than the exception (American Educational Research Association, 2003, American Evaluation Association, 2003). Hence, in this literature review, we developed a strength of evidence table (see Table 6 in the Assessing Levels of Evidence section) that diverges somewhat from the usually adopted approach influenced by the Canadian Task Force on the Periodic Health Examination (CTF) (Canadian Task Force on the Periodic Health Examination, 1979), the United States Preventive Services Task Force (USPSTF) (Jaeschke et al., 1994), and, more recently, the Cochrane Collaboration.

The evidence table takes into account the important role that qualitative research can play. The role of qualitative research goes beyond the capturing of themes and meaning as it can strengthen the explanatory power of insights derived from quasi-experiential and experiential research by bringing to light and explaining the context, dynamics, and the various voices that are bound up with such research.

Literature reviews are fundamental to the dissemination of knowledge and the shaping of future research and professional practice. The methodology underpinning such reviews, thus, is crucial (Suri, 2000). Yet bearing in mind the above discussion, it should be easy to appreciate that the methodical review of social programs/models runs into the vestiges of the methodological problems faced by evaluators. As a result, this review includes both quantitative and qualitative studies, as proposed by experts in the field (Jensen and Allen, 1996, Sandelowski, 2004). Moreover, because some of the more interesting and relevant insights come from the literature geared towards practitioners, a literature that is based on research methods whose details are often not, or only cursory, stated we decided to include such 'grey literature' (literature that has not been published in refereed academic journals). Moreover, rather than excluding contributions that, according to taxonomies widely employed in systematic reviews (see, for instance, Campbell Collaboration, 2008) constitute 'weaker' research designs, we decided to retain all the literature that satisfied the inclusion criteria. Again, key rationale for this was the fact that many studies based on 'weaker' research designs were often more valuable in terms of explanatory power, conceptual strength, and theoretical insights they provided (see, also, American Educational Research Association, 2003). Also, in light of the methodological weaknesses of most quantitative studies included in this review, we decided that it would make little sense to calculate cumulative effect sizes.

### **The state of consumer-directed aged care literature**

The literature consists of a numerous reports and articles reporting on the outcomes of three large scale, Robert Wood Johnston Foundation and UK government-funded randomised controlled trials as well as small number of minor implementation, user preference, and

outcome studies. The gaps in this literature are enormous. Most astonishingly, studies that focus on the preferences of older people regarding the basic features of a SELF-DIRECTED CARE model are absent. One major UK study (Glendinning et al., 2008) stands out in as much as it provides a more comprehensive picture of the implementation and outcome of a SELF-DIRECTED CARE model. Most other studies are less complete and fail to supply important information that would allow practitioners to learn from and replicate the experience. Other shortcomings of the existing research literature include:

- Substantial gaps in coverage of the field.
- Lack of cohesion resulting in a fragmented field.
- Relatively few studies published in peer-reviewed journals.
- The majority of articles are based on the data of a small number of original studies.
- Insufficient consideration of contextual factors contributing to outcomes.

## METHODOLOGY

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### Scope of review & search strategy

A comprehensive, focused literature search and review was undertaken to identify and critically evaluate the available effectiveness evidence, including expert opinion and stakeholder viewpoints.

Therefore, the scope of the review included:

- Any qualitative research studies
- Systematic reviews
- Randomised control trials and quasi-experimental trials
- Any other quantitative research studies of pertinence to the focus
- Other research-based literature (e.g. expert commentaries)
- Relevant public documents such as policy papers and guidelines

### Search Terms & Databases

Search terms used in this broad search included 'consumer directed care', 'individual budgets', 'direct payments', 'flexible funding', 'self-directed care', 'self-directed support', 'self-managed care', 'self-managed support', 'user-directed care', and 'user-directed support'. Publications were retrieved through searches of the following computerised citation indexes: Medline, BioMed Central, Cinahl, Expanded Academic ASAP, PsychInfo, ProQuest, Age Line, Science Direct, Social Sciences Citation Index, Sociological Abstracts, and Web of Science. These databases customarily provide the basis of literature searches because they capture primarily refereed journal articles.

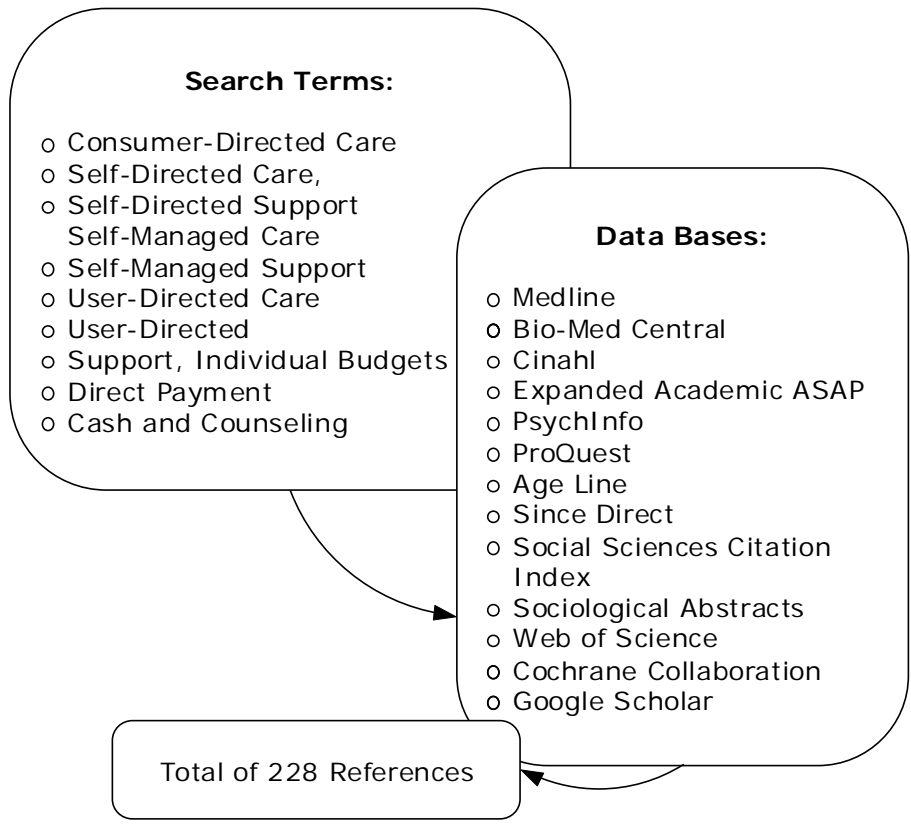


However, while conducting the search it became evident that some articles widely discussed in the literature did not show up in the search results. Therefore, it was decided to use Google Scholar in order to locate additional reports not contained within the eleven databases. Google Scholar gave us more practice-based journals that practitioners tend to publish in.

Within the context of this report, expert opinions are essentially research-based studies - contributions of practitioners who base their claims on interventions they or others conducted in the past. In this sense, expert opinions are comments that re-analyse and develop further the insights of that work.

The databases that were accessed in conjunction with the main search terms employed are given in the following Chart (Chart 1). Studies were retrieved from publication dates between January 1992 and December 2008.

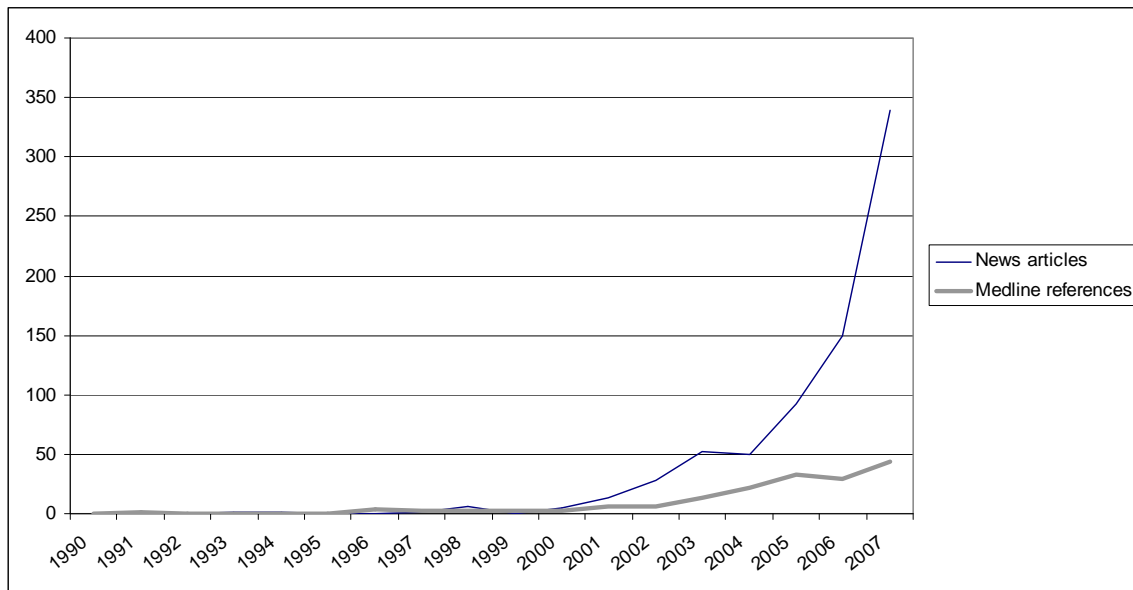
### Chart 1: Search Strategy



Additionally, practitioners and researchers were directly contacted and Google.com was searched in order to source additional grey literature. The grey literature consisted mainly of position and policy papers, guidelines, and research reports. The reference lists in retrieved publications were searched by hand for studies meeting the selection criteria in order to maximise the number of studies included in the review.

Chart 2 below tracks the acceleration of public and academic interest in consumer-directed care, beginning with single-digit annual entries in the 1990s to peaks of 339 print media items and 44 academic journal articles on the subject in 2007 alone.

**Chart 2: Frequency of news and journal articles on Consumer-Directed Care, 1990-2007**



Data source: LexisNexis Academic was used to retrieve 737 English language full-text news articles and 167 Medline references using the search term 'consumer-directed care' for the period 1990-2007.

Searches of news article regarding the less commonly used terms 'self-directed care' and 'self-managed care' displayed similar trajectories over time but of smaller magnitude. The steep spike in numbers of news articles from 2004 onwards is due also to the initiation of consumer-driven health plans in the United States, which are designed to reduce costs for insurers and employers by passing greater responsibility and risk for medical expenditure onto employees (Moriarty, 2004, Goldfarb, 2008).

### Inclusion criteria

As the focus of the current review is to describe and explore the literature in relation to self-directed care, inclusion criteria are broad ranging, aiming to maximise the selection of investigations and descriptions of models utilising varying evaluation approaches and methods (formative, summative, qualitative and quantitative).

Numerous models and programs of community care have been developed and trialled in the UK, USA and Europe where care recipients plan, direct and evaluate their own care services. Examples include the 'Cash and Counseling' programs in the USA, and 'Direct Payments' and 'Individual Budgets' in the UK. To be included, a report was required to present a model of community-based care where consumers or their families/carers were the principal agents directing support services. These 'models' differ substantially between countries, states, and even local government areas. Differences exist in the way consumers are able to make decisions regarding how their funding is to be spent and the degree to which consumers are assisted in their decision making and management of funds. Hence, this review includes a wide range of self-directed care models.

Generally, reviews of this nature nominate relevant outcome variables of interest for pooling of data and an estimation of the magnitude of the intervention effect on the relevant outcome. However in practice, models of care are embedded in varying cultural, socio-political, policy contexts. These contexts are expected to moderate outcomes and shape how models develop and how they are experienced by stakeholders. In light of this, varying outcomes and stakeholder perspectives, as captured in the literature; are presented, described and discussed within the specific context of the relevant model of care under inquiry.

The self directed care literature focuses on numerous participant groups, including children, adolescents, and adults with physical and learning disabilities (for a recent review of this literature, see for instance (Arksey and Kemp, 2008). However, as this review is focused on older people entitled to community aged care, only research based on programs for which older adults and their carers were eligible were included.

## Studies excluded from the review

Studies that did not report on the implementation of a program or intervention were excluded. In a similar manner, expert opinion pieces were only included if they were recognisably based on research and/or stakeholder consultations geared to provide insights about implementation issues. As emerged during the evaluation of the literature, numerous articles draw on the same datasets. In order to maintain the independence of data and in order not to bias the 'strength of evidence', results from one study were included only once. Most articles and to a lesser degree reports failed to provide the kind of data that would allow readers to fully appraise the method underlying the study findings. To supplement incomplete information describing research methods, the authors visited a range of sources focusing on the same original study. An initial screening process brought into focus several extremely poorly-conducted studies (examples include qualitative studies where the authors' conclusions were not substantiated by the information presented, studies with inappropriate research designs, or quantitative studies using research tools inappropriate for the research question). Studies that clearly failed the most basic requisites of rigour were excluded from the report.

## Evaluation Process

A total of 228 references were collected for a potential inclusion into this report. The references were divided into 12 preliminary categories and stored in Endnotes files. The articles were screened to further eliminate duplicates. Any adult disability sector studies with few aged participants and/or reporting on insufficient data or outcomes were removed. Three Australian disability sector studies (Fisher and Campbell-Mclean, 2008, Ottmann et al., 2008, Brown and Ringma, 1989) were excepted as although they did not include older adults in the evaluation per se, they do provide insights regarding the implementation of a self-directed care model for older people in Australia.

A total of 41 publications remained for review: they comprised qualitative and quantitative studies, mixed method evaluations, as well as review articles and expert commentaries. The authors devised evaluation protocols for different study design categories with reference to

guidelines from the McMaster University Occupational Therapy Evidence- Based Practice Research Group (Law et al., 1998) and evaluation tools developed by the University of Salford's Health Care Practice Research and Development Unit<sup>2</sup>. In essence, the evaluation appraised the appropriateness of the

- study design,
- sampling/enrolment procedures, and
- tools and interview questions.

Moreover, evaluators verified that the research proposal underwent an ethics approval process and, if conclusions were justified and integrated in the wider research field. Finally, evaluators included conceptual innovation and strength as a category. The reviewers thought it useful to include this category to highlight studies that make a significant and/or innovative contribution to the field. As mentioned above, rather than producing an aggregate score denoting methodological 'rigour', the authors decided to present the appraisal outcomes in a tabular format (see Table 1 over page) allowing readers to gain a better understanding of the robustness of a particular study.

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<sup>2</sup>Available at: (<http://www.fhsc.salford.ac.uk/hcprdu/tools.htm>).

Table 1: Strengths and weaknesses in the literature

Authors/Year/ Study type	Study Design			Sample/Participants		Evaluation Tools		Ethics	Conclusions			
	Answers fit eval. Questions	Mixed methods are mutually supportive	Use of triangulation	Selection/ recruitment method reported?	Appropriate in relation to claims	Appropriate in content?	Reports how they were developed		Approval Reported?	Justified by the data/ findings	Integrated with the literature	Provide recommen- dations for practice
<b>USA Cash &amp; Counseling</b>												
Carlson et al. (2007) Q1	+	N/A	N/A	+	+	-	-	-	+	+	+	+
Foster et al. (2005) Q1	+	N/A	N/A	+	+	+	-	-	+	+	+	
Mahoney et al. (2002) Q1	+	N/A	N/A	+	+	+	-	-	+	+	+	+
Mathematica Policy Research Inc (2003) Q1	+	N/A	N/A	+	+	-	-	-	+	-	+	+
San Antonio, Eckert & Simon-Rusinowitz (2006) Q1	+	N/A	-	+	+	-	-	+	+	+	+	+
Schore, Foster & Phillips (2007) MM	+	+	N/A	+	+	+	-	-	+	+	+	-
Sciegaj, Capitman & Kyriacou (2004) Q1	+	N/A	N/A	+	+	+	-	-	-	+	+	-

Shen et al. (2008) Q1	+	N/A	N/A	+	+	-	-	-	+	+	+	-
Simon-Rusinowitz et al. (2000) Q2	+	NA	-	+	+	+	-	-	+	+	+	+
Simon-Rusinowitz et al. (2005) Q2	+	N/A	-	+	+	-	+	-	+	-	+	-
USA CD-PAS												
Beatty et al. (1998) Q1	+	NA	NA	+	+	+	-	-	+	+	+	+
Benjamin & Matthias (2001) Q1	+	NA	NA	+	+	+	+	-	+	+	+	+
Benjamin & Matthias (2004) Q1	+	NA	NA	+	+	+	+	-	+	+	+	+
Benjamin, Matthias & Franke (2000) Q1	+	NA	NA	+	+	+	+	-	+	+	+	+
Doty, Kasper & Litvak (1996) Q1	+	NA	NA	+	+	+	-	-	+	+	+	+
Feinberg & Whitlatch (1998) Q1	+	NA	NA	+	+	+	+	-	+	+	+	+
Grossman et al. (2007) Q2	+	NA	+	+	-	+	-	-	+	+	-	-
Hagglund et al. (2004) Q1	+	NA	NA	+	+	+	+	-	+	+	+	+
Keigher (2000) Q2	+	+	+	+	+	+	-	-	+	+	+	+



<b>Matthias &amp; Benjamin (2003) Q1</b>	+	NA	NA	+	+	+	+	-	+	+	+	+
<b>Meng et al. (2005; 2006) Q1</b>	-	N/A	N/A	+	+	+	-	-	-	+	+	-
<b>Micco et al. (1995) Q1</b>	+	NA	NA	+	+	-	-	-	+	+	+	-
<b>Young &amp; Sikma (2003) Q2</b>	+	+	+	+	+	+	-	-	+	+	+	+
<b>Wiener et al. (2007) Q1</b>	+	NA	NA	+	-	+	+	-	+	+	+	+
<b>UK literature</b>												
<b>Arksey, Glendinning et al. (2009) MM</b>	+	+	+	+	+	+	+	-	+	+	+	+
<b>Baxter, Glendinning et al. (2008) Q1, Q2</b>	+	+	+	+	+	+	-	-	+	+	+	+
<b>Carmichael &amp; Brown (2002) R</b>	-			-			-	-		+	+	-
<b>Davey, Fernandez et al. (2007) Q1</b>	-		n/a	+	+	+	+	-		+	+	-
<b>Nicholls, DH &amp; CSIP (2007) Q2</b>	+	+	+	+	+		-	-	+	-	+	++
<b>Glendinning &amp; Halliwell (2000) MM</b>	+	+		+	+		-	+	+	+	+	+
<b>Glendinning Challis et al. (2008) MM</b>	+	+	+	+	+	+	+	-	+	+	+	+

Henwood & Hudson (2007) R				-	-						+	+
Poll, Duffy et al. (2006) Q1	+	n/a	n/a	-	-		-	-		-	+	-
Priestly et al. (2007) Q2	+	+		-	+	+	-	-	+	+	+	+
Riddell, Priestley et al. (2006) MM	+	+	+	+	+		-	+	+	+	+	+
Spandler (2004) R	+	+	+						+	+	+	+
Stainton & Boyce (2004) MM	-	-	+	+	+			-	+	+	-	-
<b>Australia</b>												
Fisher & Campbell-McLean (2007) MM	+	+	+	-	-	-	+	-	-	+	+	-
Ottmann et al (2008) Q2	+	n/a	+	-	+	+	-	-	-	+	+	+
Spall et al. (2005) Q2	-			+	+			-	+	+	+	+

## INTEGRATING THE LITERATURE

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The following section provides a critical overview over the reviewed literature. It briefly outlines the historical emergence of self directed care programs in each country, critically reflects on the quality and robustness of the methodology employed, and highlights the insights and implications that can be derived from the research. A quick reference summary table of the literature reviewed in this section has been added as an appendix.

### Consumer-directed care in the United States

#### Overview

The course of consumer-directed home care in the United States has been shaped substantially by the consumer rights movements and by the conservative ideological and fiscal concerns that underpinned US politics for much of the last two decades. Although social movements demanding greater self-determination for people with disabilities emerged as early as the 1970s (Eustis, 2000),<sup>3</sup> it was not until the late 1990s that those interests coincided with the interests of governments and health insurers creating the preconditions for a more systematic integration of consumer direction into mainstream welfare and social care.<sup>4</sup> The legislative foundation for Consumer-Directed Care (CDC) programs was laid in 1981 when Federal legislation was altered so that states were able to use Medicaid funds – the largest source of institutional non-medical care funds – for home and community-based care as an alternative to institutional care.<sup>5</sup> Though the original aim of this legislation was to support non-institutional care for people with disabilities, the Home and Community Based Service (HCBS) Waiver program provides the financial

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<sup>3</sup> In the US, the self-advocacy movement arose from grassroots political activity promoting independent living for people living with developmental disabilities (Young and Sikma, 2003, National Council on Disability, 2004). Self-advocacy was more formally organised in the early 1970s with the establishment of groups such as the 'Center for Independent Living' in Berkeley in 1972 and 'People first of Oregon' in 1973 (National Council on Disability, 2004, Bradley et al., 2001). Increasingly, these groups focused on influencing policy and changing the way services are directed and delivered. Consumer rights and control over how public health dollars are spent on their care is at the heart of the self-advocacy movement underpinning consumer directed care programs such as Cash and Counseling.

<sup>4</sup> Consumer-directed care made it possible to direct spending away from expensive medically skilled personnel (funded by Medicare) towards a cheaper social care system, supported by Medicaid (Benjamin et al., 2000).

<sup>5</sup> It is important to bear in mind that Medicaid funding in the US is means tested, providing a safety net for a lower socio-economic stratum with limited access to private health insurance.

underpinning for the majority of Consumer-Directed Care programs to date (Crisp et al., 2009).<sup>6</sup> More recently, the US Federal *Deficit Reduction Act* of 2005 established the legislative framework for states to offer Medicaid participants broad authority over the self-direction of services.

## Cash and Counseling Demonstration Programs

The Cash and Counseling Demonstration programs were funded in the late 1990s by the US government and by the Robert Wood Johnson Foundation.<sup>7</sup> Three US states took part: Arkansas, New Jersey and Florida. In these programs, consumers could cash out their personal assistance services benefit as funded within the Medicaid State plan (personal care services or Medicaid waiver program), to pay for disability related services and equipment to meet their self-identified care needs. All three Cash and Counseling programs were designed to provide counselling assistance to support decision making, planning and fund management (Robert Wood Johnson Foundation, 2006). These three state based demonstration programs targeted a broad range of people living with disabilities requiring long term community care including children with developmental disabilities and their families, adults with physical disabilities and elderly people requiring supportive assistance with daily living activities. The demonstration programs, designed to be cost neutral, were implemented over a five year period with evaluation data captured at baseline and 9-10 month follow-up (Foster et al., 2005a, Brown et al., 2007)

### Program description

Based on the earlier experiences of the Self-Determination Initiatives,<sup>8</sup> The Cash and Counseling demonstration programs aimed to further operationalise consumer-directed services where consumers could decide on their own care needs and how to spend their allowance to meet their self-determined care requirements. Each state program required

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<sup>6</sup> The HCBS waiver spawned numerous smaller projects run by state- or county-based agencies that aimed to expand their existing consumer directed programs or to create new ones. A national audit of consumer-directed HCBS programs reported that 23% of the 139 programs in existence in 2002 were created during the 1980s, and a further 11% had existed prior to 1980 (Doty and Flanagan, 2002).

<sup>7</sup> The Robert Wood Johnson Foundation is the United States' largest philanthropic organisation devoted exclusively to improving the health and health care of people living in that country.

<sup>8</sup> The Self-Determination Initiatives (SDI) funded by the Robert Wood Johnson Foundation in the mid 1990s (Bradley et al., 2001) were initially funded in 19 US states. The programs emphasised choice and self-determination for people living with developmental disabilities in the community.

consumers to provide a written spending plan specifying personal care services and goods to be purchased (Brown et al., 2007). Goods and services related to the person's disability could be purchased in relation to: transport, insurance, varying household appliances and home modification (consumers could elect to save portions of their allowance for more expensive items/projects). Although Consumer-Directed Care had developed from the self-advocacy movement for people living with developmental disabilities, the Cash and Counseling programs also offered consumer direction to community dwelling elders requiring care (Brown et al., 2007).

There were significant variations between the three Cash and Counseling programs (National Council on Disability, 2004, Robert Wood Johnson Foundation, 2006, Foster et al., 2005a, Brown et al., 2007). **The Arkansas program** (Independent Choices) began implementation in 1998 and targeted adults and older adults. People who were eligible for funded care and those already receiving funded care were eligible (Foster et al., 2005a). Additionally, in Arkansas people were eligible for Cash and Counseling when they were also receiving assistance from one of two other initiatives – Elder Choices<sup>9</sup> and Alternatives<sup>10</sup> (Foster et al., 2005a; Brown et al., 2007). In the Arkansas Cash and Counseling demonstration, personal care services, housework, meal preparation, equipment and supplies could be purchased from the allowance. Consumers could hire family members or friends to undertake personal care however they could not hire legally responsible relatives or representatives (e.g. spouses or parents). The median monthly prospective allowance in Independent Choices was US\$313 per person (Robert Wood Johnson Foundation, 2006).

The Cash and Counseling program undertaken in **New Jersey** (Personal Preference Program) was implemented from 1999 onward and only targeted adults and older adults who were already enrolled in the state Medicaid funded personal care program (Foster et al., 2005a). Personal care was included in the allowance. People participating in this program could not participate in other state funded consumer directed programs (Brown et al., 2007). New Jersey Cash and Counseling consumers could not hire legal representatives but could hire

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<sup>9</sup> A nurse supervised home care for elders qualifying for placement in a nursing home. 62% of elderly Cash and Counseling demonstration enrolees participated in this program.

<sup>10</sup> An attendant care services for non elderly adults allowing consumer choice and supervision of paid carers. Nine percent of non elderly Cash and Counseling enrolees participated in this program.

other family members or friends. The median monthly prospective allowance was US\$1,097 per person (Robert Wood Johnson Foundation, 2006).

**The Florida program** (Consumer Directed Care) was implemented in 2000 and targeted children living with developmental disabilities and their families, and adults and older adults. Only people who were already receiving services under HCBS could participate (Robert Wood Johnson Foundation, 2006; Foster et al., 2005a). All HCBS services could be purchased with the exception of case management services (Brown et al., 2007). Behavioural therapy and personal care supplies could also be purchased. There were no restrictions on hiring. The median monthly prospective allowance was US\$829 per adult and US\$831 per child (Robert Wood Johnson Foundation, 2006). These variations in key program areas (summarised in Table 2) clearly limit meaningful comparisons between states.

Table 2: Differences between states

State	Year of implementation	Target group	Eligibility criteria	Median monthly prospective allowance (per person)
Arkansas	1998	Adults, older adults 65+	<ul style="list-style-type: none"> <li>• Those eligible for and already receiving publically funded personal care</li> <li>• Those participating in other community-based initiatives</li> </ul>	US\$313
New Jersey	1999	Adults, older adults 65+	<ul style="list-style-type: none"> <li>• Only those already receiving publically funded personal care</li> </ul>	US\$1,097
Florida	2000	Children with developmental disability, adults, older adults 60+	<ul style="list-style-type: none"> <li>• Only those already receiving publically funded personal care</li> </ul>	US\$829 (US\$831 per child)

Source Robert Wood Johnson Foundation (2006), Brown et al. (2007)

### The evaluation approach

Reports and studies of the Cash and Counseling schemes in the three states draw predominantly on one major evaluation. This evaluation was funded by the Robert Wood Johnson Foundation and US government and was undertaken by Mathematica Policy

Research Inc and the University of Maryland Center on Aging (Foster et al., 2005a, Simon-Rusinowitz et al., 2005). In addition a handful of minor background studies were conducted mainly by Mathematica affiliated staff.

### Selection and recruitment

Evaluation enrolment sample size targets were initially set for 3,100 adults in Arkansas and New Jersey and 4,650 adults and children (including 1,550 children) in Florida ( Brown & Dale, 2007; Foster et al., 2005a). The Mathematica team note that due to enrolment difficulties the period of enrolment was extended and the initial sample size targets were reduced to 2,000 adults in each state and 1,000 children in Florida (Foster et al., 2005a). Each state did eventually come close to its revised target enrolment as presented in Table 3.

Table 3: Cash and Counseling enrolments

State	Enrolment Duration in months	Total participant sample size	Age Cohort n (%*)		
			Children under 18 yrs	Adults	Elderly+
Arkansas	29	2,008	-	556 (27.8)	1,452 (72.3)
New Jersey	33	1,755	-	817 (46.4)	938 (53.7)
Florida	26 (adults) 15 (children)	1,818 (adults) 1,002 (children)	1,002 (35.6)	914 (32.2)	904 (32.1)

+65 years and over in Arkansas and New Jersey, and 60 years and over in Florida

\*Percentages are calculated from the total participant sample size for the particular state

Source Foster et al. (2005a); Schore et al (2007); Brown and Dale (2007)

According to the Mathematica team, key barriers to recruitment included resistance to the demonstration projects by some service providers, gate-keeping and other discriminatory practices, limited time available for service providers to recruit people, and language barriers (Foster et al. 2005a; Schore, et al., 2007; Brown et al., 2007). Available recruitment/enrolment information suggests that not all eligible people may have been invited to participate and that some people may not have been invited due to service provider beliefs that they would not be able to manage if allocated to a Cash and Counseling model.

Some attempts were made to overcome these barriers, for example some bilingual recruiters assisted with enrolments in New Jersey and Florida (Foster et al., 2005a). Moreover, the employment of dedicated recruiters later during the enrolment period was perhaps the main strategy used to counteract gate-keeping (Foster et al., 2005a).

Actual enrolment numbers remained significantly below 10%. Table 4 presents the number of known eligible people who agreed to participate in Cash and Counseling programs. The table suggests that people who agreed to participate in the demonstrations constituted a relatively small, self-selected group.

Table 4: Number of known eligible people and percentages\* of participants

State	Number of known eligible participants	Overall %	Age Cohort %		
			Children under 18 yrs	Adults	Elderly+
Arkansas	21,891	7.8	-	8.4	7.6
New Jersey	24,736	6.3	-	8.1	5.3
Florida	34,119	8.2	16.0	5.6	7.6

+65 years and over in Arkansas and New Jersey, and 60 years and over in Florida

\*Percentages are calculated from the number of known eligible participants for each state

Source Foster et al (2005a)

### Participation and preference surveys

One Participation Survey (Foster et al., 2005a) and several other preference studies employing focus groups and a telephone survey (Simon-Rusinowitz et al., 2005, Mahoney et al., 2002) and a survey with older adults from varying racial and ethnic backgrounds (Sciegaj et al., 2004) were undertaken. The Participation Survey (Foster et al., 2005a) and the focus groups and phone survey (Simon-Rusinowitz et al., 2005; Mahoney et al., 2002) are reported as part of the evaluation of Cash and Counseling demonstration programs and aim to ascertain the appeal of self-directed care. The survey by Sciegaj et al. (2004) evaluated peoples' preferences for Cash and Counseling from different racial groups in the city of Boston.



The Participation Survey (Foster et al., 2005a) assessed demographic and cost differences, ascertained from Medicaid enrolment and claim data, for those people invited to undertake the Cash and Counseling programs including those agreeing to participate and those who declined (non participants). This survey further aimed to identify peoples' reasons for either choosing to participate in Cash and Counseling or declining participation. Across the three states, older adults with higher personal care costs (>US\$300.00) and those already using personal care services when enrolment began were more likely to participate (Foster et al., 2005a). People who were less likely to participate included those in their last year or two of life. Predictors of participation were also identified within each state. In Arkansas, people living in metropolitan areas were more likely to participate (Foster et al., 2005a). Age was the strongest predictor of participation in New Jersey where younger adults (aged 18-39) were more likely to participate than the elderly.

Reasons for participation or not in self-directed care such as the Cash and Counseling programs were further appraised by an anonymous survey in each state. Survey collection methods and procedures varied significantly (Foster et al., 2005a) and may have influenced findings. Response rates for those agreeing to participate in this survey were 47% in Arkansas, 67% in Florida, and 54% in New Jersey (Foster et al., 2005a). Response rates for those declining to participate in the anonymous survey are not known as the numbers of people invited to participate overall were not collected (Brown and Dale, 2007). In the three states the four most common reasons for agreeing to take part in one of the Cash and Counseling demonstration were:

- Greater control over hiring,
- Payment for family or friends,
- Care provision at more convenient times, and
- Better or more care.

People who declined to take part in the demonstrations provided the following two main reasons for their decision:

- Satisfaction with current care and
- Concern that the cash allowance would not meet their care needs.

Importantly, in this sample elderly adults were much more likely to nominate these two reasons for declining to take part in the Cash and Counseling demonstrations than younger adults (Foster et al., 2005a).

Results indicate that in these self-selected convenience samples, people with larger budgets, and those already using personal care services were more likely to want to exert greater control over their care arrangements (Foster et al., 2005a). Findings further suggest that people experiencing some dissatisfaction with existing services were more interested in the Cash and Counseling schemes.

The background study, including focus groups and a telephone survey, undertaken by the University of Maryland in preparation for the Cash and Counseling demonstration programs also aimed to ascertain people's preferences for consumer directed care to guide program planning (Simon-Rusinowitz et al., 2005; Mahoney et al., 2002). Findings report on information collected in 1996 and 1997 from two sets of focus groups; one comprising 11 groups with 96 people receiving personal care services in Westchester County, New York city, and Florida, and the other undertaken in Florida, New York, New Jersey and Arkansas with 16 groups of 120 participants (Simon-Rusinowitz et al., 2005). The study identified that some participants, including adults and older adults, would like increased control over care services. Additionally, the study brought to light a degree of scepticism regarding the proposed cash option. Older adults were generally more satisfied with existing personal assistant services than younger adults and they were less interested in the cash option (Simon-Rusinowitz et al., 2005).

Results from the phone survey are reported by Mahoney et al. (2002). Although the initial sample of 3,207 people receiving personal care services in New Jersey in 1996 were randomly selected, 62% declined to participate. Non participants were less likely to speak English, have less money spent on their services and they were significantly more likely to be older adults (Mahoney et al., 2002). The resulting self-selected sample included 683 people mainly younger female (75%) adults from lower socio-economic backgrounds and lower educational attainment (46% had less than high school education). Those people more likely to want Consumer-Directed Care in this sample expressed a greater wish to be

more involved in decisions regarding their own care, willingness to undertake 'employer' type tasks and dissatisfaction with current personal care services (Mahoney et al., 2002). Around one third of older consumers expressed interest in the cash option (Mahoney et al., 2002).

Sciegaj et al. (2004) aimed to assess the effects of race and ethnicity on elderly consumers' preferences for self directed care options including the Cash and Counseling program. The convenience sample of American elders receiving Medicaid funded personal assistance services included 200 African American, 200 Chinese American, 131 Latino American and 200 European Americans. In this survey study, 71% of participants selected traditional case management over consumer directed and negotiated care and no clear patterns of preferences for increased control over services emerged among different racial and ethnic groups.

In summary, older adults in these samples expressed a wide range of preferences. Some indicated a preference for greater participation in their care and related decisions (Foster et al., 2005a; Simon-Rusinowitz et al., 2005; Mahoney et al., 2002), while others expressed satisfaction with their existing agency directed services (Foster et al., 2005a; Simon-Rusinowitz et al., 2005; Mahoney et al., 2002; Sciegaj et al., 2004). Age variations appear to be an important determinant of interest in Cash for Care schemes. Yet older people may be more interested when good support and training are provided to deal with administrative and accounting tasks (Simon-Rusinowitz et al., 2005). Finally, program information may need to be in a straightforward language taking into account the educational background of potential consumers (Mahoney et al., 2002). In other words, these studies (Foster et al., 2005a; Simon-Rusinowitz et al., 2005; Mahoney et al., 2002; Sciegaj et al., 2004) suggest that consumer-directed community aged care programs should offer a broad range of flexible options. Furthermore, they suggest that older adults may require different approaches to involve them in the decision making process. Yet research that could inform such approaches is woefully scarce.

To be sure, there are a number of considerations to take into account when interpreting the above findings (Foster et al., 2005a; Simon-Rusinowitz et al., 2005; Mahoney et al., 2002;

Sciegaj et al., 2004). Besides issues of representativeness of the sample readers have to consider methodological issues. Most importantly, participants in each study (Foster et al., 2005a; Simon-Rusinowitz et al., 2005; Mahoney et al., 2002; Sciegaj et al., 2004) were asked to consider Cash and Counseling hypothetically. They did not actually experience the program for themselves. Moreover, detailed methodological information that would allow readers to draw conclusions regarding the robustness of the studies' findings is not provided. Future research has to shed light on the explanatory power of these publications.

### Implementation and outcomes

According to the Mathematica evaluators (Brown et al., 2007; Brown and Dale, 2007), an intention to treat approach was initially chosen (but not consequently followed) allocating all people randomly to treatment or control groups irrespective of whether they actually received their cash allowance or whether they were included in the evaluation. This approach was chosen to maintain the effects of randomisation and minimise bias.<sup>11</sup> Table 5 presents frequency data regarding the number of people initially recruited, allocated to treatment and control groups, who received the allowance (treatment group) and who completed 9 month follow-up measures. The table visualises the dwindling of numbers during each consecutive research phase.

Of the older people initially enrolled in the treatment group a large percentage (58% in Florida, 11% in Arkansas) failed to receive their monthly allowance during the first year (Brown et al., 2007). In fact, across all three states older adults were less likely to receive the monthly allowance than younger adults. The Mathematica team list the following implementation difficulties to account for this fact (Brown et al., 2007):

- Complex enrolment processing process in New Jersey discouraged ongoing participation.
- Service provider resistance to Cash and Counseling in Florida resulted in elderly consumers who were allocated to the treatment group continuing to receive agency-directed care.

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<sup>11</sup> Use of intention to treat approaches are strongly recommended in randomised trials to avoid the introduction of bias that may accompany development of potentially non-random subsets when some people 'drop out' of the trial and do not complete follow-up assessments (Lachin, 2000).

- Consumers with difficulty budgeting and undertaking paperwork were less likely to receive their allowance (Brown et al., 2007).

According to Brown et al. (2007), between 20 to 50% of people who were allocated to the Cash and Counseling groups across the three states unenrolled in the first year for the following reasons:

- Loss of a representative
- Loss of eligibility for PCS including death and entering a nursing home
- Failure to receive the allowance
- Satisfaction with agency-directed care
- Difficulty with employer responsibilities
- Difficulty hiring a worker.

Most consumer participants spent their allowance on personal assistants with many hiring family members to undertake these tasks for them. Brown et al. (2007) concluded that hiring relatives was pivotal to program success and there was no evidence of poorer health outcomes, neglect of consumers, fraudulent use of funds or abuse of workers in people allocated to the Cash and Counseling models.

Respondents' unmet needs and satisfaction with service were appraised in the nine month follow-up survey comparing treatment and control groups. Numerous single item measures capturing unmet needs for help, and satisfaction with caregiver reliability, paid caregiver behaviour, and assistance received, were analysed using multivariate statistical procedures to control for differences in demographic factors appraised at baseline between treatment and control groups. Across the three states and different age groups the treatment group ratings on many of these indicators were significantly better than for the control group. Respondents in Florida were the exception. The greater data concordance between treatment and control groups in the elderly cohort in Florida is explained by the Mathematica team as being due to the low numbers of people who actually received the monthly allowance in this state (Brown et al., 2007). Importantly in these samples,

respondents in the treatment group were significantly more satisfied with the way they were spending their lives than those respondents allocated to agency-directed care.

As is to be expected with a social intervention on this scale, the researchers had to make numerous pragmatic decisions that undermined the methodological rigour of their study.

Table 5: Frequency data for the Cash and Counseling demonstrations (N=6583)

	<b>Initially recruited/completed baseline interviews n (%)</b>	<b>Allocated to treatment group n (%)</b>	<b>Allocated to control group n (%)</b>	<b>Treatment group who completed 9 month follow up measures n (%)</b>	<b>Control group who completed 9 month follow up measures n (%)</b>	<b>Treatment group who received allowance at any time over first 12 months of enrolment n (%)</b>
<b>Arkansas (n=2,008)</b>						
Age Cohort n(%)						
Adults	556 (27.8*)	279 (50.2 <sup>#</sup> )	277 (49.8 <sup>#</sup> )	243 (87.1 <sup>^</sup> )	230 (83.0 <sup>^</sup> )	248 (88.8 <sup>^</sup> )
Elderly+	1,452 (72.3*)	725 (49.9 <sup>#</sup> )	727 (50.1 <sup>#</sup> )	642 (88.6 <sup>^</sup> )	624 (85.8 <sup>^</sup> )	592 (81.7 <sup>^</sup> )
<b>New Jersey (n=1,755)</b>						
Age Cohort n(%)						
Adults	817 (46.4*)	404 (49.5 <sup>#</sup> )	413 (50.5 <sup>#</sup> )	345 (85.4 <sup>^</sup> )	337 (81.6 <sup>^</sup> )	272 (67.2 <sup>^</sup> )
Elderly+	938 (53.7*)	467 (49.8 <sup>#</sup> )	471 (50.2 <sup>#</sup> )	402 (86.1 <sup>^</sup> )	381 (80.9 <sup>^</sup> )	299 (64.1 <sup>^</sup> )
<b>Florida (n=1,818 adults, n=1,002 children)</b>						
Children	1,002 (35.6*)	501(50.0 <sup>#</sup> )	501(50.0 <sup>#</sup> )	441 (88.0 <sup>^</sup> )	418 (83.4 <sup>^</sup> )	356 (71.1 <sup>^</sup> )
Adults	914 (32.2*)	456 (49.8 <sup>#</sup> )	458 (50.2 <sup>#</sup> )	419 (91.9 <sup>^</sup> )	392 (85.6 <sup>^</sup> )	262 (57.5 <sup>^</sup> )
Elderly+	904 (32.1*)	453 (50.1 <sup>#</sup> )	451 (49.9 <sup>#</sup> )	373 (82.3 <sup>^</sup> )	363 (80.5 <sup>^</sup> )	189 (41.7 <sup>^</sup> )

+65 years and over in Arkansas and New Jersey, and 60 years and over in Florida

\*Percentages are calculated from the total number of known eligible participants for each state see Table 3

<sup>#</sup>Percentages are calculated from those who were initially recruited/completed baseline interviews for the relevant age group

<sup>^</sup> Percentages are calculated from those allocated to the relevant treatment or control group

Source Brown et al. (2007)

### Effects on informal caregivers

The Cash and Counseling evaluation also captured effects on primary informal caregivers. A phone survey with caregivers was undertaken approximately 10 months following the baseline interview with consumers (Arkansas n=1,433 adults; Florida n=1,193 adults, n=829 children; New Jersey n=1,042 adults). Almost all responding caregiver were relatives. The evaluators note that as results were consistent across caregiver respondents for adults and older adults (Brown et al., 2007).

In the treatment and control groups, caregivers provided more than 100 hours of care over a two week reference period (approximately 7 hours per day). Live-in caregivers reported twice as many hours as visiting caregivers (Brown et al., 2007). Hours of care provision did not differ significantly between intervention and comparator groups with the exception of Arkansas where the treatment group live-in caregivers provided significantly fewer hours of care (Foster et al., 2005b).

Indicators of satisfaction with care were however, significantly higher for caregivers in the Cash and Counseling stream and indicators of dissatisfaction with care were significantly higher for caregivers in agency-directed care models (Brown et al., 2007). Other outcome measures related to caregiver burden were also lower for those respondents in the treatment group. Experiences of physical strain related to caregiving and perceptions that physical health had deteriorated due to caregiving were each significantly greater for carers in the agency directed care stream (Brown et al., 2007). Importantly, caregivers in the treatment group reported significantly greater satisfaction with their lives overall. Additionally, Brown et al. (2007) note that caregivers who were not themselves hired to provide care had similar outcomes to those caregivers who were hired.

### Summary and implications of findings

The above-mentioned evaluations spell out a range of important findings for practitioners as well as for policy makers. While a significant proportion of older people would like more control over their care arrangements, only relatively few older adults wish to become involved in a Cash for Care scheme. It is not unreasonable to suggest that this low take up might be related to the fact that Cash and Counseling programs were developed for/with



people with disabilities and their families. Indeed, older people had very little say regarding program design. Thus, it is reasonable to suggest that Cash for Care should be one among a number of options for older adults to choose from. Moreover, as older adults' wishes, health and functioning may change over time care options should be flexible enabling people to change their arrangements. Older adults may require different support from younger adults in relation to undertaking employer type activities (e.g. hiring personal care staff) and related accounting tasks.

Overall, involvement in the Cash and Counseling models appears to be associated with greater satisfaction with service received, reduced unmet need, and greater satisfaction with life in general. Generally positive outcomes and a reduction in carer burden are also recorded for informal caregivers enrolled in a Cash and Counseling program. As the Cash and Counseling demonstration evaluations did not capture quality of life or health outcomes in detail or appraise outcomes over longer periods of time, additional research is required to explore these domains. Additional research is also required in relation to quality of life and other health related outcomes using valid and reliable tools to improve understanding of the effects of self directed care similar to Cash and Counseling for both consumers and informal caregivers.

## **Other North American programs:**

### **Consumer-directed Personal Assistance Services**

A number of localised consumer-directed home care programs in states such as California, Colorado, Michigan, Oregon, Virginia, Washington and Wisconsin (Heumann, 2003, Wiener et al., 2007) pre-date the national *Cash and Counseling* initiative. These programs are funded for the most part by Medicaid and topped up with state or county funds. Collectively these programs are often referred to in the literature as Consumer-Directed Personal Assistance Services (CD-PAS) programs.

### **Background studies and commentaries**

The decision-making processes that Consumer Directed Care demands of consumers and the 'decision supports' that enable informed decision-making, are discussed by Hibbard et

al. (2003) in the broader context of consumer-directed health plans in the private/public healthcare market. The authors posit that consumer-directed planning assumes that consumers are:

- able to identify their interests;
- completely informed about the possible courses of action and their consequences;
- sensitive to differences among alternatives; and
- able to make decisions that maximize their interests (Hibbard et al. 2003:2).

Drawing on the literature around decision-making, Hibbard et al. note that people tend to underestimate personal risk; have difficulty separating relevant from irrelevant information; and take 'short-cuts' by simply ignoring the bulk of information when the quantity is overwhelming. People tend to use instead just one or two factors to make their decisions. The authors proposed three strategies to equip consumers better in making decisions about their care management:

- Reduce the 'cognitive load' on consumers by sorting and consolidating diverse data into simple information displays with strong visual cues.
- Help consumers understand the meaning of choice and the implications of their choices by providing stories of other people's experiences.
- Highlight important information so it is not overlooked.

Keigher (2000) examined the differential interests of three types of stakeholders: aged care consumers, their independently hired workers, and their family caregivers. From interviews with 40 disabled elders and their workers (41 unrelated workers and 18 paid family carers) Keigher found that consumers primarily wanted to maintain their lives and habitual activities as far as possible. Family caregivers wanted to know that their relatives would be safe, thereby relieving themselves from 'destabilizing anxiety'. Care workers – many of them getting older and in poor physical health themselves – wanted to provide good care and sought the conditions where that would be possible. Hence care workers valued reliable and honest clients and family members, who were committed to their clients' wellbeing. The

author concludes with a warning that government cost-cutting through the privatisation of community care has the potential to erode workers' pay and conditions, and consequently care quality (Keigher, 2000).

This theme also appeared in a survey canvassing the attitudes of policy experts towards proposed Cash and Counseling programs (Simon-Rusinowitz et al., 2000). Alongside concerns over declining working conditions for formal carers, experts expressed fears regarding fraud, consumer exploitation, and potential incompatibilities of consumer-directed services with case management directed care, in part due to resistance from traditional agency providers.

### **Implementation studies**

Micco et al. (1995) surveyed case managers during the early phase of consumer-directed program implementation in British Columbia, Canada. As well as voicing concerns similar to those of the policy experts cited above, the case managers were far from convinced that their workloads would diminish as a result of consumer-directed care: in fact many believed that client contacts around financial issues would increase their total job demands. The strong antipathy for CDC among respondents led the authors to recommend that case managers should be included and consulted early on in the program planning and implementation phases; and that sufficient and necessary program documentation be completed before implementation (Micco et al., 1995).

### **Outcomes studies**

Studies of CD-PAS programs generally employ subjective ratings scales and additional self-reported measures to compare the experiences of consumers directing their own care with those of consumers using agency-based services. All of the outcomes studies that follow reported some positive benefits for consumers who were directing their own care, with the worst outcomes being no significant differences between outcomes for CD-PAS users and for those receiving agency-based services.

### **California's In-Home Supportive Services (IHSS)**

At the time of data collection in 1996/97, California's In-Home Supportive Services (IHSS) program used mostly Medicaid funding to provide assistance to 190,000 low-income recipients, with a maximum individual cap of 283 hours per month. All recipients were eligible for the default Consumer-Directed Care (CDC) program, but if recipients preferred agency direction they were assigned to the Professional Agency Model (PAM). People who lived alone or were otherwise likely to have difficulty recruiting workers also were likely to be assigned to the PAM model, as were people with less severe needs, since agency hours cost twice as much as consumer-employed services. CDC users could hire any family member, even spouses and parents of minors, which though against Federal regulations was achieved by using state and local funds to pay them (Benjamin et al., 2000). In CDC, the participant was responsible for recruiting, training and supervising workers, who were paid directly by the State after the participant verified the hours claimed. In PAM, the agencies assigned and co-ordinated all providers, services and finances. The IHSS program provided consumers directing their own services with very little help in the employment and training of workers, and social work involvement was normally limited to annual in-home assessments. The PAM agencies too were 'lean and low-cost', again with minimal social work involvement. The support system for self-directing consumers was upgraded in later years, to be more in line with the supports offered by the Cash and Counseling Demonstration programs (Matthias and Benjamin, 2003).

In the major study of IHSS conducted in 1996/97, a stratified random sample of 1095 clients aged 18 and over was surveyed by telephone. Participants with severe cognitive impairment were excluded from the sample. The questionnaire covered client demographics, functional status, mental and emotional status, informal and community supports, service use and service experience. The response rate was 78%. Fifty-three percent of the sample used the consumer-directed model (CDC) and the remainder the Professional Agency Model (PAM); there were roughly equal proportions of people under- and over- 65; 47% of CDC participants employed family members as workers, and a further 27% employed friends or acquaintances (Benjamin et al., 2000)

This study is unique in so far as it provides large-sample data on a *mature* program which by 1996 had been offering Consumer-Directed Care for more than a decade. The CDC

participants over the age of 65 had been with the service for an average of 7 years, and had been using the same care worker for an average period of 3.7 years (Benjamin and Matthias, 2001) .

Benjamin et al. (2000) analysed client outcomes across nine domains: physical and psychological risk; sense of security; unmet activities of daily living (ADL) needs; unmet instrumental activities of daily living (IADL) needs; service technical quality; provider shortcomings; service impact; general service satisfaction; and provider interpersonal manner. Both the CDC and PAM models scored well in all domains. Using unadjusted data, there were no significant differences between service models in the domains of: physical and psychological risk; unmet IADL needs; and provider shortcomings. CDC rated better than PAM by small but significant amounts in five of the six remaining domains. For example: sense of security, mean scores out of 10: PAM=8.96, CDC=9.18,  $p=.021$ ; general satisfaction with personal care and housekeeping, mean scores out of 10: PAM=8.66, CDC=9.06,  $p=.001$ . PAM rated better than CDC in the domain of unmet ADL needs, mean scores out of 10: PAM=5.38, CDC=5.07,  $p=.001$ . After adjusting for recipient characteristics and condition, differences in favour of CDC remained in the domains of safety, unmet IADL needs and service satisfaction. Participants using CDC with family members as workers reported more positive outcomes in safety and service satisfaction than CDC users with non-family workers, after adjusting for service model and recipient characteristics.

In summary, Benjamin et al. proposed that the ability of consumers to choose their workers, particularly family members, increases the likelihood of compatibility and therefore satisfaction. Despite having less formal training for the role than agency-supplied workers, CDC workers can meet their clients' needs better by: being more flexible in terms of working hours and task performance; having longer working relationships with their employers; and therefore having more exposure to client-specific informal training from visiting health professionals.

In a subsequent analysis of the same IHSS survey data, Benjamin and Matthias (2001) compared the consumer-directed experiences in empowerment, unmet needs, and service satisfaction, of three different ages groups: under 65 (30.6% of sample); 65-74 (33.9%); and

people 75 and older (29.6%). Age differences were not statistically significant in 6 out of 10 outcome measures, but the over-65 groups experienced less choice in decision-making about services and showed less preference for self-direction than people under-65, but they also reported fewer unmet IADL needs than those under 65. Similar differences also existed in exactly the same direction between the two elder groups: those over 75 experienced less choice, fewer unmet IADL needs, and also lower satisfaction than those aged 65-74. Both elder groups were slightly more likely to hire family members compared to those under 65, who were more likely to hire either family or friends, backing up the general finding that younger participants have greater circles of support to draw on.

The authors' (Benjamin and Matthias 2001) overall interpretation of the analyses was that, while younger people may like Consumer-Directed Care more, older people may also benefit. However, they also warn that older people have less access to support from family and friends than younger participants: hence program providers need to build in compensatory features and safeguards into their consumer-directed models.

Matthias and Benjamin (2003) used the same IHSS survey data again to examine the relationships between service model (CDC and PAM), worker-client relationship (family and non-family providers)<sup>12</sup> and casemix factors (impairment, paramedical and ADL/IADL needs, participants' other resources) with participants' reports of abuse or neglect. Abuse and neglect were measured with ten questions: Did the provider (1) neglect you (2) yell at you (3) threaten you (4) injure you when assisting you (5) push, shove or hurt you physically (6) steal money or other items (7) come to work under the influence of alcohol or drugs (8) make unwanted sexual advances (9) Do you get along with provider (10) feel safe with provider's assistance. The authors (Matthias and Benjamin 2003) acknowledged that they were unable to interview potentially most vulnerable participants with high level cognitive impairment, and that CDC participants may have been more reluctant to make complaints about family members, even in a confidential research context. The raw scores for the PAM and CDC participants were too close to nominate differences between service models on seven of the measures. Significantly more PAM participants reported problems in the

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<sup>12</sup> In California this can be any family members.

measures of 'neglect' (PAM=17.8%, CDC=9.2%,  $p=.001$ ) and 'stealing' (PAM=5.3%, CDC=4.2%,  $p=.030$ ); and significantly more CDC participants reported problems in the measure of 'yelling' (PAM=6.1%, CDC=7.8%). However, when other factors of demographics and case-mix were taken into account, there were no significant differences between agency- and consumer-directed services. A comparison between CDC participants with family workers and CDC participants with non-family workers showed significant and sizable differences on raw scores for six of the measures, all indicating greater risk from non-family workers: neglect (5.5% vs. 12.7%,  $p=.001$ ), injure you when assisting you (4.3 vs. 5.7%,  $p=.042$ ), push/shove or hurt you physically (0.0% vs. 1.8%,  $p=.001$ ), steal money or other items (0.8% vs. 7.2%,  $p=.001$ ), (not)get along with provider (3.7% vs. 14.2%,  $p=.001$ ), (not)feel safe with provider's assistance (4.6% vs. 11.5%,  $p=.028$ ). However after adjusting for other factors, only the differences relating to feelings of security (getting along with provider, feeling safe with provider's assistance) remained significant. Overall, clients who needed more paramedical help, had more complex needs, had less stable provider relationships and less backup from family and friends were at greater risk of abuse and neglect. There appears to be no difference in risk between agency- and consumer-directed service models, and the employment of family and friends appears to be a protective factor. This however points towards the possibility of greater vulnerability for CDC users who must hire workers outside of their support circle, particularly when the program is poorly resourced in terms of training and monitoring.

A separate survey of 253 consumer-directed workers and 365 agency workers who were working for respondents of the main IHSS study was also conducted in 1996/97. In this study 10 worker outcome dimensions for stress and satisfaction were measured. The stress dimensions were: concern about client safety; issues with client's family; client behavioural issues; getting along with client; worker emotional state; clarity of work roles. The satisfaction dimensions were: work role satisfaction; performance self-assessment; career advancement; independence and flexibility (Benjamin and Matthias, 2004).

Differences between service models were found to be minimal. After adjusting for worker and recipient characteristics, it was found that: Consumer-Directed Care workers got along better with clients and their work roles were better defined, whereas agency workers

worried less about the client away from work. Within Consumer-Directed Care workers, family members had better relationships with clients than unrelated workers, but the latter had better emotional states. Consumer-Directed Care workers, and within them the family workers, did more hours of unpaid work than agency and unrelated Consumer-Directed Care workers.

The IHSS program at the time of the study offered fewer fringe benefits to agency workers and fewer supports in consumer-direction to CDC recipients than more recent projects such as Cash and Counseling. The authors (Benjamin and Matthias 2004) speculated that these suboptimal arrangements may have contributed to the lack of difference one way or another on most dimensions. Again, the study suffered from the exclusion of the most cognitively impaired older people and, thus, failed to include the views of their carers.

## Washington State

Like California's IHSS, Washington's CD-PAS program was the dominant model for mainstream home-based aged and disability services in that State. Additionally, it had been mandatory for consumers who required more than 112 hours per month of service to use CD-PAS instead of agency-directed services, although this policy was rescinded before the study commenced. In a comparative survey of 517 consumers using consumer-directed or agency-directed services, Wiener, Anderson et al. (2007) found no difference in overall satisfaction with services for consumers under 65; but consumers over the age of 65 (38% of the sample) rated CDC significantly higher than agency-direction. The authors were unable to account for this reversal of the more usual finding, which is that younger people are more satisfied with CDC than older people.

A primarily qualitative evaluation of the Washington program (Young and Sikma, 2003) found that participants were satisfied with the self-directed care program. The evaluators did not detect any negative outcomes, and considered that the two substantiated reports of abuse or neglect during the evaluation timeframe were not directly attributable to self-directed care. The evaluators concluded that the program reduced use of more expensive



medical services such as nursing homes and emergency rooms. However, they also stated that the low pay and relatively poor working conditions of individual providers constituted institutionalised exploitation, a situation that both consumers and providers wished to change. In general, case managers had less confidence in consumers' abilities to self-direct than the consumers and their individual providers. Young and Sikma suggested that case managers needed to reframe their relationships with clients as consultants rather than gatekeepers and overseers.

### **USA Medicare Primary & Consumer-Directed Care Demonstration**

The Medicare Primary and Consumer Directed Care demonstration was funded by the US Centers for Medicare and Medicaid Services to appraise the effects of two interventions on service use and cost. This demonstration was undertaken in New York, West Virginia and Ohio over a 2 year period commencing in 1998. The two evaluated interventions were a consumer directed voucher and a community-based nurse providing chronic disease self-management and health promotion (nurse intervention). These interventions were compared with Medicaid personal assistance services directed by agencies.

Two studies (Meng et al., 2005, Meng et al., 2006) presented data from this randomised controlled trial. The study by Meng et al. (2005) aimed to describe the effects of the consumer directed voucher and nurse intervention on the probability of use of personal assistance services. The sample of 1,394 people was selected from those attending Medicare funded primary care physicians and presenting frequently to emergency departments. Meng et al. (2005) found that the nurse intervention alone had no effect on the use of personal assistance services. The voucher intervention resulted in increased use of personal assistance services by 13% and the combination of the voucher and nurse interventions increased the probability of use of personal assistance services by 18%.

The second study by Meng et al. (2006) aimed to capture the effect of the voucher benefit on the demand for personal assistance services by Medicaid beneficiaries 65 years and older with functional disabilities. This secondary analysis of data included 645 people from the

sample described above (Meng et al. 2005). The voucher benefit was associated with a trend towards increased average annual expenditure by 10%. The authors (Meng et al. 2005; Meng et al. 2006) conclude that although the use of the consumer directed voucher intervention was associated with slightly increased costs this may be off set by greater efficiencies and savings for other Medicare covered services such as health services due to potential improvements in health outcomes.

## CD-PAS Studies in Other States

Doty, Kasper et al. (1996) compared Personal Care Services in the states of Maryland, Michigan and Texas, which differed by the levels of consumer direction allowed to participants. Face-to-face interviews were conducted with a total of 879 service recipients aged 65 or older across the three states. The authors examined the relationships between measures of client control (knew worker before hiring; schedules and supervises work; signs timesheets/pay-check; selects and dismisses worker) and satisfaction with services. All of these indicators associated positively with higher levels of satisfaction with worker competence and 'humaneness'. The first three indicators were also associated with greater overall satisfaction with services (Doty et al., 1996).

Several smaller studies (Beatty et al., 1998, Hagglund et al., 2004, Grossman et al., 2007) also make findings of no difference or marginal differences in favour of consumer-directed services in the domains of overall satisfaction with services, and also for unmet needs and feelings of safety where these factors were measured. These smaller studies include: a report on survey results in the state of Virginia with 60 CD-PAS users, and 62 clients using agency services but waitlisted for CD-PAS (Beatty et al., 1998); a comparison of survey results from 61 CD-PAS users and 53 agency-directed users in Missouri (Hagglund et al., 2004); and a set of interviews with 10 consumers with agency-directed services and 14 consumers hiring their own staff directly, drawn from the seven states of Arizona, California, Kansas, New York, Ohio, Texas and New Mexico (Grossman et al., 2007).

Feinberg and Whitlatch (1998) interviewed 168 family caregivers who used in-home respite care facilitated by California's Caregiver Resource Centers. Compared to those using agency-based services (n=52), caregiver directly hiring their staff were more satisfied due to their greater ability to schedule and control the respite care; and they were able to purchase more hours of care since direct-pay rates were lower (Feinberg and Whitlatch, 1998).

## Reviews

Heumann (2003) reviewed evidence from four state CD programs (Colorado Home Care Allowance; Oregon Client-Employed Provider program; Michigan Home Help; and California's In-Home Supportive Services program [IHSS]), and from the Cash and Counseling (CaC) Demonstration Projects in Arkansas, New Jersey and Florida. As the Cash and Counseling programs and California's IHSS are dealt with elsewhere in this paper, their details are not reported here.

The Colorado Home Care Allowance program started in 1979, and by 2003 had a caseload of 4,800 persons with almost half being 65 years or older. Depending on individual eligibility, the Home Care Allowance, which in 2003 was capped at a low level of \$269 per month for maximum impairment) was topped up with Medicaid waiver funds. Most participants chose to hire family members and could decide how much they paid them. No budgetary or managerial training was provided, and case workers visited clients every six months. No formal evaluation of the program had been conducted, but State officials said that no evidence of fraud or abuse had been reported. A new CDC model that included training and evaluation was launched in 2002 (Heumann, 2003).

The Oregon Client-Employed Provider program (originated in 1981) serviced people at risk of nursing home placement with Medicaid waiver funding, using a voucher payment system with a highest rate cap of \$1950 per month. In 2003 the program had 13,700 participants. Participants were responsible for employee supervision, hiring and firing. Payment rates were set by the program, and any family member except spouses could be employed. Case managers conducted annual needs assessments. A 1999 survey of 546 client/provider pairs reported strong satisfaction with the quality, reliability and helpfulness of the workers.

Oregon launched the Independent Choices (Cash and Counseling) trial program in 2001 (Heumann, 2003).

The Michigan Home Help (begun 1982) had 42,000 participants in 2002, with 60% being 65 or older. In this program the case worker determined the number of hours of entitlement, the county determined the pay rates and the state held the funds, while the participant hired the worker and scheduled services. Most participants received between \$100-\$300 per month, and opted for their family members to be workers. Case workers conducted home visits twice a year. A survey of 750 participants, 43% of whom were aged 65 or older, found that 98% of consumers were satisfied with their services, with insufficient hours and slow workers being the main source of dissatisfaction (Heumann, 2003).

In a summary assessment of the three Cash and Counseling projects and the four other programs, Heumann (2003) concluded that older consumers were highly satisfied with consumer-directed services, and that the ability to hire family members was a major contributing factor. The author suggested that states should allow consumers to choose their level of self-direction; to offer fiscal agents and counselling and training programs; and provide backfill arrangements for when workers do not turn up.

## Discussion

The findings from the above studies are uniformly favourable to consumer-directed care. This lack of variation answers some questions, with qualifiers, and raises others. In the US, for people who rely on Medicaid funding to meet their home care needs, Consumer-Directed Care appears to be no worse and possibly better for some people. How much better may depend upon the complexity of a person's needs, and the scope of the family and friendship networks they can draw on to recruit sympathetic and committed workers. It is not clear at all to what extent the most vulnerable people e.g. those experiencing cognitive impairment and social isolation – are inappropriately assigned to consumer-directed care, or what becomes of them when this happens. Studies that rely on limited

self-assessment schedules and satisfaction scales provide no illumination of those questions.

In keeping with national character, Consumer-Directed Care in the US is framed by concerns for the rights of the individual and value-for-money. Consumers who direct their own care are for the large part entering the labour market as private employers and making contracts with family members and friends, or with unrelated low-paid workers. Oversight and interference by the state is kept to a minimum. Evaluations of CDC programs in the US tend to reflect this individualistic approach by reporting on consumer satisfaction and safety surveys without delving too deeply, if at all, into the relationship between pay rates and service quality/worker satisfaction; or into the plight of consumers who report that they are unsatisfied or unsafe. This is in stark contrast to the social responsibility ethos that frames discussions of care delivery in the UK.

The development phase of Consumer-Directed Care (CDC) programs in the US occurred largely without the input of older people. Pilot studies such as the Robert Wood Johnson Foundation-funded Self-Determination Demonstration program that generated the blueprint for the current Cash and Counseling programs focused exclusively on people with developmental disabilities. In fact, outside the pioneering states like California and Washington, older people were regarded as not suitable for or unfit to direct their own care. This view was eventually refuted by research findings such as those cited above. Still, most current US CDC programs that cater for older people are essentially based on models developed for younger adult users. Contributions to the literature that explicitly focus on the needs of older people regarding CDC are very few.

## The UK Experience

In the UK, user-directed social services have their origins in the claims of social and advocacy movements, such as the Movement For Independent Living during the 1970s and 1980s. The MIL launched a vociferous campaign demanding greater choice, flexibility and control in the lives of people with a disability (Priestley, 1998). During the 1980s, such demands translated into pilot projects that placed financial resources under the control of individuals or small groups of disabled people. As the 'cashing out' of services was prohibited under the existing legislation, these pilots typically used a variety of third-party arrangements to allow for the self-direction of support services. The management of these schemes gave rise to a range of user-led support groups and community-based organisations that helped to popularise the notion of self-directed support.

During the 1990s, consecutive governments attempted to dismantle the welfare state in order to introduce greater user control over the composition, timing and flexibility, and responsiveness of services and to cut costs. The assumption was that market-driven social care services funded by local authorities (and increasingly also by individuals funding their own care entirely from their own private resources) but provided by a range of charitable and for-profit organisations would bring about greater flexibility, responsiveness and better 'value for money'. Also, during the 1980s and 1990s, the rhetoric of user involvement in service design and delivery encapsulated by the term 'co-production' enjoyed increasing popularity among policy makers and academic commentators. The establishment of the Independent Living Funds in the late 1980s further reinforced demands for user-led support options. The foundation for Direct Payments (DP), the fore-runner program of Individual Budgets (IB), the most recent version of user-led support in the UK, was laid in the form of various Acts of Parliament during the early and mid 1990s. During the second half of the 1990s, Direct Payments was widely and forcefully promoted by government and became a mainstream option in the menu of social service provision. Initially restricted to those aged between 18 and 65, older people were entitled to enrol in DP programs only in 1999 and 2000 (Riddell et al., 2006). However, older people appeared to be less interested in DPs. In

2008, only approximately 6% of those enrolled in a DP program were aged 65 and over. Currently, local authorities are required to offer direct payment options to all those eligible for community care services who are willing and able to manage their own care.

Whereas user-directed support services entered the policy mainstream relatively quickly, academic discussions focusing on the benefits and drawbacks of DPs persisted well into the new millennium. These discussions became increasingly polarised and pitted consumer advocates against those who questioned whether the confluence of market forces and Labour's 'Third Way' would indeed represent a remedy against the insensitivities of the welfare state or whether user-direction would result in a hollowing out of social care programs transferring the duty of care of local authorities to service users themselves. Whereas DP supporters saw the new program as a significant step towards a re-distribution of power and resources (Spandler, 2004), others questioned whether Direct Payments were indeed generating more choice, especially in the absence of adequate support structures, and whether they were appropriate for all (Ungerson, 2004, Ungerson, 1997, Ungerson, 2002). They raised concerns about the changing nature of the social care provision, the potentially declining support base for service recipients (Spandler, 2004), the quality of paid care assistance, as well as the supply, pay and working conditions of paid carers (Leece, 2006, Ungerson, 2006, Glendinning et al., 2000) and expressed concern about the potential to use DPs as a cost cutting device (Spandler, 2004). More recently, in light of a major evaluation of IBs conducted by the Individual Budgets Evaluation Network (IBSEN), a consortium consisting of five UK-based universities, such concerns gave way to a fragile consensus that well-developed user-led care arrangements can generate positive outcomes for users and carers (Baxter et al., 2008).

## Direct Payments

The research-based literature featuring interventions of Direct Payments focuses predominantly on the benefits, potential disadvantages, and risk encapsulated in the program. A more recent major evaluation conducted by a consortium led by the London

School of Economics examines the reasons underpinning the disparate implementation and limited uptake of DP in the UK and raises concerns about equity issues.

### **Background Studies & Commentaries**

Spandler's (2004) insightful introduction to and review of the contextual factors underpinning consumer choice and the implementation of DPs focuses on the political tensions and conflicting ideologies underpinning the DP program, the insufficient availability of resources, the issue of collective vs. individual needs, the political and legislative context and the impact of compulsory mainstreaming of DPs, as well as potential welfare trade-offs.

### **Implementation Studies**

A major evaluation conducted by the London School of Economics and Political Science's Personal Social Services Research Unit focuses on the uneven uptake of DPs in different parts of the UK and examines differences in implementation and support structures. The main report is based on a multi-method, multisite, multi-tiered study drawing on a secondary analysis of existing statistical data, 21 semi-structured interviews with key informants, a phone survey (n=102) with staff managing DPs in local authorities (response rate 88%), a postal questionnaire mailed to all (215) purchasing authorities (response rates in England, Scotland, and Ireland were 75%, 66% and 30% respectively), a postal questionnaire to all organisations supporting DP users (response rate and population not stated), as well as the recording of eight case studies.

The study focuses on implementation differentials and highlights a comparative lack of consumer activism and user-led support organisations in the north as well as a number of barriers identified by local authorities. Among the obstacles was the absence of an effective support scheme, staff training and support, uncertainty among staff, workload pressures, lack of knowledge, local authority leadership and provision of accessible information to potential recipients, staff attitudes, a lack of demand for DPs, national legislation, and ambiguous policy guidelines. The three most important issues hindering implementation progress were concerns among service users and carers about their capacity to manage DPs, staff resistance to DPs, and labour market issues such as a shortage of care assistants (Riddell et al., 2006, Davey et al., 2007). Moreover, the interviews brought out the politically



motivated resistance against the implementation of DPs in the north of the country (Priestley, 1998). The most widespread concern voiced by local authority managers was how to promote direct payment usage while maintaining a duty of care. A second concern was the uncertainty held by front line staff about eligibility boundaries, an issue compounded by the vague definitions of capacity, consent and risk. The introduction of mandatory duties, performance indicators and local targets appeared to have a significant positive impact on policy implementation in terms of take up numbers. However, this raised concerns about the lack of quality indicators (Riddell et al., 2006).

As part of the same evaluation, Davey, Fernandez et al. highlighted imbalances between DPs and institutional modes of service provision raising questions regarding the equity of resource allocation. In particular, the report underscored the surprisingly low number of one-off payments as well as the marked differences in hourly rates and the items included in the rates. Moreover, the report stated that hourly rates were generally too low, that wide variations existed in the levels of funding provided to support organisations, and that there was little evidence that DPs have transformed the service industry and purchasing practices (Davey et al., 2007).

### Outcome Studies

Two insightful studies that did not include older people focus on the impact of DPs on relationships between Care Assistants and disabled users (Glendinning et al., 2000, Carmichael and Brown, 2002). The study conducted by Glendinning, Halliwell et al. recruited 45 DP users in 3 local authority areas as well as 13 paid carers. Findings suggest that enrolment in the DP program may provide help with a greater range of tasks, greater choice regarding service provision, more continuity of care, the ability to control recruitment and training of care assistants, enhanced quality of life, and generate long-term relationships with care assistants that benefits both parties. These effects were less apparent when care assistants were hired through an agency. However, the study also indicates that the recruitment and training of care assistants can be difficult, that employer roles and responsibilities can be burdensome, and that it can be difficult to balance the employer-employee relationship. The study concludes that disabled people need support and resources to be good employers and that working for disabled people needs to be more

attractive to prospective employees especially during times of full employment (Glendinning et al., 2000).

## In Control

In Control, a user-led community organisation providing support to people who seek to manage their own care arrangements was formally commenced in 2003. In Control developed its own implementation manuals of self-directed support programs that feature person-centred planning, social role valorisation, and consumer involvement in the decision making process. The organisation implemented and trialled its program with 15 service recipients in each of the 6 pilot sites between 2003 and 2005. The pilots included only people with disabilities and their families/carers. However, In Control claims that its program can be employed with other user groups. A report compiled by Poll, Duffy et al. (2006) summarises the experiences of 31 users. The evaluation consisted essentially of a pre/post questionnaire with repeat measures conducted 18 to 61 weeks after implementation. It focused on the domains of self-determination, support, home, direction, cost, and community life. The report also draws on a non-specified number of semi-structured interviews with users. The report suggests that the In Control method resulted in significant improvements across all domains. To be sure, In Control is an advocacy organisation as reflected in the report and evaluation; the tools used in this study are not validated and their investigative and explanatory power appears to be limited (Poll et al., 2006).

## Individual Budgets

The Individual Budgets program represent the most recent generation of user-directed social care models. The IB program has far reaching implications as they foreshadow profound changes in social care provision and their administration. It builds on the experiences of Direct Payments and the In Control pilot program implemented in six local authority areas and is geared to offer more flexible opportunities for personalised social care. The key principles that conceptually distinguish the Individual Budgets program from conventional as well as former user-directed programs are greater flexibility, greater role of

self assessment, greater opportunities for self-definition of needs and desired outcomes, and increased opportunities for users to determine for themselves how they want those outcomes to be achieved. The IB program 'pools' several funding streams or packages with the idea to reduce multiple assessments and bureaucratic processes. Transparency is central to IBs. IB users should know what they are entitled to and be informed about the cost of services. Furthermore, they should be offered adequate support in planning how best to use their funds to meet their needs (Baxter et al., 2008). IBs offer a wider range of options to users enabling them to, instead of receiving cash payments, contract local authority care managers to purchase services for them or to manage their care through a trust fund on behalf of the user. The IB program was the focus of a major evaluation conducted by the IBSEN conglomerate that accompanied its implementation in 13 local authority regions in the UK between 2005 and 2008. All of the following studies draw on data generated by this evaluation.

### Implementation Studies

A qualitative prospective study conducted by Manthorpe focuses on risk, adult protection, and safeguarding. Drawing on semi-structured interviews with 13 staff responsible for adult protection in all the participating pilot sites the study examines the linkage between Individual Budgets and wider adult protection context in terms of risk management and safeguarding (Glendinning et al., 2008). Whilst adult protection policies were in place in all 13 pilot sites, incorporation of IB-specific risks were either at an embryonic stage, or had not yet been undertaken. Also, safeguards designed to protect IB users against potential risks remained generally underexplored and included actions such as firming up adult protection policies, regular reviews of expenditure, identifying risk factors for abuse in an individual's support plan, preparing a guide for social workers regarding protection and risk management, preparing an information pack for service users focusing on essential checks, use of support brokers to assist individuals with their employment responsibilities, seeking confirmation from service users that they have understood the employment responsibilities especially when the employee is a friend, incorporating IBs into adult protection training, and developing audit trails. While adult protection officers recognised the benefits of IBs, they feared that especially vulnerable people were at risk of abuse in case users did not conduct the customary police and criminal record checks. Moreover, they feared that IB

would isolate them from other service users and that they would lack protection within the context of 'privatised' services. Moreover, adult protection officers expressed concern that users would not be coming forth in case of abuse, especially when family carers are involved. The author argued that this heightened sense of vulnerability regarding IB users could lead to an over protection of service users that would limit their control over their support program.

Focusing on service provider response to IB programs in all 13 pilot sites, Baxter, Glendinning et al. (2008) report on a two-stage evaluation research project consisting of a secondary quantitative analysis of data provided by 99 home care agencies and semi-structured interviews with 32 managers of home care agencies based in four local authorities. Home care agencies were generally ill prepared for the expansion of IBs. Local Authorities introduced contracts with independent home care agencies based on geographical zones. This essentially limited the choice of service providers available to IB users. Whilst commissioning officers were committed to IBs, they knew little about the local market for home care services apart from those services they directly contracted. This clearly limited their ability to inform IB users about alternative service providers in their area. Moreover, home care officers were under the impression that services had become less flexible because funding constraints allowed only for the most basic of assistance tasks. Supported living providers were able to provide more flexible services, however. Smaller agencies had more personal contact, were more prepared for negotiating care arrangements directly with IB holders, and had more privately paying clients, employed more mature workforce, and had lower turnover. Larger agencies were expected to be better protected against new financial risks from IBs. Risks include non-payment, increased demands for more flexibility and intermittent timetabling. IB funding was considered too low to allow users to purchase agency-directed care. It was feared that this would leading to reduced demand for services. Concerns were voiced about maintaining a qualified workforce in a context in which staff training becomes more complex due to more complex and more diverse service demands. Agencies had no clear advertising strategy. Normally targeting purchasing officer, agencies used a range of incentives and controls to retain workers and to discourage them to work for clients directly. Because the uptake of IBs was

relatively small, the demands of IB users had hardly any impact on service delivery (Baxter et al., 2008).

A Care Service Improvement Partnership (CSIP) publication (Care Services Improvement Partnership, 2007) provides a summary of good practice regarding the implementation of IBs for older people. The publication is based on semi-structured interviews with 14 local authority staff in 8 pilot sites. The survey was conducted when most pilot sites were still implementing the IB program and examples of older people actually using IBs were few. Key findings of the publication are as follows:

- IB requires total revision of how people's wishes are viewed and addressed.
- IBs should be introduced in conjunction with a cultural change strategy that highlights the benefits of IBs. Training all staff members, identifying champions, and fostering commitment and enthusiasm are required.
- New processes need to be embedded in operational processes.
- IBs need support from all levels of staff.
- Engaging older people is often difficult. Starting small is recommended.
- The introduction of IBs during times of crisis should be avoided.
- It is important to give people choice from the outset.
- When people understand how much money their package contains they start wondering if they get value for money.
- Small differences can make a big difference.
- Many older people adopt a mix and match approach combining conventional and DP to buy additional support or equipment.
- The flexibility of DPs is much appreciated by some.
- Many like to retain certain elements of traditional services.
- Older people may choose direct payments to family or friends over indirect payments.
- Services are generally underfunded.
- Many people want a continuing relationship with their care coordinator/social worker.

- Changing needs represent a major problem for older people. For people whose needs fluctuate greatly, contingency needs to be taken into account in the form of a capped roll-over fund made up of 10% of a monthly allowance.
- Care planning requires applied examples.
- Too much paperwork and complexity will put older people off.
- Support planning and brokerage should be provided together.
- Shorter support plans work better for older people.
- Reviews should be outcome focused.
- Risk management needs to change enabling older people to take more control.

Older people particularly enjoyed alternatives to conventional meals on wheels as well as the ability to employ a neighbour or friend or family. The publication also makes it clear that information is crucial for older people. In fact, some local authorities are routinely checking whether families have correctly understood information that was passed on. Others underscore the need to involve the voluntary sector in the provision of information and support. Many care packages are quite small leaving little scope for flexibility or changes. Informal peer support schemes were not successful in one pilot site.

### Outcome Studies

Henwood and Hudson (2007) provide a mid-point evaluation of six IB and four In Control pilot sites to provide strategic direction in the implementation process (Henwood and Hudson, 2007). The evaluation brings together the outcomes of two studies, which have been published independently. The authors do not provide details regarding the methodologies employed in these studies. Among the key findings were that support among staff for IBs at the level of principle did not necessarily translate into action and that a clear change management strategy was required. In fact, staff may adopt a wait and see attitude attempting to 'ride out' the wave of bureaucratic enthusiasm for user-directed support services. Furthermore, the integration of funding streams, one of the core propositions of the IB program, was problematic due to the fact that existing funding guidelines remained in place. This undermined attempts to use the funding more flexibly. There was indication that IBs and In Control resulted in a reduction of paper work at the local authority level. The

report highlights that significant support is needed to come to terms with core processes such as self assessment, care planning, and budgeting. Also, the evaluation reports that the pricing of services met significant technical and practical challenges. At mid point, support planning and brokerage services were under-developed as the main focus was on the development of budgets and a resource allocation system. Moreover, independent 3rd party providers appeared to be interested to move into the planning and brokerage market. However, how such external support and brokerage should be paid for was not clear. There was little practical evidence that a 'market' was developing.

While some staff viewed IBs as an opportunity to move to a more traditional social work role, local authorities faced demands for new types of workers. Concerns about the balance between duty of care and rights persisted, generating calls for a new approach to risk management.

The main study of the IB program in 13 pilot sites was conducted by Glendinning, Challis et al. (2008). The evaluation employs a mixed method design consisting of a randomised controlled trial comparing costs, outcomes, and cost-effectiveness of IBs with conventional services. A total of 959 people were interviewed around 6 months after they were allocated to either the intervention or the control arm of the study. In addition, in-depth interviews with a subsample of 130 IB users were conducted to explore their first experiences with the new process. Moreover, managers and key staff members in all 13 sites were interviewed to gather information about the implementation process and the impact of IBs on workforce and risk management. Around 28 % of participants were older people.

The report highlighted the fact that around half of the participants were unclear about their entitlements and that even those who received detailed information found it difficult to understand the process. Around six months after program implementation around one third of the participants received self-directed support and around 59% used IBs to purchase conventional support elements. Over half employed their own care assistants. After the employment of care assistants, leisure was the most common expenditure domain. However, outcomes were not uniform across user groups. For instance, older people were less likely to report higher aspirations, but stated lower psychological wellbeing and higher

levels of anxiety. This was especially the case among the more vulnerable older people who had their IBs managed by proxy respondents answering for them. Many older people did not want the additional responsibility of planning and managing their own support and assessing the risk associated with directly employing support staff. However, IB users were much more likely to feel in control of their lives. No other statistically significant differences were recorded in other domains, although IB users generally appeared to enjoy better social care outcomes. Moreover, people with higher cost support had better outcomes.

In terms of costs, little difference between IB users and conventional service users was found. It is likely, thus, that IBs would be at least cost neutral. IB holders generally reported higher use and higher costs of health care services. It appears that the initial rather intensive joint care plan development uncovered unmet health care needs. Staff reported an increased use of care coordination and a better relationship with IB users translating into higher support cost. Also, the report describes a tension between economy of scale and individual choices resulting in higher costs to IB users. In terms of service delivery, IBs appear to focus funds more narrowly on ADL activities. In terms of administration of budgets, participants found it difficult to deal with the paper work during planning stage.

In terms of risk management, the report foregrounds a lack of clear mechanisms for monitoring and identification of risk to IB users once arrangements were in place. Moreover, tension between safeguarding responsibilities and a new positive risk culture were apparent. Risk management incurred higher monitoring and support costs. Service providers tended to embrace IB but found that they had to bear additional costs as a result. As a result, they generally agreed that it was not practical to meet all user demands. Service providers were unsure about how to market their services to consumers. The report concludes that IBs may not be suitable for older people with more complex needs. Similarly the authors argue that IBs are not suitable for users that are at a crisis point. The majority of IB holders used direct payments and only a few participants used other arrangements such as agents or trust accounts. The authors argue that these options need to be explored in greater detail. Although this evaluation employed a very robust research design, the fact that the follow-up was conducted only six months after implementation, a period during which many IB users were still trying to come to terms with the new processes, may have



influenced outcomes. In particular, reports of lowered psychological wellbeing and higher anxiety levels require confirmation by future research.

The most recent report focusing on the 13 IB pilot sites addresses the impact and outcomes of the program on informal carers (Glendinning et al., 2009). In particular the report focuses on changes in informal support provided and changes in quality of life as experienced by carers. The carer study was designed as an add-on to the main evaluation and consisted of structured interviews with carers of people in the intervention and control arms, in-depth semi-structured interviews with carers of people in the IB group, a reanalysis of staff interviews collected during the main evaluation, and phone interviews with local authority staff responsible for carers in 12 of the sites. The authors report that IBs have a significant positive impact on carers' reported quality of life. In fact, carers' satisfaction with the service users' support planning was an important predictor of carer outcomes. In contrast to other user groups, older people appreciated a more holistic, family-based IB approach that took account of their roles. No significant cost differences were found between the IB and conventional services. However, the report identifies important differences in how carer needs were assessed among the pilot sites, differences that were overlooked by earlier reports. Sites varied in the way carer help was used to limit payments. Only a minority of carers received any payment from the IB payments of service users. Local authority staff regarded carers' issues as relatively marginal in the IB process. However, as the program proceeded the concerns of carers were regarded as more important in several sites. On occasions tensions between carers and service users were fathomable. Carers seem to spend more time in their caring roles under IB arrangement than under standard arrangement. Moreover, carers were more involved in the care plan development in the IB program.

## Discussion

The UK literature on DPs and IBs is heavily influenced by the major government-commissioned evaluations that provided empirical data that significantly re-shaped the lively debates of the early and mid 1990s. Notwithstanding several methodological shortcomings, the evaluations shifted the central axis of the debate as they demonstrate

that market-driven social care arrangements do not automatically lead to more flexible and responsive care arrangements and that well-designed user-directed services can have positive outcomes for care recipients and carers. Yet, the evaluation suggests that the positive impact of IBs on older people may be smaller and that IBs may psychologically unsettle some more frail older people. However, the evaluations add little to our understanding of the range of supports older people require to effectively direct their care.

Until 1999 and 2000, pilot studies included only people with disabilities. Older people were only entitled to enrol in user-led programs at the turn of the millennium. As a result, they played, at best, a minor role in the development process of user-directed support options. In most sites, older people were enrolled into programs that catered to the needs of people with disabilities. Most pilot sites adapted these programs to correspond better to the needs of older people once it became evident that they were not entirely suitable for seniors and when it became evident that uptake remained low. Only one publication focuses directly on the needs of older people who want to enrol in a self-direction program. Interestingly, this publication seems to suggest that, although interested in directing certain aspects of their care arrangements, older people do not want the paperwork and bureaucratic processes that accompany DPs and IBs. If anything, the UK literature highlights the need to develop a user-directed support services approach that is unconditionally 'person centred' and fully responds to the needs of older people.

## The Australian Experience

Substantial research into self-directed care for older people in Australia is still in its infancy. As with international experience, changes in service models have come first in the adult disability sector, albeit much later than in the United States. Brown and Ringma (1989) reported on one of the first Australian demonstration projects in consumer-directed, community-based disability care that flowed from Federal legislative changes contained in the *Disability Services Act* of 1986 (Brown and Ringma, 1989). A number of studies of consumer direction have appeared since that time, but again all reporting on small sample data from adult disability programs with either no aged participants, or too few to draw meaningful conclusions in regard to aged care consumers. For example, Western Australia's Local Area Coordination Program (Disability Services Commission, 2003), Disability Services Queensland (Spall et al., 2005), the Direct Payments Project in Victoria (LDC Group, 2007), and the Attendant Care Program in New South Wales (Fisher and Campbell-Mclean, 2008). Nevertheless, these studies do provide useful insights from within the Australian care system, thereby informing consumer direction in aged care position papers from major agencies such as the Brotherhood of St Laurence (Laragy and Naughtin, 2008), alongside evidence from international studies.

The evaluation of a piloted direct-funding model for adults with disabilities in New South Wales by Fisher and Campbell-McLean (2008) sheds some light on the potential for consumer control in Australia. Despite the study's limitations due to the use of poorly matched comparator groups, it does indicate that consumer control, including the complete self-management of funds and worker employment, has real benefits for some consumers and carers. The study's findings suggest that a fiscal intermediary model that allows participants to pay workers higher wages can deliver substantial benefits to care users who may not be willing or able to take on full direct-funding responsibilities.

Ottmann et al. (2008), reporting on the experiences of twelve families with dependent family members, found that after four years of self-direction the families' overall evaluation was positive. The ability to employ their own staff enhanced the relationships between

support workers and the care recipients and families, which translated into better care outcomes. However participants also found that increased self-reliance could result in greater isolation from social and practical supports. The authors recommend that agencies offering self-directed care maintain strong programmatic safeguards for participants, including the linking of families into formal and informal support networks (Ottmann et al., 2008).

### Expert views and sectoral comment

Australian industry perspectives on consumer direction in aged care are largely informed by international studies and expert views. Tilly and Rees (2007) on behalf of Alzheimers Australia reported overwhelmingly positive findings from studies of CDC programs across the globe, and recommended the immediate trialling of Consumer-Directed Care models through building on existing care system elements: for example, by utilising Aged Care Assessment Teams to assess a recipient's capacity to direct their own care and identify the supports they would need to do so (Tilly and Rees, 2007). Ian Hardy (CEO of Helping Hand) reported back from a Churchill Fellowship study tour of Europe and Japan in generally positive terms, recommending that consumer control in long-term and respite care should be debated and piloted in Australia with a view to developing a consistent national approach (Hardy, 2009).

With a brief to examine the entire community care sector, the Allen Consulting Group (2007) analysed national care services trends, reviewed local and international literature, and conducted a series of consultations with providers and consumers. Their report proposed widespread sectoral reform towards more flexible, client-focused arrangements. The authors envisaged this would include optional participation in a Consumer-Directed Care program that offered stepped levels of involvement to match the variable wishes and capacities of consumers (Allen Consulting Group, 2007).

The discussion paper prepared by the peak provider organisation Aged & Community Services Australia (2008), based on industrial considerations as well as local and international research, adopts a more guarded perspective. The authors also recommend that CDC be viewed as one option within a universal care program, with the proviso that a

long list of consumer and provider issues be considered prior to any implementation (Aged & Community Services Australia, 2008).

The position paper from the Brotherhood of St Laurence (Laragy and Naughtin, 2008), after considering local and international research, takes a more consumer-advocacy approach recommending that aged care decision makers introduce CDC as an option, beginning with independently evaluated large scale trials across the country.

## ASSESSING LEVELS OF EVIDENCE

Formal guidelines hierarchically ordering ‘levels of evidence’ and ‘grades of recommendations’ were first popularized by the Canadian Task Force on the Periodic Health Examination (CTF) (Canadian Task Force on the Periodic Health Examination, 1979). The CTF’s recommendations were later revised in collaboration with the United States Preventive Services Task Force (USPSTF) (Jaeschke et al., 1994). More recently the hierarchical ordering of research designs has been a key point in the evidence based practice movement and its various exponents.

Since the CTF’s taxonomy was developed with systematic reviews of clinical trials in mind, it tends to ignore or exclude mixed method and qualitative designs and is, as such, not appropriate for this review. As mentioned previously, if the task is to evaluate social programs or models, it is highly likely that well design mixed methods studies where quantitative and qualitative research functions complement and strengthen each other produce better outcomes than uni-dimensional research designs. Hence, to bring this complementarity to bear on the outcomes of the research synthesis, this review incorporates wholly qualitative research as well as study-based expert opinion. Hence, the extended taxonomy presented here features mixed method, quantitative and qualitative research designs. This approach is in keeping with more recent literature reviews focusing on the implementation of programs in non-clinical settings (Street and Ottmann, 2006, Rytechnik et al., 2002, Law et al., 1998). The following table (Table 6) gives an overview of the hierarchy of research designs that underpins the strength of evidence taxonomy.

**Table 6: Research Designs and Associated Levels of Evidence**

<b>Study design</b>	<b>Level of evidence</b>
Evidence from 2 or more appropriately designed mixed-method evaluation incorporating an RCT	A+
Appropriately designed mixed method evaluation incorporating an RCT <b>OR</b> Evidence from 2 or more appropriately designed RCTs	A
An appropriately designed RCT	A-
Evidence from 2 or more comparative studies of interventions with non-randomised controls e.g. cohort, case-control, interrupted time series	B+

Comparative studies of interventions with non-randomised controls e.g. cohort, case-control, interrupted time series, historical control <b>OR</b> Methodologically sophisticated qualitative studies#	B
Comparative studies of nascent interventions with non-randomised controls e.g. cohort, case-control, interrupted time series, historical control	B-
Case series, simple pre-post quantitative designs.	C
Primarily descriptive qualitative studies	C
Evidence from a single panel of experts or key informants	D

A minus sign (-) also denotes that the evaluation or study occurred during or soon after implementation of the intervention, thereby not reflecting necessarily the operations and outcomes of a mature program. This excludes formative and implementation research.

#Level B qualitative studies should incorporate confirmation of findings by triangulation within the research design and demonstrate confirmation of findings by other qualitative and/or quantitative studies for similar population groups/sites.

## IMPLICATIONS FOR PRACTICE

Where study findings were deemed to have implications that reached beyond their local contexts, those findings were carried forward to a master table along with the level of evidence ratings for the parent studies. The findings were grouped thematically and the table reduced where possible by combining comparable findings across separate studies.

This summary table of implications for practice is presented below, showing the types(s) of studies and the level of evidence supporting the implications. The level of evidence ratings are those described in Table 6 in the previous section. The coding for the type of study is as follows:

- Q1 = Quantitative Studies
- Q2 = Qualitative Studies
- MM = Multimethod Studies
- R = Reviews /Commentaries/Expert Opinions
- **Bold font indicates identical findings from multiple studies**
- **Shaded pairs indicate findings are contradictory**

The implications for practice outlined below form the basis of the recommendations stated in the executive summary.

Table 7: Key Implications and Strength of Evidence

Key implications	Type of study & level of evidence	Program location
<b>1. Case management</b>		
<b>1.1 care planning</b>		
Changing needs represent a major problem for older people under CDC arrangements. Fluctuations in care needs may require the setting up of a contingency plan with saved resources for emergency (around 10% of a monthly allowance to be rolled over for up to 8 weeks). For some elderly people planning a year ahead is next to impossible due to these fluctuations. As a result shorter support plans and review cycles should be considered.	Q2 - C/D	UK
Information is crucial for older people. Case managers should routinely check whether families have correctly understood information provided to them.	Q2 - C/D	UK
Care planning for older people requires the use of applied examples. Overall, there is a need to simplify bureaucratic complexities. Too much paperwork and complexity will function as a deterrent for older people.	Q2 - C/D	UK



CDC may accentuate tensions between carers and service recipients. Case managers have to be aware of this possibility and should be able/skilled to manage such conflicts.	MM - A-	UK
Carers' issues tend to be regarded as marginal in CDC programs. Implementing agencies have to make sure that appropriate policies are in place to incorporate the interests of families and informal carers.	MM - A-	UK
Family caregivers rank the safety, quality, and reliability of services above price as choice factors	Q1, B	US
Older people appreciate holistic, family-based IB approaches that take into account their roles/identity.	MM - A-	UK
CDC arrangements tend to involve informal carers/families more in the care plan development than standard service modalities.	MM - A-	UK
IB tends to focus funds more narrowly on ADL activities. CDC users and case managers need to make sure community integration strategies are in place in order to cushion this effect.	MM - A-	UK
<b>1.2 case management role</b>		
<b>Case managers may not be confident in consumers' abilities to self-direct, and thereby need support to reframe their relationships with clients towards being consultants rather than gatekeepers and overseers.</b>	Q1 B Q2, B	US
Support planners tend to develop better relationship with client under CDC arrangements than under conventional case management.	MM - A-	UK
Older people want a continuing relationship with their social worker. Support planning, assessment, and brokerage should be provided by one person.	Q2 - C/D	UK
CDC arrangements may generate a move to more traditional social work roles. This will give rise to demands for 'new' types of social workers that are no longer available. If CDC is to be implemented at a national level, administrators of social work courses need to be alerted to a likely change in demand resulting from this.	R - D	UK
IB requires a total revision of how people's wishes are viewed by agency staff. Also new processes need to be embedded in operational structures. The successful implementation of CDC arrangements requires support from all levels of staff, the training all staff members, the identification of 'change champions', and the fostering commitment and enthusiasm for the project.	Q2 - C/D	UK
<b>2. Cost comparison</b>		
<b>The Individual Budgets programs are generally cost neutral.</b>	MM, A- MM, A-	UK
SELF-DIRECTED CARE prevents use of more expensive medical services such as nursing homes and emergency rooms.	Q2, B	US
<b>3. Marketisation</b>		
<b>There is little evidence that Direct Payments are transforming the service industry and purchasing practices to develop a 'market'.</b>	Q1. C Q2, D	UK
The development of a 'market' for home care that offers the kind of services required and expected by consumers is a major challenge. Small numbers of CDC 'consumers' fail to give rise to a more 'market oriented' service delivery industry. Local governments may have to actively encourage the development of a home care market.	Q1 - C, Q2 - C	UK
The knowledge of local government officers of the home care market is limited. LG officers have to be up-skilled to work within a new market-like home care context.	Q1 - C, Q2 - C	UK

Home care agencies generally lack effective marketing strategies. Agencies have to engage in marketing capacity building.	Q1 - C, Q2 - C	UK
Marketing represents a problem for service providers.	MM - A-	UK
CDC arrangements are likely to generate tension between an economy of scale and individual choices.	MM - A-	UK
<b>4. Outcomes</b>		
<b>4.1 outcomes for informal carers</b>		
CDC arrangements tend to translate into longer support hours for informal carers/families. Longitudinal research is required to explore the long-term impact of this on the burden on carers. [contradicts next finding]	MM - A-	UK
The Cash and Counseling program may reduce caregiver burden in relation to the number of hours spent providing care.	Q1, B	US
IB has significant positive impact on carers' reported quality of life.	MM - A-	UK
Caregivers who felt they had more choice or control over services were more satisfied with services	Q1, B	US
<b>4.2 outcomes for family members who are paid carers</b>		
Paid family members had better relationships with clients but did more unpaid work and suffered more emotional stress. [contradicts next finding]	Q1, B	US
Where carers become paid for personal assistance provided to the consumer, carers may experience better emotional, physical and financial wellbeing.	Q1, B	US
<b>4.3 outcomes for participants in general</b>		
<b>Consumer-directed care arrangements generate more creative care options, greater choice and control, and greater satisfaction with services. This leads to more independence and self-determination. There are no detectable increases in risk to quality, trustworthiness, reliability and safety when compared with agency-directed services.</b>	MM - C Q1, B Q1, B Q1, B Q1, B Q1, B Q1, C	UK, US
<b>4.4 outcomes for older participants</b>		
<b>Older recipients can receive the same benefits from consumer-directed care as younger people, in terms of feeling in control, satisfaction with services and positive care outcomes.</b>	Q1, B Q1, B MM, A-	US UK
Older people tend to make more use of care coordination. This translates into cost for CDC users.	MM - A-	UK
<b>4.5 outcomes for participants with paid family carers</b>		
<b>The employment of family members enhances positive outcomes in service satisfaction and recipient safety.</b>	Q1,B Q1,B Q2, C	US
<b>4.6 risk to users</b>		
No difference in risk for care recipient between agency- and consumer-directed service models.	Q1, B	US
Clients who needed more paramedical help, had more complex needs, less stable provider relationships and less backup from family and friends were at greater risk of abuse and neglect.	Q1, B	US
<b>4.7 service uptake</b>		
<b>The majority of consumer-directed service purchases are for conventional personal care supports.</b>	MM, C MM, A-	UK

Provision of CD voucher system increases the likelihood of use of personal assistance services (by 13% in this study). The CDC voucher plus nurse health promotion intervention has a synergistic effect and increases the likelihood of use of personal assistance services (by 18% in this study). Suggests that nurse coached consumers in use of voucher thereby increasing uptake.	Q1, B	US
Re consumers aged 65 +. CDC voucher was an incentive to increase use of personal assistants in this age group. Introduction of a voucher would therefore increase costs (in this case to Medicaid) of personal assistance services.	Q1, B	US
<b>5. Program funding</b>		
Integration of funding streams (pooled funding) can be difficult to achieve if guidelines directing the use of funding are not 'integrated'. However, the integration of funding streams can result in a reduction of paper work locally.	R - D	UK
Home care services for older people are generally underfunded.	Q2 - C/D	UK
<b>6. Program Planning and Implementation</b>		
<b>6.1 care professionals' concerns</b>		
There are common stakeholder concerns around CDC that should be addressed in project planning and monitored thereafter: fraud, misuse of funds and consumer exploitation; worker pay, conditions and rights; resistance from traditional provider agencies; and potential incompatibilities of consumer-directed services with managed care.	Q2, D	US
Program planning and implementation processes should be inclusive of and address the concerns of care agency professionals.	Q1, D	US
<b>6.2 engagement</b>		
Social marketing of these type of programs require careful consideration as there may be differences in peoples interest in consumer directed type programs depending on their age.	Q2, B-	US
Innovative participant and staff training tend to translate into a better acceptance of CDC programs.	MM - C	UK
Explaining to older people understand how much money is spent on services spark their interest in obtaining better outcomes.	Q2 - C/D	UK
<b>6.3 equity issues</b>		
IB pilots vary widely in terms of features and implementation.	MM - A-	UK
Mandatory targets in conjunction with performance and quality indicators can strengthen implementation outcomes.	Q2 - C	UK
Large variations in implementation of CDC programs and uptake exist throughout the UK. This generates equity issues.	Q1 - C	UK
CDC arrangement may generate imbalances between CDC and traditional modes of service provision. A careful global planning process addressing questions regarding the equity of resource allocation, marked differences in hourly rates and wide variations in level of funding of support organizations is crucial for a successful implementation of CDC programs nation wide.	Q1 - C	UK
CDC arrangements can give rise to inequities between client groups. Extreme care should be taken during the policy and program design stage to avoid potential inequitable access to resources.	Q2 - C/D	UK
<b>6.4 risk management</b>		
Older people have less access to support (and pool of potential paid carers) from family and friends than younger participants: hence program providers need to build in compensatory features and safeguards into their consumer-directed models.	Q1, B	US

Older people are less likely to report higher aspirations and tend to report lower psychological wellbeing. In particular, more vulnerable older people tend to experience higher levels of anxiety. Careful collaborative risk assessment accompanied with an effective suite of safeguards is required to reduce insecurity and anxiety levels. Also, CDC is not suitable during times of crisis. As the conditions of older people may fluctuate significantly, CDC programs need to feature a simple way to transit people from CDC to conventional service provision and back. CDC may not be suitable for older people with more complex needs	MM - A-	UK
Adult Protection officers generally fear that CDC exposes the most vulnerable to an increased risk of abuse. Adult Protection officers have to be well informed about potential risks and have to be involved in the development of safeguards.	Q2 - C	UK
Many older people do not want the additional burden of planning and managing their own support, or the risk associated with directly employing support. CDC programs have to be designed to accommodate these preferences.	MM - A-	UK
Implementations of CDC programs have to be designed collaboratively with all major stakeholders making use of change management strategies. They have to include a clear definition of risk management boundaries and an agency's duty of care, staff training and program marketing strategies.	Q2 - C	UK
CDC agencies should implement clear mechanisms for monitoring and identifying risk to older people once CDC arrangements are in place. CDC is likely to generate tensions between safeguarding responsibilities and a more positive risk culture. Risk Management under CDC arrangements tends to incur higher monitoring and support costs. Agencies have to make sure that these costs are budgeted for.	MM - A-	UK
CDC tends to give rise to concerns about the balance of duty of care and rights. A new approach to risk management is needed to abate these concerns.	R - D	UK
The link between risk and CDC is poorly explored. More research is needed to develop sound risk management strategies.	Q2 - C	UK
Traditional risk management approaches tend to undermine the decision-making processes underpinning CDC arrangements and need to change. Agencies should consider implementing an enabling risk management approach (focusing on how something can be done, rather than on whether something can be done) that directly involves consumers.	Q2 - C/D	UK
<b>6.5 barriers</b>		
Low uptake may be associated with uncertainties among staff, workload pressures, and lack of knowledge. CDC implementation requires extensive staff training, clear guidelines, and a careful workforce planning approach.	Q1 - C	UK
A lack of effective support schemes, staff training and support, local authority leadership and provision of accessible information to potential recipients, staff attitudes, incompatible legislation, unclear eligibility boundaries, and a lack of policy guidance are barriers in the implementation of CDC programs.	MM - C	UK
<b>6.6 user options</b>		
<b>Older people should be offered choice over the amount of self-direction they take on, so that they can retain the elements of traditional agency services they want to keep and try out self-direction in areas where they want more control.</b>	Q1, B MM, A- Q1, B- Q2, B- Q2, C/D Q1, B	US UK
<b>6.7 user support</b>		

Older people tend to have difficulties with the paper work during planning stage. Well-designed support structures are required to enable older people to navigate the planning stage.	MM - A-	UK
Elderly consumers require support to implement a program where they decide how to spend a cash allowance.	Q1, B	US
Programs should offer fiscal agents and counselling and training programs.	Q1, B-	US
Programs should provide backfill arrangements when workers do not turn up.	Q1, B-	US
Although CDC programs aspire to greater transparency and accountability, it can be expected that a large proportion of program participants will be unclear about their entitlements and will find it difficult to understand information. Innovative information strategies have to be devised in order to provide consumer information.	MM - A-	UK
Participants with direct funding should receive appropriate education and support in the areas of care system knowledge, financial and contractual management, personnel management, and information technology skills.	MM, C	AUST
Education/information materials need to be simple and straightforward for consumers with limited educational background.	Q2, B-	US
It may be beneficial to involve the voluntary sector to provide information and support to participants.	Q2 - C/D	UK
Peer support groups may not function properly without adequate support. Appropriate support (community development) and budgeting (over medium and long-term) considerations needs to be given when developing peer support groups.	Q2 - C/D	UK
CDC users require effective support services in order to make effective use of CDC arrangements.	Q2, D	UK
People may be more interested in a cash option and more receptive to the associated administrative tasks when well supported (e.g. good training and assistance).	Q2, B-	US
<b>7. Program suitability</b>		
Consumer directed option can work equally well for those with and without a mental health diagnosis.	Q1, B	US
Consumer directed type of care is a suitable choice for older adults and their family caregivers.	Q2, C	US
<b>8. Provider agency risk</b>		
Service Providers tend to welcome IBs. However, CDC arrangements tend to be more costly for providers. Providers may identify a point at which it is not practical to meet the demands of the care recipient.	MM - A-	UK
Service providers generally view failure of payment of bills and the prospect of losing qualified staff to care recipients as major threats. This risk translates into higher costs for service recipients and more restrictive work contracts for care assistants.	Q1 - C, Q2 - C	UK
Smaller agencies are more prepared to personalise their services and tend to attract a more effective and committed workforce.	Q1 - C, Q2 - C	UK
<b>9. Carer workforce</b>		
<b>9.1 pay and conditions and care quality</b>		
<b>Offering better pay and conditions to carers improves the flexibility and standards of paid care.</b>	MM,C Q2, C	AUST US
The privatisation of personal care has the potential to erode the remuneration, rights and protections of care workers thereby making it harder for clients to hire skilled and committed workers. Therefore, all stakeholders need to be	Q2, B	US

sufficiently funded for consumer-directed care to function successfully.		
The low pay and relatively poor working conditions of individual providers constitute institutionalised exploitation, which both consumers and individual providers wished to change.	Q2, B	US

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## APPENDIX: SUMMARY OF ARTICLES REVIEWED

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### UNITED STATES: CD-PAS PROGRAMS JOURNAL LITERATURE

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#### **Authors**

Beatty et al. (1998)

#### **Program details**

CD-PAS (consumer-directed personal assistance services) in Virginia. Adult disability sector

#### **Methodology**

Cross-sectional study using mail and telephone surveys to compare service satisfaction ratings between CD-PAS recipients and people on the waiting list for CD-PAS. Sample: 60 CD-PAS and 62 on waiting list.

#### **Results / findings**

CD-PAS recipients had significant higher total satisfaction scores, as well as significant higher scores on: amount of control over choice of Pas; authority over their PAs' and their work schedules; availability of PA off-hours or in an emergency. Other satisfaction ratings showed no significant differences. The main dimensions of difference were cost, control and flexibility. Dimensions of similarity were assistance safety, dependability, thoughtfulness, and relationship with carer.

#### **Level of evidence**

B-

#### **Implications from this study**

Indicates that greater control over carer scheduling brings flexibility that enables greater independence. However, the data was not disaggregated by age, so the relevance of the findings for older people only is not known.

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#### **Authors**

Benjamin, Matthias & Franke (2000)

#### **Program details**

California In-Home Supportive Services Program, which had 190,000 low income recipients in 1996/97.

#### **Methodology**

Cross-sectional quantitative phone survey. Random sample of 1095 recipients aged 18 and over. Roughly 50% of sample were 65 and over. Participants with severe cognitive impairment were excluded

#### **Results / findings**

Using unadjusted data, there were no significant differences between service models in the domains of: physical and psychological risk; unmet IADL needs; and provider shortcomings. CDC rated better than PAM by small but significant amounts in the domains of: sense of security; service technical quality; service impact; general service satisfaction; and provider interpersonal manner. PAM rated better than CDC by a small but significant amount in the domain of unmet activities of daily living (ADL) needs. After adjusting for recipient characteristics and condition, differences in favour of CDC remained in the domains of safety, unmet IADL needs and service satisfaction. Participants using CDC with family members as workers reported more positive outcomes in safety and service satisfaction than CDC users with non-family workers, after adjusting for service model and recipient characteristics

#### **Level of evidence**

B

#### **Implications from this study**

This is a competent study of a large-scale mature program with 50% of the sample aged 65 or over. It shows how the model can work year after year in business-as-usual mode, rather than a demonstration pilot or newly implemented model. The study shows overall positive impact of consumer direction with no detectable risks to safety, with additional positive outcomes in safety and service satisfaction for those who hire family members.

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#### **Authors**

Benjamin & Matthias (2001)

**Program details**

California In-Home Supportive Services Program, which had 190,000 low income recipients in 1996/97.

**Methodology**

Cross-sectional quantitative phone survey. Random sample of 1095 recipients aged 18 and over. Roughly 50% of sample were 65 and over. Participants with severe cognitive impairment were excluded

**Results / findings**

Age differences were not statistically significant in 6 out of 10 outcome measures, but over 65s experienced less choice in decision-making about services and showed less preference for self-direction. They also reported less unmet IADL needs than the under 65s. Similar differences also existed in exactly the same direction between the two elder groups: over 75s experienced less choice, fewer IADL unmet needs, and also lesser satisfaction than those aged 65-74. Both elder groups were slightly more likely to hire family members compared to the under 65s, who were more likely to hire either family or friends, backing up the general finding that younger participants have greater circles of support to draw on.

**Level of evidence**

B

**Implications from this study**

Although younger people may like consumer-directed care more, older people can receive a similar magnitude of benefit. However, older people have less access to support from family and friends than younger participants: hence program providers need to build in compensatory features and safeguards into their consumer-directed models.

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**Authors**

Benjamin & Matthias (2004)

**Program details**

California In-Home Supportive Services Program, which had 190,000 low income recipients in 1996/97.

**Methodology**

Cross-sectional quantitative phone survey. Random sample of 253 consumer-directed workers and 365 agency workers who were working for respondents of the main IHSS study (see Benjamin, Matthias & Franke 2000). Worker samples were stratified by service model and age of recipient.

**Results / findings**

10 worker-outcome dimensions for stress and satisfaction were measured: Stress dimensions were : concern about client safety; issues with client's family; client behavioural issues; getting along with client; worker emotional state; clarity of work roles. Satisfaction dimensions were: work role satisfaction; performance self-assessment; career advancement; independence and flexibility. Differences between service models were found to be minimal. After adjusting for worker and recipient characteristics: CDC workers got along better with clients, and work roles were better defined; whereas agency workers worried less about the client away from work. Within CDC workers, family members had better relationships with clients, but unrelated workers had better emotional states. CDC workers, and within them the family workers, did more hours of unpaid work.

**Level of evidence**

B

**Implications from this study**

The authors found that there was little difference in outcomes for agency and consumer-directed workers, noting however that the IHSS program at the time of the study offered fewer fringe benefits to agency workers and less consumer direction support to CDC recipients than more recent projects. The findings that family workers had better relationships with clients but did more unpaid work and suffered more emotional stress are more generalisable and somewhat obvious. The exclusion of the most cognitively impaired - and difficult - recipients from the main study excluded perhaps the most stressed and dissatisfied workers from the sampling frame

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**Authors**

Doty, Kasper & Litvak (1996)

**Program details**

Different state-based PAS programs in Michigan, Maryland and Montana which allow for varying levels of consumer direction

### **Methodology**

Cross-sectional survey by face-to-face interview. Sample: 879 interviewees aged 65 and over (300 in Maryland, 276 in Michigan and 303 in Texas). Sample drawn from Medicaid lists. Response rate of 88%.

### **Results / findings**

The consumer-direction indicators of prior consumer/worker acquaintance, scheduling and supervising work, signing timesheets/paycheck, hiring and firing, were all significantly associated with higher levels of satisfaction with worker competence and 'humaneness'. The first three indicators were also associated with greater overall satisfaction with services.

### **Level of evidence**

B

### **Implications from this study**

The study finds positive relationships between consumer control and service satisfaction across three different programs, thereby to some extent establishing these links independently of program design.

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### **Authors**

Feinberg & Whitlatch (1998)

### **Program details**

Caregiver Resource Centers' Respite Program (California). For caregivers who live with cognitively impaired adult family members. Program offers both options of agency-managed and 'direct pay' (consumer-managed) in-home respite care.

### **Methodology**

Cross-sectional postal survey of 168 caregivers recruited from all 9 CRCs that offer the program. Questionnaire covered care recipient characteristics, caregiver demographics, and 57 closed questions and one open-ended Q about their respite care. 216 surveys sent out, 174 complete surveys returned (81%) of which 168 usable. 68.5% of respondents were using direct pay program, and 31.5% using agency-based respite program. Average duration of care at time of survey was 10 years.

### **Results / findings**

Family caregivers using direct pay more likely to be employed outside the home (30% vs 15%) and non-white (28% vs 11%). Caregivers using agency more likely to be caring for relatives with Alzheimer's (33% vs 22%). No differences between groups in levels of distress or depression; and both groups reported decline in distress since receiving CRC respite; and both groups score high on depressive symptoms. Both groups ranked the safety, quality, and reliability of services above price as choice factors. The more depressed caregivers scored lower on physical health, service satisfaction and feeling in control. There were no significant differences between groups in satisfaction with service quality, support, trustworthiness, administration, safety, reliability. However, across both groups, caregivers who felt they had more choice or control scored higher on satisfaction; and the direct pay users had higher overall satisfaction scores. The direct pay group had significantly lower hourly costs and received significantly more average hours per week of respite (8.4 vs 6.5), with a slightly higher monthly spend (\$251 vs \$234).

### **Level of evidence**

B

### **Implications from this study**

Well reported and credible. The between group differences are mild but do bring benefits. Important to note that all family caregivers were following their option of choice. Across both groups, caregivers who felt they had more choice or control scored higher on satisfaction; Authors make the point that direct pay system popular with caregivers regardless of their age, but does not suit all. Agencies need to offer both options.

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### **Authors**

Grossman et al (2007)

### **Program details**

Personal Assistance Services (PAS) . Adult disability sector

### **Methodology**

Semi-structured interview by telephone. Convenience sample of 24 experienced PAS users, majority aged 18-64, recruited through Centers for Independent Living in seven US states. 10 respondents used agency-based services, 14 hired providers directly.

### **Results / findings**

Respondents regarded PAS as preferable to institutionalisation. Group average hours of PA service per week were 44.3 hours of paid service and 38.0 hours of unpaid (informal) service. Service gaps for public programs included childcare, transportation, recreation, some personal hygiene, and home maintenance. All respondents were satisfied currently with the quality of services, though most had had bad experiences in the past. Chronic worker shortages were seen to be due to low wages (\$7-\$10 p/h in 2004) and lack of benefits. 75% reported unmet needs, including out-of-hours care, shopping, recreation and not enough total allotted hours. Almost all respondents preferred consumer-directed care and many had negative views on agency-based services especially in regards to reliability. The greatest barriers to PAS access were the means testing processes, long program waiting lists, and lack of information about PAS programs.

### **Level of evidence**

C

### **Implications from this study**

The authors admit that the use of a self-selecting small sample may be responsible for positive bias in their findings. However, the study reinforces findings elsewhere that increasing the pay rates for carers is a key to raising the flexibility and standards of paid care.

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### **Authors**

Hagglund et al (2004)

### **Program details**

CD-PAS (consumer-directed personal assistance services) in Missouri. Adult disability sector.

### **Methodology**

Cross-sectional study using in-person interviews to compare outcomes between CD-PAS recipients and agency-based PAS recipients. Independent variables were CDPAS vs agency PAS, type of provider (family vs non-family member) and participant's rating of importance of self-hiring and managing an assistant. Sample: 61 CD-PAS and 53 agency-directed PAS. All adults with physical disabilities, average age 48 yrs.

### **Results / findings**

No significant differences between groups on unmet needs (both rated high unmet needs) or safety; CDPAS rated significant higher on service choice and satisfaction, consumer assertiveness, daily and community living satisfaction. One contributing factor is that agency assistants were limited to in-home services only, whereas CDPAS assistants could accompany recipient to shops and appointments etc. Enrolment in CDPAS was a predictor of more empowerment, satisfaction and better quality of life. Having a family member as personal assistant was predictor of more satisfaction with personal services

### **Level of evidence**

B-

### **Implications from this study**

The study provides supporting evidence for the empowerment and satisfaction advantages of CDC for people over 65; and that having a family member as carer correlates positively with service satisfaction. The small convenience sample used limits confidence in the findings however.

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### **Authors**

Keigher (2000)

### **Program details**

Milwaukee. Private and self-pay arrangements, and Medicaid beneficiaries (CD-PAS)

### **Methodology**

Semi-structured interview . Sample: 40 disabled elders; 41 workers and 18 paid family carers who work for the 40 elders.

### **Results / findings**

Predominant interest of clients was for stasis: to be able to maintain their daily life and routines and activities. Only higher-income clients or those with 20+ hours of care had workers with time free for 'just talk'. Families' primary interest was safety of the elder relative and partial release from anxiety; and subsidy for or relief from formerly unpaid carer work carried out by female relatives. Care workers

needed to carefully weigh up each client before taking one on, in terms of hours, pay, relationship qualities with the prospective client and family, transport issues, as well as the carer's own family needs. Carers received low pay, few if any benefits, and were likely to be in poor health themselves. The workers have few if any other employment options but on the other hand demonstrate high levels of commitment and goodwill.

**Level of evidence**

B

**Implications from this study**

The privatisation of personal care has the potential to erode further the remuneration, rights and protections of care workers thereby making it even harder for clients to hire skilled and committed workers. Therefore, all stakeholders need to be sufficiently funded for consumer-directed care to function successfully.

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**Authors**

Matthias & Benjamin (2003)

**Program details**

California In-Home Supportive Services Program, which had 190,000 low income recipients in 1996/97.

**Methodology**

Cross-sectional quantitative phone survey. Random sample of 1095 recipients aged 18 and over. Roughly 50% of sample were 65 and over. Participants with severe cognitive impairment were excluded

**Results / findings**

The raw scores for the agency (PAM) and consumer-directed (CDC) participants were too close to nominate differences between service models on seven of the measures. Significantly more PAM participants reported problems in the measures of 'neglect' and 'stealing' ; and significantly more CDC participants reported problems in the measure of 'yelling' . When other factors of demographics and casemix were taken into account, there were no significant differences between agency- and consumer-directed services. A comparison between CDC participants with family workers and CDC participants with non-family workers showed significant and sizable differences on raw scores for six of the measures, all indicating greater risk from non-family workers: neglect , injure you when assisting you , push/shove or hurt you physically, steal money or other items , (not)get along with provider), (not)feel safe with provider's assistance). After adjusting for other factors, only the differences relating to feelings of security (getting along with provider, feeling safe with provider's assistance) remained significant.

**Level of evidence**

B

**Implications from this study**

Overall, clients who needed more paramedical help, had more complex needs, less stable provider relationships and less backup from family and friends were at greater risk of abuse and neglect. There appears to be no difference in risk between agency- and consumer-directed service models, and the employment of family and friends appears to be a protective factor rather than enhancing risk. This however points towards the possibility of heightened vulnerability for CDC users who must hire workers outside of their support circle, when the program is poorly resourced in terms of training, monitoring and safeguards.

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**Authors**

Meng et al. (2005)

**Program details**

Medicare Primary and Consumer Directed Care demonstration program funded by the US Centers for Medicare and Medicaid Services. This demonstration was undertaken in New York, West Virginia and Ohio over a 2 year period commencing in 1998. The two evaluated interventions were a consumer directed voucher and a community-based nurse providing chronic disease self-management and health promotion (nurse intervention).

**Methodology**

Randomised controlled trial to appraise the effects of the two interventions on service use and cost. A sample of 1,394 people was selected from those attending Medicare funded primary care physicians



and presenting frequently to emergency departments. These interventions were compared with Medicaid personal assistance services directed by agencies.

**Results / findings**

Provision of CD voucher system increases the likelihood of use of personal assistance services by 13%. The CDC voucher plus nurse health promotion intervention has a synergistic effect and increases the likelihood of use of personal assistance services by 18%.

**Level of evidence**

B

**Implications from this study**

Suggests that service uptake can be increased significantly where consumers in a voucher system receive coaching from nurses.

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**Authors**

Meng et al. (2006)

**Program details**

Same as for Meng et al. (2005)

**Methodology**

Secondary analysis of data from 645 people aged 65 and over from the sample described in the Meng et al. (2005) study

**Results / findings**

The voucher benefit was associated with a trend towards increased average annual expenditure by 10%.

**Level of evidence**

B

**Implications from this study**

The CDC voucher program was an incentive to increase the use of personal assistants by older people, thereby increasing expenditure on personal assistance services. This may be offset by greater efficiencies and savings for other publicly funded services such as health services due to potential improvements in health outcomes.

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**Authors**

Micco et al (1995)

**Program details**

Choice in Supports for Independent Living. British Columbia, Canada. Adult disability sector

**Methodology**

Cross-sectional questionnaire covering client wellbeing, staff workload, and clients as employers. Surveys were sent to case managers at all health units in BC. Sample: 176 usable surveys returned out of 306 sent. Response rate of 57%.

**Results / findings**

Case managers saw the new programs as exposing the clients to increased risks, with little or no benefit to the clients and no reduction of workload for case managers. The authors noted that CSIL implementation was inadequate in terms of engaging case managers in planning and implementation, education about the program, and a too brief implementation period.

**Level of evidence**

D

**Implications from this study**

While some issues raised would be concerns that case managers anywhere would have regarding consumer-directed care, others related more to the specific context of the program and its implementation. However, the study does emphasise the need for inclusive program planning and implementation processes that address the concerns of care agency professionals.

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**Authors**

Wiener, Anderson & Khatutsky (2007)

**Program details**

Adult disability sector. Consumer-directed home care is the dominant model in that state, with less than half of Medicaid home care beneficiaries using agencies. Note that all individuals could choose their service mode.

#### **Methodology**

Cross-sectional telephone survey to compare service satisfaction ratings between Independent Provider care recipients and agency care recipients. Younger than 65 and 65 and older analysed separately to allow for age-related differences in abilities and expectations. Sample: 232 with Independent Provider Option, and a comparison group of 281 with agency-directed care. The latter included individuals in residential care facilities. 54% of younger clients and 38% of older clients used consumer-directed care.

#### **Results / findings**

Between the two groups as a whole, and for people under 65, there were no significant differences on satisfaction with services. People 65 and older with CDC rated satisfaction with services higher than elders with agency-directed care. Elderly Asians were more likely to choose CDC than other ethnic groups.

#### **Level of evidence**

B-- (questionable sampling design)

#### **Implications from this study**

Provides evidence for people over 65 from a mature state-wide CDC program in which all recipients have chosen their mode of care (apart from those in residential care). Over 65s more satisfied with CDC than agency users. Confidence in the findings is diminished though by the inclusion of residential care recipients in the agency-based sample.

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#### **Authors**

Young & Sikma (2003)

#### **Program details**

Washington State self-directed care program Medicaid funded for home-dwelling people with disabilities. Case mgrs asses needs and approve number of hours per month. 37% of self-directing clients over 65.

#### **Methodology**

Descriptive longitudinal, primarily qualitative, using surveys, interviews, and document review. Sample: Survey Time 1: 125 consumers (av age 52 yrs), 29 case mgrs, 69 providers. Time 2: 12 months later. Also focused interviews with 28 consumers and their case mgrs and providers.

#### **Results / findings**

All participants were satisfied with self-directed care, there were no negative outcomes, and the two substantiated reports of abuse or neglect were not directly attributable to SELF-DIRECTED CARE. SELF-DIRECTED CARE prevents use of more expensive medical services such as nursing homes and emergency rooms. The low pay and relatively poor working conditions of individual providers constitute institutionalised exploitation, which both consumers and providers wished to change. Greatest conflict occurs at interface with case managers who had less confidence in consumers' abilities to self-direct. Authors concluded that they needed to reframe their relationships with clients towards being consultants rather than gatekeepers and overseers.

#### **Level of evidence**

B

#### **Implications from this study**

SELF-DIRECTED CARE prevents use of more expensive medical services such as nursing homes and emergency rooms. The low pay and relatively poor working conditions of individual providers constitute institutionalised exploitation, which both consumers and providers wished to change. Greatest conflict occurs at interface with case managers who had less confidence in consumers' abilities to self-direct. Authors concluded that they needed to reframe their relationship with clients towards being consultants rather than gatekeepers and overseers.

### **UNITED STATES: CD-PAS PROGRAMS GREY LITERATURE**

#### **Authors**

Heumann (2000)

#### **Program details**

Four state CD-PAS programs and Cash and Counseling in three states

#### **Methodology**

synthetic review

### **Results / findings**

Older consumers were highly satisfied with consumer-directed services, and that the ability to hire family members was a major contributing factor. The author suggested that states should allow consumers to choose their level of self-direction; to offer fiscal agents and counselling and training programs; and backfill arrangements when workers do not turn up

### **Level of evidence**

B-

### **Implications from this study**

The article provides some original details about three CD-PAS programs not reported elsewhere, but rigorous evaluation of those programs is largely absent. Key findings: allow consumers to choose their level of self-direction; to offer fiscal agents and counselling and training programs; and backfill arrangements when workers do not turn up.

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### **Authors**

Hibbard, Dubow & Peters (2003)

### **Program details**

consumer-directed health care plans, primarily in the private sector

### **Methodology**

analytic commentary

### **Results / findings**

CD planning requires consumers to make informed choices based on awareness and knowledge of their own needs, the care system, a weighting of factors and understanding of risks. Three strategies to enhance consumer decision-making were proposed:

- Reduce the 'cognitive load' on consumers by sorting and consolidating diverse data into simple information displays with strong visual cues.

- Help consumers understand the meaning of choice and the implications of their choices. Providing stories of other people's experiences improves consumers' ability to make considered choices.

- Highlight important information so it is not overlooked.

### **Level of evidence**

D

### **Implications from this study**

The article identifies key issues in consumer decision making and offers operable strategies to enable consumers to make choices in their interests (see results column)

## **UNITED STATES: CASH AND COUNSELING JOURNAL LITERATURE**

### **Authors**

Mahoney et al (2002)

### **Program details**

Cash and Counseling - Not 'tested' per se. Current users of personal assistance services (as per US Medicaid program) were participants in this 'preference' study - to assist in design of the cash option in Cash and Counseling. This background research was undertaken in New Jersey

### **Methodology**

**Preference study/background research.** Telephone survey results quantitative. Study aimed to ascertain consumer preferences for a cash option re personal assistance services. Sample. N=683, 75% female, sample tended to comprise lower socio-economic group with high school education or less, 46% had less than a high school education. Sample was from New Jersey US.

### **Results / findings**

Younger consumers were significantly more interested in the cash option than older consumers (65+).

Almost one third of older consumers were interested in the cash option. Predictors of interest in the cash option included - a desire to be more involved in PAS, willingness to perform employer tasks, dissatisfaction with current service.

### **Level of evidence**

B-

### **Implications from this study**

Findings suggest that education/information materials need to be simple and straightforward for consumers with limited educational background. Consumers of all ages are interested in the cash option - but not all therefore this should be one among other choices. Support may be required.

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**Authors**

Sciegaj, Capitman & Kyriacou (2004)

**Program details**

Nil intervention. Participants were asked to choose 'hypothetically' between different models including Cash and Counseling, Negotiated Care management, Social health maintenance organisation and Traditional case management and rank them according to the one they liked best. Community dwelling elders recruited through three community based services - Greater Boston Chinese Golden Age Center, LaAlianza Hispania, Central Boston Elder Services. Each provides home and community based services to varying cultural & ethnic groups of older adults.

**Methodology**

Cross-sectional design. Survey - face-to-face interviews. N=731. n=200 African American, n=200 Chinese, n=131 Latino, n=200 Anglo American older adults.

**Results / findings**

71% of participants selected traditional care management over consumer directed care and no clear patterns of preferences for increased control over services emerged for these different racial and ethnic groups of people.

**Level of evidence**

B-

**Implications from this study**

Need for flexibility for older adults and provision of a range of options allowing greater control in some areas of services but not necessarily all.

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**Authors**

Simon-Rusinowitz et al. (2000)

**Program details**

Cash and Counseling Demonstration and Evaluation. The information was gathered to inform implementation of CCDE

**Methodology**

Semi-structured interview by telephone. Sample: 20 'policy experts' from the ageing and disability sectors.

**Results / findings**

The major concerns of experts revolved around issues of fraud, misuse of funds and consumer exploitation; worker pay, conditions and rights; resistance from traditional provider agencies; and potential incompatibilities of consumer-directed services with managed care.

**Level of evidence**

D

**Implications from this study**

The paper makes explicit some of the generic stakeholder concerns around CDC that should be addressed in project planning and monitored thereafter: fraud, misuse of funds and consumer exploitation; worker pay, conditions and rights; resistance from traditional provider agencies; and potential incompatibilities of consumer-directed services with managed care.

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**Authors**

Simon-Rusinowitz et al (2005)

**Program details**

Cash and Counseling - Not 'tested' per se. Current users of personal assistance services (as per US Medicaid program) were participants in this 'preference' study - to assist in design of Cash and Counseling. This background research was undertaken in New York city, Florida, New York, New Jersey, Arkansas

**Methodology**

Preference Study/background research. Qualitative focus groups. Inquiry aimed to explore consumer preferences for a cash option as part of the Cash and Counseling program and identify messages to include when informing consumers and in order to effectively market the program. Sample 'pre survey' (in New York City and Florida) included 11 focus groups with n=96 adults including older adults and parents of children with intellectual disability; 'post survey' (Florida, New York, New Jersey, Arkansas) included 16 groups of n=120 people

**Results / findings**

Some people considered that the potential for increased control over service was appealing and welcomed consumer directed care options. Some participants expressed skepticism re the proposed cash option. Older adults were generally more satisfied with existing personal assistant service arrangements than younger adults. Elders have less interest in the cash option compared with younger adults.

**Level of evidence**

B-

**Implications from this study**

These findings indicate that social marketing of these type of programs require careful consideration as there may be differences in peoples interest in consumer directed type programs depending on their age. People may be more interested in a cash option and more receptive to the associated administrative tasks when they are well supported for example by good training and assistance in administrative and accounting activities.

**UNITED STATES: CASH AND COUNSELING GREY LITERATURE**

**Authors**

Mathematica Policy Research - Foster, Brown & Shapiro (2005)

**Program details**

Intervention not 'tested': Participation Survey (all those invited to take part in the Cash and Counseling demonstration programs including those who agreed and those who declined were assessed & compared on demographic variables and costs of personal care services), and anonymous survey (including the same people as for the Participation Survey who agreed to complete this survey) re their reasons for agreeing or declining to take part in the Cash and Counseling demonstration programs). Participation and preference studies undertaken with those people invited to take part in the Cash and Counseling demonstrations in Florida, New Jersey and Arkansas.

**Methodology**

Preference Study/background research. Quantitative and qualitative. Data collected from Medicaid enrolment and claim information (Participation Survey). Anonymous surveys collected by recruiters (during a home visit, over the phone, by family members, by the service provider worker, or by the person themselves). Number of anonymous survey respondents varied by state: Arkansas (n=953 agreed, n=585 declined), Florida (n=1,877 agreed, n=2,792 declined), New Jersey (n=950 agreed, n=1,735 declined).

**Results / findings**

Participation Survey: In Arkansas - people living in metropolitan areas were more likely to participate and those who died within 24 months of intake were less likely to participate. In Florida, the elderly were more likely to participate if their monthly costs were US\$300.00 or greater. In New Jersey, age was the strongest predictor of participation and younger adults (aged 18-39) were more likely to participate than the elderly. Anonymous survey: In the three states the most common reasons for agreeing to take part in the Cash and Counseling demonstration included: greater control over hiring, payment for family or friends, care provision at more convenient times and better or more care. Reasons for declining to take part included: satisfaction with current care, concern that the cash allowance would not meet their care needs. The elderly were much more likely than younger people to note these two reasons for declining to take part in the Cash and Counseling demonstrations.

**Level of evidence**

B

**Implications from this study**

Older people in these samples expressed variable wishes for consumer directed care. Some indicated a preference for greater participation in their care and some did not. Older people may be more interested when good support and training are provided re administrative and accounting tasks.

**Authors**

Brown et al (2007)

**Program details**

Cash and Counseling in three states (Arkansas, Florida and new Jersey). Consumers could cash out their personal care services allowance and decide themselves how to spend these funds. Considerable variation by each state, year of implementation, target group, eligibility criteria, median monthly allowance, support provided, labour market factors affecting availability of personal carers indicate that Cash and Counseling was not one uniform program

## **Methodology**

Variable recruitment processes and gatekeeping practices of some service providers involved in recruitment may have affected the numbers of people who agreed to participate. Overall, small percentages were recruited from the number of known eligible people: in Arkansas (7.8%), in New Jersey (6.3%), in Florida (8.2%). Resulting numbers of this convenience sample comprised: in Arkansas (n=556 adults, n=1,452 elderly), in New Jersey (n=817 adults, n= 938 elderly), in Florida (n=1,002 children, n=914 adults, n=904 elderly). These people were randomly allocated to either Cash and Counseling (treatment group) or agency directed care (control group), however response rates for 9 month post enrolment treatment and control groups ranged from 80.5 - 91.9% in each state indicating that not all those randomised completed follow-up outcome measures. Therefore, this trial was a quasi-experimental design. Caregivers were also included in a caregiver survey captured at 10 months following enrolment numbers of respondents: in Arkansas (n=1,433 adults), in Florida (n=1,193 adults, n=829 children), in New Jersey (n=1,042)

## **Results / findings**

Numerous single item measures capturing unmet needs for help, and satisfaction with: caregiver reliability, paid caregiver behaviour, assistance received and satisfaction with the way they were spending their lives generally were appraised with those allocated to Cash and Counseling reporting significantly better outcomes. The elderly cohort in Florida was an exception to this finding due to the low numbers of these people who actually received their monthly allowance. Caregivers also reported satisfaction with Cash and Counseling.

## **Level of evidence**

B

## **Implications from this study**

Findings indicate that there are potential benefits for adults, older adults, children and caregivers associated with the Cash and Counseling models. Findings suggest that this may assist older people and younger adults with disabilities to remain in the community for longer and with the support of a happier caregiver.

## **UNITED KINGDOM: JOURNAL LITERATURE**

### **Authors**

Carmichael and Brown (2002)

### **Program details**

Summary Findings of Best Value Review of Direct Payments (UK) in Wiltshire. Brief historical overview of emergence of DP in the UK.

### **Methodology**

No information

### **Results / findings**

The article highlights advantages (choice, flexibility) and disadvantages (administrative and banking responsibilities, complexity of system, recruitment difficulties) of DP. Recommendations: ensure adequacy of funding, admin burden should be relieved, ensure that support services are appropriate and user-led, improve confidence and knowledge of DP among social workers, improving awareness among potential users, addressing recruitment issue during times of high employment

### **Level of evidence**

### **Implications from this study**

limited

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### **Authors**

Glendinning, Halliwell et al. (2000)

### **Program details**

Reports on outcomes of DP on quality and relationships with Care Assistants (disability focus)

### **Methodology**

Qualitative: n=44 (interviews and focus groups); Quantitative: n=27 (survey)

### **Results / findings**

Benefits: receiving help with a greater range of tasks, choice of Care Assistant, continuity of care, able to control recruitment and training of CA, enhanced quality of life, development of long-term relationships with Care assistants that benefits both parties - these effects were less apparent when CA was hired through an agency. Drawbacks of directly employing CA: recruitment and training (can



be difficult), employer role and responsibilities (CA misses support from agency, isolation), difficulties balancing appropriate employer-employee relationship with increasing level of intimacy.

Recommendations: Disabled people need support and resources to be good employers, working for disabled people needs to be more attractive to prospective employees (principally by increasing wage levels, establishing networks with other PAs).

#### **Level of evidence**

#### **Implications from this study**

Provides good analysis of pros and cons of direct employment of CA

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#### **Authors**

Manthorpe, Stevens et al. (2008)

#### **Program details**

Linkage between Individual Budget and wider adult protection context in terms of risk management and safeguarding. Short overview of the development process of IBs

#### **Methodology**

Qualitative: n=13 (interviews)

#### **Results / findings**

The link between adult protection and CDC is generally underexplored and agencies have little idea how to handle the tension underpinning the link. Actions taken: Firming up AP policies and regular reviews, processes regarding the identification of risk factors for abuse, preparing a guide for social workers regarding protection and risk management, preparing an info pack for service users, use of support brokers, seeking confirmation from service users that they have understood the CRB process, incorporating CDC into adult protection training, developing audit trails. While AP recognised the benefits of IBs, they feared that especially vulnerable people opened themselves up to abuse. Heightened sense of vulnerability fearing that people would not be coming forth in case of abuse, especially when family carers are involved. Identification of a regulatory gap.

#### **Level of evidence**

#### **Implications from this study**

One of the few articles that makes the link to the institutional context of adult protection.

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#### **Authors**

Priestley et al. (2007)

#### **Program details**

Direct Payments (UK). Social movement pressure and public sector restructuring in conjunction with neo-conservative and new-labour marketisation. Focuses on question why in England take up is much higher. Political background to resistance in the north.

#### **Methodology**

Qualitative, n=102 part of major multi-method evaluation

#### **Results / findings**

The most widespread concern in England was how to promote direct payment usage while maintaining a duty of care. A second concern was uncertainties held by front line staff about the suitability of direct payments compounded by vague definitions of capacity, consent and risk. Implementation was uneven and training and information provision lacked in some parts. To summarize, the introduction of mandatory duties, performance indicators and local targets appeared to have a significant positive impact on policy implementation in terms of take-up numbers (although this raised concerns about the lack of quality indicators). The impact of disabled people's capacity and activism varied greatly across the UK. User-led organizations took the lead in many parts of England and the major Scottish cities but were much less active elsewhere.

#### **Level of evidence**

#### **Implications from this study**

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#### **Authors**

Spandler (2004)

#### **Program details**

Direct Payments (UK). Focuses on contextual factors that underpinning consumer choice under direct payments: conflicting ideologies, insufficient resources, collective vs. individual needs, political and legislative context and move to make compulsory the offering of DPs, welfare trade-off.

**Methodology**

Expert Opinion/Review of contextual factors

**Results / findings**

Summarises arguments for and against DP. Provides an overview of ideological debate and key empirical findings. Recommendations: 1) need to resolve tension between individualistic choice and collective social service provision - can be bridged via collectively pooling DPs; 2) the promotion of individualised funding without the development of community and support networks leads to a privatisation of the social care system that actually limits choice and control of individuals, say by limiting the resources available in the system - this can be overcome by stimulating collective action networks and initiatives that lobby for adequate funding; 3) it is important to unpack the complex dynamic of the relationship between mainly underpaid PAs and care recipients - this requires the political organisation of PAs and the development of solidarity ties between recipients and PAs - this could be resolved through multi-stakeholder cooperatives; 4) it is important to develop a better understanding of the political context in which DPs are being implemented. It is this context that constrains/unlocks the potential of DPs.

**Level of evidence**

**Implications from this study**

Provides rare background analysis - extremely useful

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**Authors**

Stainton and Boyce (2004)

**Program details**

Report on 2-year evaluation of 2 Direct Payments (UK) schemes in Wales. Short overview of the development process of interventions and of evaluation

**Methodology**

Qualitative: n=10 + 25 (in-depth and semi-structured interviews) Quantitative: n=88 (survey) with social workers + 10 interviews with managers and survey with people who did not opt to take up DPs

**Results / findings**

Reasons for uptake: sensitivity and professionalism of staff, staff were disabled themselves, experience with conventional services (high turnover, services done for rather than done with people, lack of continuity, need to repeat explaining tasks and routines). Outcomes: Most regarded experience as positive, ability to choose staff most important, relationship with CA, ability to control timing and pattern of care provision, greater degree of independence, flexibility allows for greater range of activities, better health outcomes, trust in dependability of CA. Effects on other members of family: burden remains heavy, greater flexibility welcome, positive relationship with CA.

**Level of evidence**

**Implications from this study**

Moderately useful discussion of benefits of DP

**UNITED KINGDOM: GREY LITERATURE**

**Authors**

Arksey, Glendinning et al. (2009)

**Program details**

Carers (changes in informal support provided, changes in quality of life) focus in evaluation of 13 IB sites in the UK. Summary of Antecedents to IB. Underlying principles. Summary of UK research evidence.

**Methodology**

Mixed Method: Quantitative: RCT part of IBSEN evaluation (BL n=129 60 intervention, 69 control). Qualitative: in depth interviews with 24 carers and semi-structured interviews with 139 carers from 9 IB pilot sites.

**Results / findings**

IB has significant positive impact on carers' reported quality of life. Carers' satisfaction with service users' support planning was important predictor of carer outcome. Older people appreciated holistic,



family-based IB approach that took account of their roles. No cost difference. Differences in how carer needs were assessed among the pilot sites (early example overlooks them). Sites varied in the way carer help was used to limit payments. Only minority of carers received any payment from service users' IB. Carers' issues were regarded as relatively marginal in IB. However, as program proceeded carers were regarded as more important in several sites. On occasions tensions between carers and service users were fathomable. Carers seem to spend more time under IB arrangement than under standard arrangement. Carers were more involved in the care plan development under IB.

#### **Level of evidence**

#### **Implications from this study**

Good overview of IB impact on carers.

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#### **Authors**

Baxter, Glendinning et al. (2008)

#### **Program details**

Reporting on Service Provider Response to IB in UK

#### **Methodology**

Quantitative: Secondary analysis of workforce characteristics of 99 home care agencies. Qualitative: 1 purchasing manager for each of the 4 LAs and 32 home care agencies (semi-structured)

#### **Results / findings**

Government funded Personal Care has become the core business of most Service Providers. Local Authorities have introduced contracts with independent home care agencies based on geographical zones - this could limit opportunities for choice of agency. LA commissioning officers were committed to personalised budgets but knew little about the local home care market apart from directly contracted services. Smaller agencies had more personal contact, were more prepared for negotiating care arrangements directly with IB holders, and had more privately paying clients, employed more mature workforce, and had lower turnover. Larger agencies were expected to be better protected against new financial risks from IBs. Risks include non-payment, increased demands for more flexibility and intermittent timetabling. IBs were considered too low to allow users to purchase agency care, leading to reduced demand for services. Concerns about maintaining a qualified workforce in a context in which staff training becomes more complex due to more complex and more diverse service demands. Agencies had no clear advertising strategy - normally targeted at purchasing officer, agencies used a range of incentives and controls to retain workers and to discourage them to work for clients directly. Small numbers have hardly any impact on service delivery.

#### **Level of evidence**

#### **Implications from this study**

Good summary of service provider issues.

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#### **Authors**

Care Services Improvement Partnership (2007)

#### **Program details**

Best Practice Guide to Older People's Services and IB. Services and Operational Context provided

#### **Methodology**

Based on Stakeholder Consultation: Qual 14 managers, service leaders, social workers, team managers from 8 sites

#### **Results / findings**

Need to promote positive culture, engage older people - you need to start small - things are quite ordinary in what people are aiming to do - people don't want to start negotiating a new way of doing things when they're in crisis - provides control - small undramatic changes can make a profound difference to a person - older people adopt a mix and match approach combining conventional and DP to buy additional support or equipment - the flexibility of DP is much appreciated by some - design of alternatives to conventional meals of wheels for instance - the ability to employ a neighbour or friend or family was welcomed - most people chose DP to family or friends - people choose either SW or family for support services; Information is crucial for older people - some are routinely checking whether families have correctly understood the info... Many care packages are quite small leaving little scope for flexibility or changes (although small changes can help), the program has exposed

inequity between client groups; important to link to equipment funds - training all staff members, identifying champions, and fostering commitment and enthusiasm is required - peer support group was not successful in Barnsley; Need to simplify bureaucratic complexities (old people do not like ticking boxes); Support planning, assessment, and brokerage should be provided by one person ; Changing needs represent a major problem (need of contingency plan with saved resources for emergency) For people whose needs fluctuate contingency needs to be taken into account; Allow for 10% of monthly allowance to be rolled over or can keep up to 8 weeks allocation saved up before it is clawed back, They can set a mid point budget to average out; fluctuations; For some elderly people planning a year ahead is next to impossible due to these fluctuations - some consider shorter support plans; plans are objective based - not did you spend the \$ the way you said you would; Need to involve voluntary sector to provide information and support; Risk management needs to change - enabling approach involving consumer

**Level of evidence**

**Implications from this study**

Important summary of issues important for older people's IB

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**Authors**

Davey, Fernandez et al. (2007)

**Program details**

UK-wide survey of Direct Payments: implementation, resources, variations in support costs, best practice, effects of local resources on uptake

**Methodology**

Mainly Questionnaire (2x) to all local authorities in UK

**Results / findings**

Variations in implementation and uptake throughout UK. Low uptake may be associated with uncertainties among staff, workload pressures, and lack of knowledge. Imbalance between DP and institutional modes of service provision. Questions regarding the equity of resource allocation. Limited number of one-off payments surprising. Marked differences in hourly rates and what is included in rates. Concerns that rates are generally too low. Wide variation in level of funding of support orgs. Little evidence that DP are transforming the service industry and purchasing practices.

**Level of evidence**

**Implications from this study**

Detailed analysis of implementation. Usefulness limited by singular methodology.

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**Authors**

Glendinning, Challis et al. (2008)

**Program details**

Evaluation of IB in 13 pilot sites in UK

**Methodology**

Mixed Methods: RCT (n=959 510 in intervention 449 in control) BL + T+6. 28% older people. Semi-structured interviews (n= 130) T+2.

**Results / findings**

Around half unclear about entitlements, even those who received explanations found it difficult to understand them, At T+6 around 1/3 had planned support. 59% used IB to purchase some conventional supports, Over half employed their own CA. After CA, leisure most common expenditure. Outcomes for older People: Less likely to report higher aspirations, lower psychological wellbeing, Higher levels of anxiety among the more vulnerable who had IBs by their proxy respondents, many did not want additional burden of planning and managing their own support, risk associated with directly employing support, more likely to feel in control, no significant difference in other domains, better social care outcomes, cost neutral, increased used of care coordination (higher cost), IB appeared to focus funds more narrowly on ADL activities. Difficulties with paper work during planning stage, support planners develop better relationship with client, no clear mechanisms for monitoring and id of risk once in place, tension between safeguarding responsibilities and positive risk culture. Service Providers: providers embraced IB, more costly for providers, not practical to meet all demands, marketing a problem. Risk Management incurred high monitoring and support costs. May not be suitable for older people with more complex needs. Not suitable during times of crisis. Tension

between economy of scale and individual choices. Majority used direct payments only few used agents or trust accounts (options need to be explored in greater detail).

**Level of evidence**

**Implications from this study**

Very thorough evaluation of IB. Data collection too soon after implementation (6 mths) when people were still trying to re-arrange their lives.

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**Authors**

Henwood and Hudson (2007)

**Program details**

Evaluation of mid point of IB in 13 local gov't areas to provide strategic direction in the implementation process

**Methodology**

Expert Opinion, based on 2 preliminary studies

**Results / findings**

All positive - huge dividends; Better health and well-being; spending more time with well-liked people; improved quality of life; more community life; feeling safer and more secure at home; choice and control; personal dignity; economic well-being

**Level of evidence**

**Implications from this study**

Limited - mainly advocacy

**Authors**

Nichols (2007)

**Program details**

CSIP summary of good practice issues regarding IB in 13 pilot sites. Deals predominantly with contextual issues such as change management

**Methodology**

Qualitative (n=14)

**Results / findings**

IB requires total revision of how people's wishes are viewed. New processes need to be embedded in ops. Support from all levels of staff. Engaging older people by starting small, don't introduce IB during times of crisis, giving people choice from the outset, When people understand how much money is spent elsewhere they start wondering if they get value for money, small differences can make a big difference, many adopt a mix and match approach, many like to retain element of traditional services, may choose direct payments to family or friends over indirect payments, services are generally underfunded, most people want continuing relationship with social worker, care planning requires applied examples, too much paperwork and complexity, older people don't like ticking boxes, support planning and brokerage should be provided together, shorter support plans work better for older people, review should be outcome focused, should build on what older people currently use rather than imposing new model.

**Level of evidence**

**Implications from this study**

Rare overview of implementation issues.

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**Authors**

Poll, Duffy et al. (2006)

**Program details**

Disability focused report on 6 pilot sites that influenced the emergence of IB in the UK. Consumers' experience of service provision, short outline of development phase, detailed outline of In Control methodology.

**Methodology**

Quantitative: Before/After questionnaire T+16, T+61, (n=31 from 6 pilot sites)

**Results / findings**

Explores the domains of self-determination, support, home, direction, money, community life. The report shows improvements for all indicators

**Level of evidence**

**Implications from this study**

limited in terms of evaluation. Good overview of In Control method

**Authors**

Ridell, Priestley et al. (2006)

**Program details**

Four country study focusing on differences in implementation of direct payments.

**Methodology**

Multimethod/Multisite: Multi-tiered Key Informant Interviews (21), Phone Survey (102), Postal Questionnaire (to all participating organisations), Post Questionnaire to all authorities supporting DP, Case Studies (8)

**Results / findings**

Local variation is not attributable solely to local factors and that varied techniques of devolved governance impact on equity and social justice for disabled people. DP was widely welcomed for creative options, agree that DP gives greater choice, control, and flexibility, bulk of resources used for personal care, Innovative training and info to staff and users impacts on uptake. Tensions between consumers, brokers, and service providers are foreshadowed. A range of barriers were identified by local authorities (among the most important were an effective support scheme, staff training and support, local authority leadership and provision of accessible info to potential recipients, staff attitudes, demand for DP, national legislation, policy guidance). Three most important issues hindering progress: concern about managing DP among service users and carers, staff resistance to DP, and difficulties regarding the supply of personal assistants. PROBLEMS: Difficulty defining needs, unclear eligibility boundaries; difficulty to contract PAs, in most areas contracting of relatives was regarded with caution - however, was seen as way to increase labour pool; only 1/4 of support orgs were user-led; Concerns about sustainability of links between DP and disability activism.

**Level of evidence**

**Implications from this study**

Good overview of problems that occur during implementation

**AUSTRALIA: JOURNAL LITERATURE**

**Authors**

Ottmann, Laragy & Haddon (2008)

**Program details**

Pilot program operated by Uniting Care Community Options agency in Victoria for recipients of Making a Difference disability packages worth around A\$5000 per annum each. Participating families were able to 'cash out' their case management costs (40-45%) entirely; or contract the agency as fiscal intermediary at a charge of 10%, which also included some extra support services; and purchase case management support at \$50/hr.

**Methodology**

Longitudinal qualitative study, using data from semi-structured interviews with family carers conducted at T+6 months, T+36 and T+48 months. Sample: 12 participating families in total: 4 were interviewed three times; 6 twice; 2 once only at T+6 months. Nine of the interviews were with the mothers only, and three with both parents. The ages of their dependent children with a disability ranged from 5 years to in their 20s.

**Results / findings**

The ability to employ their own staff enhanced the relationships between support workers and the care recipients and families, which translated into better care outcomes. However participants also found that increased self-reliance could result in greater isolation from social and practical supports. The authors recommend that agencies offering self-directed care maintain strong programmatic safeguards for participants, including the linking of families into formal and informal support networks

**Level of evidence**

C

**Implications from this study**

Increased self-reliance may result in greater isolation from social and practical supports. Agencies offering self-directed care should maintain strong safeguards for participants, including linking families into formal and informal support networks

## AUSTRALIA: GREY LITERATURE

### **Authors**

Fisher & Campbell-McLean (2008)

### **Program details**

New South Wales Dept of Ageing, Disability and Home Care piloted a direct funding version of the Attendant Care Program to operate alongside the existing co-operative model (in which agency is fiscal intermediary) and traditional agency model. The cooperative model appears to be rigid and unresponsive compared with fiscal intermediary models in the US and UK.

### **Methodology**

Essentially cross-sectional with one intervention and two comparator groups. Measurements for intervention group at baseline and 6 months; measurements of comparators once only.

Supplemented with interviews of participants, agency managers, family, carers and government officials. Sample: 10 direct funding participants, and total of 26 in the 2 comparator groups (numbers not reported separately). Participants were aged 20-65. Interviews with all participants and 12 stakeholders. No people over 60 in the intervention group, and an unknown number aged 60-65 in the comparators. The DF group was younger and reported better baseline characteristics on all measures of disability, economic participation, social support, physical, mental and emotional wellbeing.

### **Results / findings**

Direct funding participants reported improved outcomes in health and wellbeing, confidence and self-esteem, and community, social and economic participation. Being able to offer better pay and conditions to carers improved care quality in terms of consistency, reliability and flexibility. Also lower staff turnover, more individualised staff training, better rapport. Direct funding was no more expensive than the other models. The authors recommended that participants with direct funding receive appropriate education and support in the areas of care system knowledge, financial and contractual management, personnel management, and information technology skills. Little confidence can be placed in the comparative findings however as the comparator samples were poorly matched.

### **Level of evidence**

C

### **Implications from this study**

Despite its shortcomings, the study does show that direct funding can improve outcomes for recipients who are able to and supported to direct and manage their own care. Also direct funding was found to be cost neutral and it raised the hourly income for attendant carers by up to 30% above agency rates.

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### **Authors**

Spall, McDonald et al. (2005)

### **Program details**

Queensland CDC projects. So-called market reforms are closely associated with new public management into service domains. NPM became a key instrument in Labour's public sector reform leading to a soft, quasi-market qualities.

### **Methodology**

Qualitative, narrative approach, n=63

### **Results / findings**

The notion of choice is fictitious because the quasi-market does not address the existing inadequate supply of service. In both rural and remote and metropolitan Queensland, there is little or no choice for consumers in terms of service providers. Service users also found that the introduction of individualised funding arrangements raised issues around equity and entitlements. Few consumers were in receipt of adult lifestyle support packages, and most were on the register of unmet need and perceived that they had little hope of ever being funded. The experience of service users was not much different in terms of efficiency. For consumers, these reforms resulted in perceived cut-backs in service delivery, greater attention to throughput, greater targeting of services through the use of assessment procedures and perceived longer waiting times. For many, the cost of care had risen, but the quality of care had declined.

### **Level of evidence**

C

**Implications from this study**

Provides a rare critical snapshot of subjective view of CDC over time.