

12.0 Appendix I: Methodology for this review

This section gives more details about the methodology used in this review.

12.1. Search strategy

We searched the following databases for relevant studies, in July 2011:

- Campbell library
- Cochrane library
- CRD (includes NHS EED)
- EconLit
- Embase
- HEED
- Medline
- PsycInfo
- SocIndex
- Web of Science

Search strategy: Campbell Library

Personal budget OR personalisation OR direct payment [all text]

AND

(united kingdom or england or english or scotland or scottish or wales or welsh or ireland or irish or netherlands or dutch or norway or norwegian or german* or united states of america or usa or new zealand* or australia*) [all text]

AND

(disab* or handicap* or mental* or psychiatr* or brain* or dementia*) [all text]

Search strategy: Cochrane Library

personal budget*ORpersonalisationORDirect payment*

AND

(disab* or handicap* or mental* or psychiatr* or brain* or dementia*)

AND

(united kingdom OR england OR english OR scotland OR scottish OR wales OR welsh OR ireland OR irish OR netherlands OR dutch OR norway OR norwegian OR german* OR united states of america OR usa OR new zealand* OR australia*)

Search strategy: CRD

(personal budget*) OR (personalisation) OR (direct payment*)

Publication date from 2000 to 2011

Search strategy: EconLit

(united kingdom OR england OR english OR scotland OR scottish OR wales OR welsh OR ireland OR irish OR netherlands OR dutch OR norway OR norwegian OR german* OR united states of america OR usa OR new zealand* OR australia*)

AND

disabil* OR disabl* OR handicap* OR mental* OR psychiatr* OR brain* OR dementia*

AND

personal budget* OR personalisation OR direct payment

Publication date from 2000 to 2011

Simplified search strategy: Embase

(united kingdom OR england OR english OR scotland OR scottish OR wales OR welsh OR ireland OR irish OR netherlands OR dutch OR norway OR norwegian OR german* OR united states of america OR usa OR new zealand* OR australia*)

AND

(disable* OR disabil* OR handicap*)

AND

(brain injury OR dementia)

AND

(direct payment OR personal budget)

Simplified search strategy: Medline

united states OR Australia OR germany OR great Britain OR England OR northern Ireland OR Scotland OR wales OR Ireland OR Netherlands OR New Zealand

AND

Delirium, Dementia, Amnesic, Cognitive Disorders OR Dementia, Vascular OR AIDS Dementia Complex OR Dementia, Multi-Infarct OR Dementia OR Frontotemporal Dementia

AND

brain injur*

AND

disabled persons OR amputees OR disabled children OR hearing impaired persons OR mentally disabled persons OR mentally ill persons OR visually impaired persons OR Mental Disorders

AND

(disable* OR disabil* OR handicap*).

AND

(Mental Psychiatri) OR (Health OR Disorder)

AND

personalisation.

AND

direct payment*

AND

personal budget*

AND

individualised funding

AND

portable funds

AND

individualised allocation

AND

individual

AND

self-directed support

Limited to English language

Publication date from 2000 to 2011

Search strategy: PsycInfo

personal budget* OR personalisation OR direct payment

AND

disabl* OR disabil* OR handicap* OR mental* OR psychiatr* OR brain* OR dementia*

AND

united kingdom OR england OR english OR scotland OR scottish OR wales OR welsh OR ireland
OR irish OR netherlands OR dutch OR norway OR norwegian OR german* OR united states of
america OR usa OR new zealand* OR australia*

Publication date from 2000 to 2011

Search strategy: SocIndex

Disabilities OR AIDS for people with disabilities OR communicative disorders OR developmental
disabilities" OR learning disabilities OR mental illness OR perceptual disorders OR social
disabilities

AND

brain injur*

AND

disabl*

AND

(mental health OR mental illness OR psychiatric)

AND

dementia

Publication date from 2000 to 2011

Search strategy: Web of Science

Databases=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH

united kingdom OR england OR english OR scotland OR scottish OR wales OR welsh OR ireland OR irish OR netherlands OR dutch OR norway OR norwegian OR german* OR united states of america OR usa OR new zealand* OR australia*

AND

(personal budget*) OR (personalisation) OR (direct payment*)

AND

(disab* or handicap* or mental* or psychiatr* or brain* or dementia*)

Publication date from 2000 to 2011

We also manually searched a number of websites, including:

- The University of York Social Policy Research Unit www.york.ac.uk/spru
- The Commonwealth Fund www.commonwealthfund.org
- John Rylands University Library www.manchester.ac.uk
- University of Bristol www.bristol.ac.uk
- Social Care Institute for Excellence www.scie.org.uk
- Audit Commission www.audit-commission.gov.uk
- NHS Confederation www.nhsconfed.org
- Health Foundation www.health.org.uk
- University of Leeds www.leeds.ac.uk
- Scottish Government www.scotland.gov.uk
- Third Sector Research Centre www.tsrc.ac.uk
- In Control www.in-control.org.uk
- Local Government for Improvement and Development www.idea.gov.uk
- Department of Health www.personalhealthbudgets.dh.gov.uk
- Hampshire County Council www.hants.gov.uk
- Acevo www.acevo.org.uk
- Stockport Council www.stockport.gov.uk

An additional study, van Ginneken et al. (2012) was published and included after the July 2011 searches as it was assessed as being highly relevant.

Screening

We used an explicit set of eligibility criteria to select studies that have been identified from the search to include into the review. The eligibility criteria are described in the following sections, and the inclusion criteria checklist is reported in section 13.3.

12.2. Study design

We included studies that reported primary data on relevant outcomes for the review, and systematic reviews of such studies. This included:

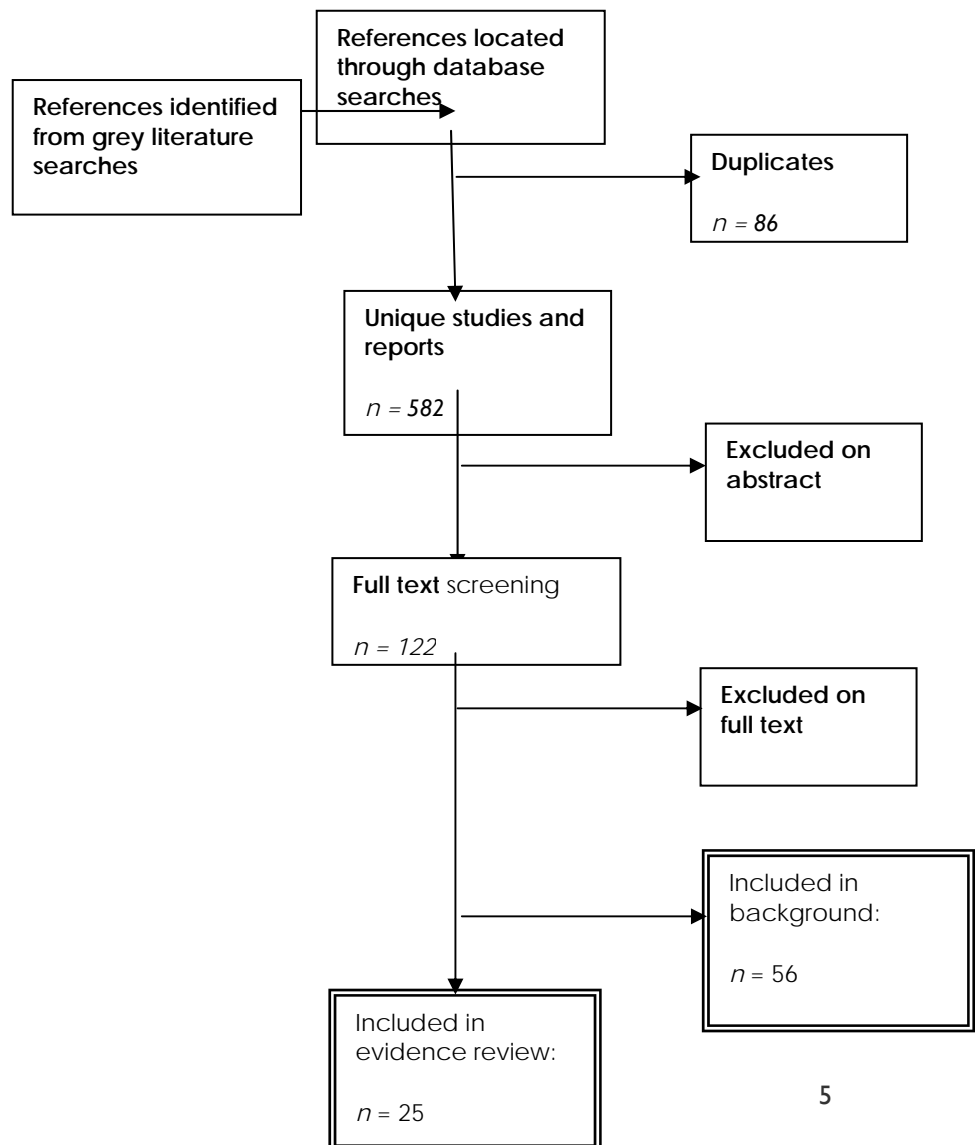
- Randomised controlled trials and other controlled trials;
- Before-and-after studies assessing outcomes after a change in policy or legislation;
- Observational studies comparing outcomes from different jurisdictions;
- Qualitative studies reporting views of service users and providers;
- Economic analyses of the interventions and policy changes;
- Systematic reviews of comparative studies; and
- Narrative reviews that report primary data from such studies.

Data extraction

We extracted data into relevant fields in a standard table to ensure transparency and reproducibility of the review. The fields reflected the methodology used by each study and relevant outcomes.

12.3. Flow of literature

(This diagram illustrates how literature was selected, locating items via searches, eliminating duplicates and studies not appearing as relevant)



12.3. Screening checklists

Table 8 below reports the inclusion criteria used for screening studies for this review.

Table 7 Screening checklists

Is the study relevant to personal budgets? Terms that are relevant include: personal budgets; individual budgets ¹ ; direct payments ² ; personalisation; In Control ³ ; self-directed support ⁴ .	YES/UNCLEAR – go to Q2	NO – exclude 1_EX Topic
Does the study report on the impact of personal budgets on people with long-term physical or mental impairment/disability?	YES/UNCLEAR – go to Q3	NO – exclude 2_EX Disability
Was the study published in 2000 or later?	YES/UNCLEAR – go to Q4	NO – exclude 3_EX Date
Is the study report published in English?	YES/UNCLEAR – go to Q5	NO – exclude 4_EX Language
Does the study include data or comment about 1 or more of our identified countries (UK, Netherlands, Norway, Germany, USA, New Zealand and Australia) or any other OECD country?*	YES/UNCLEAR – go to Q6	NO – exclude 5_EX Country
Does the study include evaluations of or data from personal budgets using any design (e.g. RCT, comparative study, one-group pre-post, economic analyses, qualitative/views), or systematic reviews of such studies?	YES/UNCLEAR – 7_IN DATA	NO – exclude 6_EX Data
Does the study report the opinions or views of a commentator on the likely impact of personal budgets on people with disability?	YES/UNCLEAR – 8_EX OPINION	
Does the study provide information that would be useful for background/context	YES/UNCLEAR – 9_EX BACKGROUND	

¹**Individual budgets:** bring together a variety of income streams from different agencies to provide a sum for an individual, who has control over the way it is spent to meet his or her care needs.

²**Direct payments:** payments given to individuals so that they can organise and pay for the social care services they need, rather than using the services offered by their local authority.

³**In Control:** A partnership of central and local government and the independent and voluntary sectors. It aims to put disabled people in control of their own lives through the power of self-directed support. This involves giving people control of a personalised budget.

⁴**Self-directed support:** This means people co-design the support they need in their lives and have control over what that support is – often a key lever for this is giving them control over the funding for their support.

For cases where inclusion is unclear, code as I0_QUERY and save to discuss with screening team.

12.4. Quality assessment criteria

We applied the criteria in table 8 to determine the overall quality and relevance of the included studies to the research question.

Table 8 Quality inclusion criteria

	Reporting, transparency	Appropriateness of study design and sample size	Quality of execution	Relevance
High	The aims of the study are clearly stated; information about methods and participants is complete; analytical strategy is made explicit.	The methods and sampling strategy used to answer the research question are adequate.	The methodological strategy is soundly carried out.	The population and topic under investigation is relevant to the aim of our review.
Mid	Some of the above are missing, but the study is still broadly transparent and could be replicated.	A better alternative approach could have been deployed, certain decisions remain controversial, or insufficient information is provided.	The study is sufficiently reliable, although there are some quality issues.	The study addresses the topic in a way or in a context that is not directly relevant to this review's research question.
Low	Most of the above are missing, severely limiting the possibility of evaluating the study. This necessarily has a negative impact for the rest of the appraisal.	There is a serious mismatch between the aims and the methods or no information is provided.	There are serious flaws in the execution, or not enough information is provided.	The focus or the approach of the study is only minimally relevant.

The quality assessment scores for the 25 included studies are reported in Table 9 below.

Table 9 Quality scores of included studies

	Reporting, transparency	Appropriateness of study design and sample size	Sample size	Quality of execution	Relevance	Total
Foster et al. (2003)	High	High	1,739	High	High	High
Jones et al. (2011)	High	High	20	High	High	High
Health Foundation (2010)	High	High		High	High	High
Rosenberg et. al. (2005)	Mid	Mid	n.a.	High	High	Mid

	Reporting, transparency	Appropriateness of study design and sample size	Sample size	Quality of execution	Relevance	Total
Spandler and Vick (2006)	High	High	27	High	High	High
Stainton et al. (2009)	High	High	23; 88	High	High	High
Fisher et al. (2011)	High	Mid	132; 32; 8	High	High	High
Dale and Brown (2006)	Mid	High	2,008	High	High	High
Glendinning et al. (2008)	High	High	959	High	Mid	High
Pearson (2010)	Mid	High	n.a.	High	High	High
SCIE (2009)	High	Mid		Mid	High	High
van Ginneken et al. (2012)	High	Mid	n.a.	Mid	High	High
Glasby et al. (2009)	Mid	Mid	n.a.	High	High	Mid
Riddell et al. (2006)	Mid	High	21; 102	High	High	High
Sikma and Young (2003)	Mid	High	125; 69; 29; 30; 30; 24	High	High	High
Alzheimer Scotland (2011)	Mid	Mid	12; 10; 28	High	High	Mid
Rabiee et al. (2009)	High	Mid	14	Mid	High	Mid
Fernandez et al. (2007)	Mid	High	n.a.	Mid	High	Mid
Scourfield (2005)	Mid	Mid	n.a.	Mid	High	Mid
Cook et al. (2008)	Low	Mid	106	Mid	High	Mid
Timonen et al. (2006)	Mid	Low		Low	Mid	Low
Laragy and Ottmann (2011)	High	Low	5; 9	Low	Mid	Low
Kremer (2006)	Low	Low	n.a.	Low	High	Low
Maglajlic et al. (2010)	High	Low	10	Low	Low	Low
Spalding et al. (2006)	High	Low	16	Low	Low	Low

13.0 Appendix 2: Evidence tables

13.1. Detailed evidence summary tables for the included research studies

Alzheimer Scotland (2011)
Study aim(s): To identify the barriers that limit the wider implementation of personalisation and provide key recommendations that will enable the majority of people with dementia and their carers to personalise their care and support. Quality assessment: Mid
Population: 12 carers of persons with dementia using direct payments, social work staff involved with direct payments and Scottish local authorities. Country: Scotland Sample size: Carers: N=12 Social workers: N=10 Local authorities: N=28
Study Methods Study design: Narrative review Sample selection: Carers: Via the distribution of an information sheet through Alzheimer Scotland networks and via the independent self-directed support organisations. Twenty local authority social work departments were also contacted with a request to identify direct payment recipients. Social workers: Twenty representative local authorities were contacted. All Scottish local authorities. Data collection: Semi-structured interviews with carers and social workers. Questionnaire for local authorities. Evaluation/intervention: Personalisation: Direct payments Implementation, benefits and barriers.
Implementation Models of personalisation: Direct payments were the main type of individualised funding in each of the local authorities. Six of the 10 local authorities were moving towards other types of personalisation such as an individual budget, home care and self-directed support. Direct payment rates: The majority of local authorities had more than one direct payment level. There was wide variation, with the lowest payment rate ranging from £6.58 to £12.07 and the higher rates from £11.42 to £22.50. There was also some variation between the seven authorities that had a single flat rate, ranging from £10.20 to £11.42. Payment of different rates: Factors to determine the level paid to each recipient: <ul style="list-style-type: none">• The assessed need and type of support required (n=7).• Whether the recipient would use it to employ a personal assistant or purchase the service of an agency, with the agency payment level being higher in each instance(n=7).• According to the client group the person was assigned to e.g. older people, learning disability (n=2).

Alzheimer Scotland (2011)

- One authority paid the hourly rate it would have cost them to provide or purchase the support directly.

Higher support costs:

Local authorities had a variety of approaches if the recipient wished to purchase support from an agency with a higher hourly rate than their set rates:

- 13 local authorities might pay a higher rate; many qualified this by adding that the circumstances would be a factor, for example if this was the only agency that could meet the person's needs.
- Eight authorities would allow the person to purchase fewer hours.
- 16 authorities would allow the person to top-up the direct payment level

Take up:

National statistics show that the number of direct payment recipients for a person with dementia can be no greater than 600 across Scotland; however, the actual number is likely to be much smaller as the national figures will include other care groups. If actual take-up across Scotland mirrors that of the 10 local authorities participating in the research then there would be approximately 300 direct payments for people with dementia.

Factors influencing up-take of direct payments:

Effective leadership, staff knowledge and positive attitude, good quality information provision for potential recipients and ongoing support for those using a direct payment.

Publicity: All 10 social work staff said their local authority undertook some level of publicity in order to inform the general public about direct payments.

"Very few people come to us and specifically say they are interested in direct payments" Social work staff member

Knowledge of direct payments:

The majority of social work interviewees believed awareness of direct payments was good amongst social work staff members.

All authorities had measures in place to support staff in delivering direct payments, through some combination of a central point of reference, training and/or ongoing support. Guidance was general and not specific to different care groups. Some interviewees highlighted the issue of staff not having the opportunity to put the knowledge into practice often, so they would therefore not be confident in using direct payments.

"If you are not putting it into practice then you lose the knowledge, plus things change so you are not keeping up-to-date" Social work staff member

Being offered a direct payment:

Half of the 10 social work staff interviewed believed everyone would be told about direct payments, whilst half said they could not be certain this was happening. Two suggested that it would be dependent on whether it was felt relevant to the person's circumstances.

"My guess is that this does not always happen, given the number of direct payment packages in relation to the number of people on our books" Social work staff member

Finding out about direct payments:

From their social worker (n=5). In most cases this was in response to expressing an interest in something different or in having an alternative to what the social work department could provide directly.

Informally (n=5). In most cases from a friend or family member.

How direct payments are presented to potential recipients:

Three of the 10 felt it would be presented as a positive option, and five believed that it would be presented realistically, highlighting the benefits whilst pointing out the requirements and responsibilities.

The remaining two felt that it would depend on the circumstances.

Support for potential and ongoing recipients:

All local authorities had arrangements to provide information and practical support to potential and ongoing recipients of direct payments. Support included initial advice and information for those thinking about taking on a direct payment, support with employing a personal assistant, help with the practicalities of setting up a

Alzheimer Scotland (2011)

direct payment and ongoing support for managing the payment.

Type of support being purchased:

National statistics do not differentiate between the types of support being purchased by different age or client group. Overall, payments are used for personal care (57%), social/recreational activities (31%), domestic tasks (29%) and respite (14%). Direct payment recipients use their payments more often to employ personal assistants (44%) than purchase services from a service provider (26%).

Benefits of direct payments for people with dementia:

Flexibility in relation to:

- support suited to the personal circumstances of the family
- better responses to fluctuating, as well as increasing, needs of people with dementia
- complementary support to what was already provided by family carers.

“If we are providing services it is very difficult to get the flexibility that people with dementia really need”

Social work staff member

Choice and control over how support is provided and the form it takes.

“The person organising support has a hands on role in who is doing what and when” Social work staff member

- Consistency in the timing of support and also who is providing it.
- Enabling family carers to respond to crisis situations.

“Should a crisis situation arise there is money sitting in an account to use to cover it without having to call half a dozen people to get permission” Social work staff member

- Using direct payments provided familiarity: it allows the opportunity to employ someone who is known to the person with dementia, and it can also keep the person in familiar surroundings with recognisable things around them.

- It can keep people at home who would otherwise be in long term care by complementing the support provided by family carers; people have continued to have a good quality of life at home.

“I have a client who would not be in the community without it, the direct payment provides the flexibility to work support around the daughter’s work” Social work staff member

- It can provide enabling support rather than task-focused care.

Direct payment adds to the quality of life for the person with dementia; it supports the person socially, providing trips out with the home and providing the friendship of the employed carer.

Barriers:

Capacity and someone to manage the direct payment

Given the progressive nature of dementia, there must be an appropriate person to manage the direct payment as the illness progresses. Many of those interviewed acknowledged the issue of people not being able to get a direct payment unless the person with dementia has capacity to consent or the family carer has appropriate legal powers in place.

Responsibilities and requirements

Some highlighted the responsibility and requirements that go along with having a direct payment being daunting for a person to take on, particularly as an employer.

“It’s a heavy responsibility and stressful; the person who takes it on personalises the responsibility and there can be a lot of stress and anxiety” Social work staff member

Staff and potential recipient attitude

“Unless you get the hearts and minds of the social workers on board it is more complicated to put in place”

Social work staff member

Positive staff attitude towards direct payments has been shown in previous research to be an important factor.

Alzheimer Scotland (2011)

Lack of awareness and promotion

Lack of advertising and promotion was considered by some as a barrier. People are not being told about direct payments until they are being assessed and are then asking for a service.

Financial constraints and existing services

Budgetary limitations and cost ceilings were considered a significant barrier. In addition money can be tied-up in pre-purchased services and there would be a desire to use this first.

Level of need and eligibility thresholds

By the time people with dementia qualify for support, given that they have to meet eligibility criteria by having critical or substantial need, the dementia will be more advanced and there is less opportunity to know the person's own wishes.

Time taken to set-up a direct payment

The length of time taken to set up a direct payment was thought prohibitive by social work staff, as people have an immediate need for support.

"It is a time consuming process, from telling people to negotiating and setting up; taking on staff is a lengthy process and ongoing" Social work staff member

Limitations on choice

A number of interviewees spoke of having limited choice of supplier of services from whom they could purchase services; monopolies existed in some areas, and there were difficulties in finding people to employ in rural areas.

What changes would help

Improved information and support for potential recipients, support for frontline social work staff, consistent practices and procedures that focus on flexible care rather than detailed audit of expenditure and clear policy guidance from central government.

Local authority staff participating in the research made a number of recommendations to improve practice. These related to both structural issues (legislation, funding and guidance) and local authority operational issues.

Structural changes suggested

- Consistency with the Independent Living Fund in rules on employing close relatives.
- Reviewing how money is given to health boards so that it can be freed up to be given as a direct payment.
- Bridging funding as resources are currently tied up in existing and pre-purchased services.
- More realistic guidance to potential recipients - existing guidance was felt to create an unrealistic expectation.

Operational changes suggested

- Outcomes focus, stopping looking at support in terms of hours and focussing instead on what support should be achieving for the individual.
- Reducing bureaucracy and making the system more straightforward so that it is not overly complicated for the recipient and ensuring there is support for the recipient.
- More funding and increasing cost ceilings put on care packages so that there is more money to keep people at home and maintain their care in the community.
- Taking a long term view on the cost of care and value for money; for example giving couples extra respite may delay the need for long term care providing a better outcome for the family and the local authority.
- Centralisation of self-directed support within the social work department, instead of responsibility lying with care management; one point of contact to advise recipients throughout the process, with hands-on support that could bow out once the arrangements were established.
- Work to increase awareness and understanding of direct payments within social work departments and to potential recipients.

Alzheimer Scotland (2011)

“Direct payments have been around for a long time and we have used them for a long time, but it still feels like something new” Social work staff member

Cook et al (2008)

Study aim(s): To evaluate mental health recovery in those using self-directed care.

Quality assessment: Mid

Population:

Persons with an axis I or II diagnosis of mental disorder.

Country: USA

Sample size: N=106

Methods:**Study design:**

Before and after study

Sample selection: NR

Data collection: Client-level outcome data, compiled by the state mental health authority for review by state legislators, were examined by researchers.

Evaluation/intervention:

Self-directed care - Individuals have direct control over their service delivery.

Limitations

Methodology is poorly reported

Results:**Number of days spent in the community (versus inpatient or forensic settings):**

Before: mean=337±54 days After: mean=354±26 days $p<.01$

Global Assessment of Functioning Scale scores:

Before: mean score=50.9±10.2 After: mean score=58.3±8.3 $p<.001$

At follow-up:

N=36 (34%) held paid employment

N=20 (19%) were receiving vocational skills training

N=17 (16%) were engaged in volunteer activities

N=7 (7%) were enrolled in postsecondary education

N=3 (3%) were enrolled in general equivalency diploma classes

Dale & Brown (2006)**Study aim(s):**

To test whether consumer direction of personal care services (PCS) under Arkansas's Cash and Counselling program reduces nursing facility use and expenditures compared with traditional Medicaid PCS, and how it affects total Medicaid cost.

Quality assessment: High

Population:

Persons with disabilities using the PCS.

Country: USA

Dale & Brown (2006)				
Sample size: N=2,008				
Treatment group: N =1,004				
Control group: N=1,004				
Study methods:				
Limitations				
The generalisability of findings could be limited in that programs that have different features or serve different populations might not experience the same results.				
It is unclear whether the source of Cash and Counseling's effects on nursing facility use is increased access to care, or to greater flexibility of the PCS benefit.				
Results				
Effect of Arkansas's Cash and Counselling Program on Medicaid Nursing Facility Use:				
Had any Medicaid nursing facility expenditures by end of:	Treatment Group Mean	Control Group Mean	Estimated Effect (P Value)	Odds Ratio (95% Confidence Interval)
Year 1	7.3	8.9	-1.5 (0.202)	0.81 (0.58 to 1.12)
Year 2	12.7	15.5	-2.8 (0.064)	0.78 (.60 to 1.02)
Year 3	15.5	18.8	-3.3 (0.044)	0.78 (0.61 to 0.99)
Spent more than 90 days in nursing facility during 3-year post-enrolment	11.5	14.4	-2.9 (0.050)	0.76 (0.58 to 1.00)
Effect of Arkansas's Cash and Counselling Program on Medicaid Expenditures:				
	Treatment Group Mean	Control Group Mean	Estimated Effect (P Value)	
Nursing facility expenditures:				
Year 1	588	777	-190 (0.160)	
Year 2	1,502	1,818	-315 (0.241)	
Year 3	1,854	2,096	-243 (0.441)	
Cumulative 3 years	3,943	4,691	-748 (0.237)	
Long-term care expenditures(Other than PCS)*:				
Year 1	3,078	3,547	-469 (0.012)	
Year 2	3,658	4,336	-678 (0.025)	
Year 3	3,719	4,474	-755 (0.035)	
Cumulative 3 years	10,454	12,357	-1903 (0.010)	

Dale & Brown (2006)			
PCS expenditures:			
Year 1	4,600	2,353	2247 (0.000)
Year 2	3,603	1,830	1773 (0.000)
Year 3	2,937	1,536	1401 (0.000)
Cumulative 3 years	11,140	5,720	5420 (0.000)
Total Medicaid expenditures†:			
Year 1	12,240	10,721	1519 (0.000)
Year 2	11,543	10,630	913 (0.041)
Year 3	10,618	10,021	596 (0.283)
Cumulative 3 years	34,400	31,372	3028 (0.006)
*Long-term care expenditures include spending for nursing facility services, home health services, and the Alternatives and Elder Choices waiver programs.			
†Total Medicaid expenditures include all Medicaid spending on PCS, other long-term care costs, and inpatient and outpatient services(not shown).			

Fernandez et al (2007)
<p>Study aim(s): To explore the demand, supply and related factors associated with patterns of local variability in uptake and intensity of care package provision</p> <p>Quality assessment: Mid</p>
<p>Population: Disabled people receiving direct payments</p> <p>Country: United Kingdom</p> <p>Sample size: N= Not clear, secondary analysis and percentages used</p>
<p>Study methods</p> <p>Study design: NR</p> <p>Sample selection: Service users of direct payments: older people, younger disabled people, mental health service users, and people with learning disabilities</p> <p>Data collection: Various databases: census, electoral commission, land registry etc</p> <p>Limitations Sample size was not clear; findings may not be generalisable or applicable</p> <p>Evaluation/intervention:</p> <p>Direct payments: Payments given to individuals so that they can organise and pay for the social care services they need, rather than using the services offered by their local authority; barriers to implementing direct payments</p>
<p>Results:</p>

Fernandez et al (2007)

Take up of direct payments

Proportion of home care provided in-house

Local authorities where a relatively low proportion of home care is provided in-house tend to have relatively high direct payments take-up by older people and people with disabilities, and the original decision to maintain extensive in-house services by Councils with Social Services Responsibilities (CSSRs) could be suggestive of resistance to the loss of control over services.

CSSRs have relinquished direct control rights over care workers' pay and conditions, and the capacity to shape service content by hierarchical control. A significant in-house capacity implies rigidity in job roles and responsibilities, such as authorities may offer a less hospitable environment for the championing of new policies and practices.

Dysfunctional hierarchical governance arrangements may also make it generally harder to exchange evidence and argument about new and effective policies, so that it will be more difficult for local authorities who have retained significant in-house capacity to cascade new policies and ideas down to the front line.

Residential care expenditure

The take-up of direct payments was reportedly low, amongst people with physical and learning disabilities, in authorities with a high ratio of traditional residential care expenditure compared to other forms of community care expenditure.

The willingness and ability to adopt direct payments may be constrained in CSSRs with high proportional residential care expenditure by the need to commit resources to sustain existing patterns of service, at least in the short term.

Population density

The take-up of direct payments for people physical and ID is greater in areas with lower population density

Informal care levels

The higher the proportion of the local population providing informal care, the lower the take-up of direct payments by people with physical disabilities and people who use mental health services

Impact of direct payments for older people

Local authorities with a relatively high take-up of direct payments by people with physical disabilities have tended to have high prevalence with respect to older people too.

Larger and wealthier local authorities tend to have higher take-up because the former have a greater capacity to move to a scale of operation which can spread their costs and thus bring down average costs, while the latter are better positioned to be appropriately generous with packages.

Local authorities that assess greater proportions of their older population aged over 64 provide relatively fewer of their clients with direct payments., However those authorities which assess and provide for relatively greater % of their older population offer more limited opportunities for older people to exercise choice in the services they wish to get

Impact of general health and deprivation on direct payments uptake

Good population health is linked to relatively low direct payments take-up in people with physical disabilities while the relationship is reversed for those with learning disabilities. There is also a low take-up for people with physical disabilities in multiply deprived areas but the opposite for people who use mental health services.

People from black and ethnic minority groups are disproportionately located in deprived areas and these groups exhibit especially low levels of engagement with direct payments

Factors associated with % of community care clients receiving direct payments: physical disabilities

General health: share of population declaring their health to be good Coefficient: -0.02; $p < 0.01$

Index of multiple deprivation - Coefficient: -0.03; $p < 0.01$

Proportion of home care provided in-house - Coefficient: -0.00007; $p = 0.04$

Proportion of physical disability social care expenditure on residential and nursing care Coefficient: -1.44;

Fernandez et al (2007)

p=0.01

Population density Coefficient: -0.06; p=0.03

Proportion of the population providing informal support Coefficient: -0.05; p<0.01

Number of observations: 372

Pseudo R²:16%

Factors associated with % of community care clients receiving direct payments: older people

Proportion of the population aged 85 plus - Coefficient: 58.56; p=0.01

Area of the local authority - Coefficient: 1.8E-04; p<0.01

Rate of receipt of direct payments among physically disabled, controlling for local demand and supply factors
Coefficient: 2.93; p<0.01

Proportion of home care provided in-house - Coefficient: -1.3E-02; p=0.03

Expenditure on social care for older people per population 65 plus - Coefficient: 1.2E-03; p<0.01

Ratio of older people assessed by social care services to population 65 plus - Coefficient: -1.0E-02; p<0.01

Number of observations: 383. Pseudo R²:18%

Factors associated with % community care clients receiving direct payments: learning disabilities

General health: share of the population declaring their health to be not good - Coefficient: -0.03; p<0.01

Standardised mortality rate - Coefficient: 0.04; p=0.03

Rate of receipt of direct payments among physically disabled, controlling for local demand and supply factors
- Coefficient: 1.32; p=0.01

Proportional learning disability social care expenditure on residential care and nursing care - Coefficient: -2.05; p=0.01

Proportion of the population receiving intensive home care - Coefficient: 0.04; p=0.01

Population density - Coefficient: -0.15; p=0.06

Average gross weekly expenditure on supporting adults with learning disabilities in residential and nursing care - Coefficient: -0.001; p=0.06

Number of observations: 354 Pseudo R²:19%

Factors associated with whether local authorities provide direct payments for mental health clients

Index of multiple deprivation - Coefficient: 8.4E-02; p<0.01

Area of the local authority - Coefficient: 5.1E-04; p<0.01

Local authority population - Coefficient: 3.1E-03; p<0.01

Ratio of number of mental health clients receiving services to population 18 – 64 - Coefficient: 0.14; p=0.04

Proportion of the population providing informal support - Coefficient: -4.9E-02; p=0.04

Number of observations: 356 Pseudo R²: 25%

Factors associated with the average intensity of direct payments for physical disability clients

Expenditure on social care for physically disabled, controlling for local demand and supply factors -
Coefficient: 4.8E-05; p=0.01

Adults aged 18 – 64 with physical disabilities helped to live at home per 1,000 population aged 18 – 64
Coefficient: 4.2E-02; p=0.03

Fernandez et al (2007)

Average gross hourly cost for home help/care - Coefficient: 7.9E-02; p<0.01

Average weekly expenditure per person on supporting adults with physical disabilities in residential and nursing care - Coefficient: 1.2E-03; p<0.01

Number of direct payments for physically disabled per population 18 – 64

Coefficient: -0.72; p=0.01

Number of observations: 301

Pseudo R²:23%

Factors associated with the average intensity of direct payments for older people

Proportional expenditure on supported accommodation - Coefficient: 12.39; p<0.01

Average gross hourly cost for home help/care - Coefficient: 5.5E-02; p=0.08

Population of over 65s receiving direct payments - Coefficient: -0.57; p=0.02

Number of observations: 119 Pseudo R²:16%

Factors associated with the average intensity of direct payments for learning disability clients

Expenditure on social care for learning disabled, controlling for local demand and supply factors Coefficient: 2.5E-05; p=0.15

Proportional learning disability social care expenditure on residential and nursing care - Coefficient: -1.14; p=0.01

Number of direct payments for learning disabled per population 18 – 64 - Coefficient: -7.48; p<0.01

Number of observations: 69 Pseudo R²:18%

Fisher et al (2010)

Study aims: to examine the effectiveness of individual funding of disability support and aimed to inform policy to improve the provision of disability support. The study was commissioned by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

Quality assessment: High

Population - people with disabilities, families, service providers and officials

Country: Australia

Sample size: 132, 32, 8

Study methods:

Study design: The research methodology included a literature review; secondary data analysis of the Commonwealth State Territory Disability Agreement National Minimum Data Set; interviews with policy officials from all states and territories; case studies with 10 disability service providers, involving interviews with people with disabilities and staff; and questionnaires for people with disabilities and service providers.

Possible limitations to the primary data collection were addressed using mixed methods, including validated scales in the instruments, & incorporating advice from people with disabilities, families and providers through piloting and draft versions.

Results:**Person-centred disability support**

Policy officials, service providers, people with disabilities and their family members agreed that, overall, individual funding in Australia facilitates control and choice in support provision. Mechanisms for facilitating consumer preferences include individual needs assessments, planning and goal setting processes, as well as flexibility in how funds are spent. These mechanisms are often successfully employed.

Fisher et al (2010)**Support according to capacity and vulnerability**

Government and advocacy organisations are the main providers of information about individual funding options. Service providers give ongoing information to existing individual funding clients through planning and reviews. Service providers support choice and decision making by involving family and friends in support planning.

Some people with disabilities and their families who manage individual funding in the open market reported that they do not have sufficient information to help them manage their individual funding.

Viability of support type and amount of funding

Individual funding managed by a single service provider is often restricted to one disability support type, such as accommodation support, which limits the effectiveness of the individual funding package to achieve holistic life goals.

Insufficient funds may be a problem for people with complex needs or few informal support networks. Some service providers have developed mechanisms to maximise the effectiveness of the available funding support, such as supporting the development of informal support networks to supplement the formal support.

Workforce and quality of care

The availability of qualified support workers for disability support under any type of individual funding is affected by the level of remuneration offered.

Contextual impact

Transition from traditional funding approaches to individual funding may be difficult for service providers and even pose a threat to their viability. To lessen this risk, governments have put mechanisms in place such as base funding and transition assistance for service providers.

Costs of individual funding

The average individual package funding size in this study was \$28,500 and ranged from \$700 to \$250,000. The variation relates to disability support type and support need. The average management cost was 14 per cent of the individual funding package and ranged from 5 to 22 per cent. This is similar to the management cost of other disability and community services.

Individual funding has not increased the total specialist disability support cost to government. Officials said some individual funding is more cost-effective than other models of organising support, particularly where it supplements social housing and informal care.

Outcomes of individual funding

The outcomes data compared people's experiences before and while using individual funding; outcomes for people with disabilities who have individual funding with the outcomes for people whose disability support is organised in other ways; and an Australian population norm for personal wellbeing. Most people using individual funding experienced personal wellbeing, and physical and mental health at levels similar to both the Australian population norm and the Victorian norm of people with intellectual disabilities. In the interviews, they attributed these positive results to the better control they have over the way they organise their disability support.

Foster et al (2003)

Study aim(s): To present findings from the first demonstration program that compared an innovative consumer direction with the traditional agency-directed approach

Quality assessment: High

Population:

All Medicaid beneficiaries who receive disability related supportive services in their homes

Country: USA, Arkansas

Sample size: N=1,739

Foster et al (2003)
Study methods:
Study design: Randomised controlled study
Sample selection: People aged eighteen or older who were eligible for Medicaid personal care services; random selection Respondents were selected for a program IndependentChoices – a cash and counselling service in Arkansas
Data collection: Computer assisted telephone interviews
Evaluation/intervention: Self-directed support: This means people co-design the support they need in their lives and have control over what that support is – often a key lever for this is giving them control over the funding for their support.
Limitations Results may not be generalisable as the sample was selected from one state in the USA. The nurse supervision that agencies provide could have reduced the likelihood that elderly treatment group members experienced adverse health effects

Foster - Results

Table 1: Estimated effects of IndependentChoices on satisfaction with paid caregivers' reliability and schedule (Age 18 – 64 years) - Treatment group members were much less likely than the control group members were to report that their paid caregivers performed poorly, and they were more likely to say that caregivers performed exceptionally well.

Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Completed tasks always	62.0%	36.8%	25.2% (<0.001)
Usually/sometimes/rarely completed tasks	16.0%	38.7%	21.8% (<0.001)
Never arrived late / left early	59.3%	37.6%	21.8% (<0.001)
Often arrived late/ left early	11.4%	25.0%	-13.6% (0.002)
Did not come as scheduled	7.7%	28.5%	-20.9% (<0.001)
Very satisfied with caregivers' schedule	85.2%	66.9%	18.3% (<0.001)
Could easily change schedule	53.5%	41.6%	11.8% (0.046)

Foster

Table 2: Estimated effects of IndependentChoices on unmet needs and satisfaction with care arrangements (Age 65+ years) - There were smaller, but significant, reductions in unmet needs for help with household activities and transportation

Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Completed tasks always	65.8%	47.2%	18.7% (<0.001)
Usually/sometimes/rarely completed tasks	15.4%	36.2%	-20.9% (<0.001)
Never arrived late /left early	56.3%	36.0%	20.3% (<0.001)
Often arrived late / left early	9.4%	19.3%	-9.8% (<0.001)
Did not come as scheduled	17.7%	30.1%	-12.4% (<0.001)
Very satisfied with caregivers' schedule	82.9%	68.7%	14.2% (<0.001)

Could easily change schedule	47.8%	45.1%	2.6% (0.497)
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Foster			
Table 3: Estimated effects of IndependentChoices on satisfaction with paid caregivers' relationships and attitudes (Age 18 – 64 years) - More than 90% of treatment group members and about 80% of control group members said they were satisfied with their caregivers. Non elderly treatment group members were about one-third likely as their control group counterparts to say that their paid caregivers had been rude or disrespectful.			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Very satisfied with relationship	95.0%	78.5%	16.5% (<0.001)
Paid caregivers neglected clients	14.1%	33.5%	-19.4% (<0.001)
Paid caregivers were rude or disrespectful	10.5%	29.5%	-18.9% (<0.001)
Paid caregivers took something without asking	1.7%	4.4%	-2.7% (0.040)

Foster			
Table 4: Estimated effects of IndependentChoices on satisfaction with paid caregivers' relationships and attitudes (Age 65+ years) - IndependentChoices appears to have reduced the reported incidence of neglect by paid caregivers by about 58%			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Very satisfied with relationship	92.2%	82.8%	9.4% (<0.001)
Paid caregivers neglected clients	10.9%	26.2 [^]	-15.3% (<0.001)
Paid caregivers were rude or disrespectful	11.8%	16.4%	-4.7% (0.051)
Paid caregivers took something without asking	4.1%	7.7%	-3.6% (0.033)

Foster			
Table 5: Estimated effects of IndependentChoices on unmet needs and satisfaction with care arrangements (Age 18 - 64 years) - Treatment group members were less likely than control group members were to report unmet needs. A significantly lower percentage of non-elderly treatment group members than control group members had unmet needs for help with personal care, household activities, and transportation			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Has an unmet need for help with daily living activities	25.8%	41.0%	-15.2% (0.001)
Has an unmet need for help with household activities	41.3%	56.0%	-14.7% (0.002)
Has an unmet need for help with transportation	27.0%	47.2%	-20.2% (<0.001)
Has an unmet need for help with routine health care	26.6%	32.3%	-5.7% (0.189)

Very satisfied with overall care arrangements	71.0%	41.9%	29.2% (<0.001)
Dissatisfied with overall care arrangements	6.0%	31.4%	-25.4% (<0.001)

Foster			
Table 6: Estimated effects of IndependentChoices on unmet needs and satisfaction with care arrangements (Age 65+ years) - There were smaller, but significant, reductions in unmet needs for help with household activities and transportation			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Has an unmet need for help with daily living activities	35.9%	36.5%	-0.7% (0.823)
Has an unmet need for help with household activities	38.1%	47.2%	-9.1% (0.003)
Has an unmet need for help with transportation	29.0%	36.5%	-7.5% (0.009)
Has an unmet need for help with routine health care	29.2%	32.3%	-3.1% (0.285)
Very satisfied with overall care arrangements	68.3%	54.0%	14.3% (<0.001)
Dissatisfied with overall care arrangements	6.2%	10.4%	-4.3% (0.026)

Foster			
Table 7: Estimated effects of IndependentChoices on adverse events in the last month, (Age 18 - 64 years) - For most measures, treatment group members had slightly better outcomes, but most treatment control differences were not statistically significant in both elderly and non-elderly consumers			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Fell	28.4%	28.7%	-0.4% (0.931)
Saw doctor because of fall	4.4%	4.1%	0.3% (0.849)
Saw doctor because of cut, burn or scald	1.3%	4.0%	-2.7% (0.70)
Was injured while receiving paid help	0.9%	2.3%	-1.4% (0.221)

Foster			
Table 8: Estimated effects of IndependentChoices on adverse events in the last month, (Age 65+ years)			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Fell	19.0%	18.6%	0.4% (0.869)
Saw doctor because of fall	5.4%	4.6%	0.7% (0.587)
Saw doctor because of cut, burn or	1.4%	1.9%	-0.5% (0.479)

scald			
Was injured while receiving paid help	1.8%	1.4%	0.3% (0.673)

Foster			
Table 9: Estimated effects of IndependentChoices on health problems in the last month, (Age 18-64)			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Shortness of breath developed or worsened	29.8%	39.7%	-10.0% (0.016)
Had respiratory infection	31.4%	32.1%	-0.7% (0.872)
Contractures developed or worsened	26.0%	25.2%	0.8% (0.826)
Had urinary tract infection	19.4%	21.6%	-2.2% (0.560)
Bedsores developed or worsened	5.9%	12.6%	-6.7% (0.012)

Foster			
Table 10: Estimated effects of IndependentChoices on health problems in the last month, (Age 65+ years)			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Shortness of breath developed or worsened	32.3%	36.1%	-3.8% (0.161)
Had respiratory infection	23.3%	25.3%	-2.1 (0.404)
Contractures developed or worsened	15.9%	19.7%	-3.9% (0.089)
Had urinary tract infection	18.2%	21.0%	-2.8% (0.230)
Bedsores developed or worsened	7.5%	6.8%	0.7% (0.640)

Foster			
Table 11: Estimated effects of IndependentChoices on general health status, (Age 18 - 64 years)			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Current health poor relative to peers	56.4%	53.5%	2.9% (0.476)
Spent night in hospital or nursing home in past two months	16.6%	15.9%	0.7% (0.842)

Foster			
Table 12: Estimated effects of IndependentChoices on general health status, (Age 65+ years)			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Current health poor relative to peers	48.0%	50.0%	-2.0% (0.462)
Spent night in hospital or nursing home in past two months	25.2%	23.7%	1.5% (0.551)

Foster			
Table 13: Estimated effects of IndependentChoices on satisfaction with life, (Age 18 - 64 years)			
- Treatment group members were more likely than control group members to say they were satisfied with the way they were spending their lives			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Very satisfied with the way spending life these days	43.4%	22.9%	20.5% (<0.001)
Dissatisfied with the way spending life these days	24.1%	46.9%	-22.7% (<0.001)

Foster			
Table 14: Estimated effects of IndependentChoices on satisfaction with life, (Age 65+ years) -			
The treatment control difference in the percentage of elderly consumers who were dissatisfied was statistically significant but less pronounced			
Outcome	Predicted treatment group mean	Predicted control group mean	Estimated effect (p-value)
Very satisfied with the way spending life these days	55.5%	37.0%	18.5% (<0.001)
Dissatisfied with the way spending life these days	17.0%	25.3%	-8.3% (0.004)

van Ginneken et al. (2012)
Study aim(s): to establish lessons from the Dutch implementation and restriction of personal budgets for implementation in England.
Quality assessment: High
Population: Personal budget holders
Country: Netherlands
Sample size: NA
Study Methods:
Study design: Commentary
Sample selection: NA
Data collection: NA

van Ginneken et al. (2012)
Evaluation/intervention: Personal budgets in Netherlands
Limitations Commentary and analysis rather than primary research but highly relevant.
Results <p>“The composition and characteristics of the budget holders in the Netherlands have changed substantially over the years. The average age of personal budget holders has fallen over time (currently, about 45% are under 18) and people with somatic diseases, once a majority of budget holders, now comprise only about 20%.</p> <p>This is largely explained by increased uptake by children and adolescents with learning disabilities, autistic spectrum diagnoses, and intellectual disabilities who previously received informal, and often unpaid, care.</p> <p>From this year the eligibility criteria for personal budgets will change substantially. A series of incremental measures will be implemented that, by January 2014, will substantially restrict access to the scheme. Only people who would otherwise have to move to a nursing or residential home will be able to keep their budget or apply for one. The money would be used to enable them to continue living at home by purchasing services not available in the formal health and social care system. The Ministry of Health estimates that this will comprise about 10% of current budget holders”.</p>

Glendinning et al., 2008
Study aim(s): The aims of the evaluation were to: <ul style="list-style-type: none"> • Identify whether IBs offer a better way of supporting older people and adults with social care needs, compared to conventional methods; assess different models of IBs. <p>Specific aims were to:</p> <ul style="list-style-type: none"> • Assess the experiences of IBs among different groups of service users and carers. • Assess the wider consequences of IBs for adult social care and other services.
Quality assessment: High
Population: 13 individual budget pilot sites Country: England Sample size: 959 in RCT, 130 semi-structured interviews
Study methods : Study design: RCT and in-depth interviews Sample selection: 13 pilot sites in England Data collection: outcome structured interviews after six months and semi-structured with 130. Evaluation/intervention: Individual budget for six months
Results: The evaluation found that IBs were generally welcomed by users because they gave them more control over their lives, but there were variations in outcomes between user groups. IBs were typically used to purchase personal care, assistance with domestic chores, and social, leisure and educational activities; People receiving an IB were more likely to feel in control of their daily lives, compared with those receiving conventional social care support; Satisfaction was highest among mental health service users and physically disabled people and lowest among

<p>Glendinning et al., 2008</p> <p>older people;</p> <p>Little difference was found between the average cost of an IB and the costs of conventional social care support, although there were variations between user groups;</p> <p>IBs appear cost-effective in relation to social care outcomes, but with respect to psychological well-being, there were differences in outcomes between user groups.</p> <p>Staff involved in piloting IBs encountered many challenges, including devising processes for determining levels of individual IBs and establishing legitimate boundaries for how IBs are used; there were particular concerns about safeguarding vulnerable adults;</p> <p>Despite the intention that IBs should include resources from different funding streams, staff experienced numerous legal and accountability barriers to integrating funding streams; at the same time there was frustration that NHS resources were not included in IBs;</p> <p>IBs raise important issues for debate, including the appropriate principles underpinning the allocation of resources to individuals and the legitimate use of social care resources.</p>
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<p>Glasby et al. (2009)</p> <p>Study aim(s): To conduct a narrative review the social care evidence concerning direct payments/personal budgets, before arguing for an extension of these concepts to the National Health Service (NHS)</p> <p>Quality assessment: Mid</p>
<p>Population: NA</p> <p>Country: NR</p> <p>Sample size: NA, secondary analysis</p>
<p>Study methods :</p> <p>Study design: Narrative review</p> <p>Sample selection: NA</p> <p>Data collection: NA</p> <p>Evaluation/intervention: Direct payments/personal budgets: social care evidence, facilitators and barriers</p> <p>Limitations: Due to its narrative nature, there is no data on the methodology of the review.</p>
<p>Results: Impact of personal budgets (within one year):</p> <p>Desired change % achieved</p> <p>Where I live: 76%</p> <p>Who I live with: 81%</p> <p>What I do with my time: 69%</p> <p>Who supports me: 89%</p> <p>Outcomes of personal budgets:</p> <p>Participants reported improvement in:</p> <ul style="list-style-type: none"> • Quality of life: 76% • Choice and control: 72% • Taking part in and contributing to the community: 64% • Personal dignity 59% • Spending time with people they like: 55% • Health and well-being: 47% • Economic well-being: 36% • Feeling safe and secure at home: 29%

Glasby et al. (2009)

Outcomes for different user groups:

- Mental health service users reported a significantly higher quality of life.
- Physically disabled adults reported receiving higher-quality care and were more satisfied with the help they received.
- People with learning disabilities were more likely to feel they had control over their daily lives.
- Older people reported lower psychological well-being, perhaps because they felt that the processes of planning and managing their own support were burdens.

Introduction of individualised funding into the NHS could lead to:

- Greater personalisation of care;
- The ability to overcome capacity constraints in the NHS;
- Better coordination of care;
- Greater transparency in the allocation of NHS funds;
- Greater equity, by allowing personalisation within the NHS rather than through the marketplace;
- Better value for money through the development of personalised care that leads to health improvements without increasing costs;
- Greater innovation and service development, with people enabled to explore different ways of meeting their health needs.

Facilitators:

Seven key steps to self-directed support

Step 1: Using In Control's resource allocation system (RAS), everyone is told their financial allocation – their personal budget – and they decide what level of control they wish to take over their budget.

Step 2: People plan how they will use their personal budget to get the help that is best for them; if they need help to plan, then advocates, brokers or others can support them.

Step 3: The local authority helps people to create good support plans, checks they are safe and makes sure that people have any necessary representation. This is a particularly important part of the safeguarding process, as local authorities retain a duty of care and therefore have a key role to play in signing off support plans.

Step 4: People control their personal budget to the extent they want (there are currently six distinct degrees of control, ranging from direct payments at one extreme to local authority control at the other).

Step 5: People can use their personal budget flexibly (including for statutory services).

Indeed, the only real restriction imposed is that the budget cannot be used on something illegal (as long as people are meeting their eligible needs).

Step 6: People can use their personal budget to achieve the outcomes that are important to them in the context of their whole life and their role and contribution within the wider community.

Step 7: The authority continues to check that people are okay, shares what is being learned and can change things if people are not achieving the outcomes they need to achieve.

Barriers:

Common objections to direct payments and personal budgets:

Question: Won't people just misuse the money?

Answer: No – the individual has more of a vested interest than public services in spending the money as effectively as possible. Evidence to date has revealed no significant misuse, and a large amount of creativity and innovation.

Glasby et al. (2009)

Question: Isn't this best left to the experts?

Answer: It depends who you think the expert is – the person with the technical knowledge (who has a key role to play) or the person who knows what it is like to live with their condition and what they want their life to be like. In an ideal world, the relationship between 'professional' and 'service user' would be one of equals, with each bringing complimentary expertise.

Question: Isn't this just about privatisation?

Answer: No – it's about citizenship and the right to be in control of your life. At present, people with more money can afford to supplement or bypass public services. In contrast, direct payments/personal budgets nationalise these opportunities – creating a fair and universal service for everyone (see below for further discussion).

Q: Surely this won't work in practice as healthcare (unlike social care) is free at the point of delivery?

A: No – and this question is slightly disingenuous. While the divide between means tested social care and free healthcare remains problematic, there is no essential difference between trying to integrate directly provided health and social care (which is current government policy) and trying to join up direct payments/personal budgets for health and social care (which until recently was not).

Challenges faced in delivering PBs:

- Demographic pressures and rising public expectations, health services are increasingly being asked to deliver a person-centred approach that fits services around the needs of the individual rather than the other way round.
- Following previous high-profile financial difficulties (and faced with a much tighter economic situation), health services are having to concentrate on managing rising demand within cash-limited budgets.

Health Foundation (2010)**Study aim(s):**

What does the international evidence say about the efficacy of personal budgets for better health or improved health outcomes for people with long-term conditions?

What does the international evidence tell us about the effects of personal budgets for improving patient-centred care?

Do patients have greater control over their health and their treatments?

Does the evidence tell us whether personal budgets offer value for money, such as evidence that costs per patient are reduced by enabling people to purchase what they judge they need?

Where do the majority of studies come from – which countries are developing personal budget programmes?

Has anybody explored which patient groups (or perhaps families or carers) benefit the most from personal budgets?

What does the published research tell us about individual budgets for social care in the UK?

Quality assessment: High

Population

Included studies mainly from USA, Netherlands, Germany and UK.

Study methods

Research scan: searched bibliographic databases, reference lists of identified articles and reviews and the websites of relevant agencies for information available as at August 2010.

Health Foundation (2010)

Results

This report concludes that: “the amount of high quality research available to guide policy and practice is limited. The scan found that personal budgets are implemented differently in various countries. Sometimes people are given cash payments to spend as they wish. Alternatively, organisations keep responsibility for making payments but service users state what they want purchased on their behalf. There is some evidence that personal budgets help people feel more confident and empowered because they are taking control of decisions over their care.

Evidence about impacts on health outcomes and service use is mixed. There is limited information about value for money, largely because there are few rigorous effectiveness studies and the costs of traditional care and personal budgets tend to be underestimated.

The majority of international studies come from the US, Germany and the Netherlands. But an important body of literature has examined social care budgets and direct payments in the UK. This literature points to differences in implementation across the four countries of the UK and suggests, to be successful, personal budgets need to offer adequate infrastructure, staff training and signposting, and support to service users. Older people may be more likely to find managing their own budget a burden. Most of the information available is descriptive rather than empirical research and there are particular gaps around impacts on health outcomes and cost effectiveness. The literature suggests this approach may be worth exploring further”.

Limitations

“When interpreting the findings it is important to bear in mind several caveats. The research scan is not exhaustive. It presents examples of studies and interventions but does not purport to represent every international study about personal budgets. It is difficult to draw conclusions about the usefulness of personal budgets given the paucity of empirical research. Even where empirical studies were available, the level of detail was sometimes insufficient to provide a meaningful summary. A lack of evidence does not necessarily indicate a lack of effect, just that there may be few high-quality studies available from which to draw conclusions. The empirical evidence did not usually define personal budgets in any depth. The approaches in various countries may differ somewhat, and it is difficult to draw comparisons without finding out more about how the systems are run. There is also a paucity of comparative evidence so it is difficult to say whether personal budgets may be more or less effective than alternative initiatives”.

Jones et al (2011)

Study aim(s): To explore the implementation process for personal budgets by examining the financial costs.

Quality assessment: High

Population:

Pilot sites involved in the implementation of personal budgets

Country: United Kingdom

Sample size: N=20

Study methods :

Study design: Cross-sectional study

Sample selection:

All pilot sites that were 12 months into project implementation; purposive sampling

Small sample size; so results may not be generalizable.

Data collection: In-depth evaluation using a costing template

Jones et al (2011)**Evaluation/intervention:** Facilitators of individual budgets:

Costs of implementing personal budgets

Results Overall direct expenditure from the project board**Overall available resource**

Mean: £146,800

Median: £126,890

Standard deviation: £54,630

Range: £91,560 to £258,460

Overall cost of project management

Mean: £100,900

Median: £98,110

Standard deviation: £40,250

Range: £45,920 to £208,460

Overall costs associated with implementing personal budgets

Mean: £93,280

Median: £81,680

Standard deviation: £42,760

Range: £35,000 to £173,750

Overall additional expenditure once salaries have been taken into account

Number of observations: 12

Mean: £19,150

Median: £9,220

Standard deviation: £23,190

Range: £580 to £75,500

Cost of specific activities once salaries have been taken into account

Brokerage service

Number of observations: 5

Mean: £32,000

Median: £40,000

Standard deviation: £16,880

Range: £12,580 to £48,000

Direct payment service

Number of observations: 4

Mean: £4,090

Median: £3,520

Standard deviation: £2,050

Range: £2,500 to £6,820

Emergency carer support

Number of observations: 1

Mean: £22,500

Premises/Office costs

Number of observations: 9

Mean: £3,600

Median: £3,750

Standard deviation: £2,230

Range: £580 to £6,500

Overall additional resource for the development of systems (Overall resource use)

Overall additional expenditure for the development of systems

Number of observations: 10

Jones et al (2011)

Mean: £38,980
Median: £37,200
Standard deviation: £22,220
Range: £13,130 to £75,200

Cost of specific activities for the development of systems

Assessment process

Number of observations: 4
Mean: £19,820
Median: £13,760
Standard deviation: £7,120
Range: £6,750 to £45,000

Budget-setting

Number of observations: 3
Mean: £4,240
Median: £3,310
Standard deviation: £2,720
Range: £2,110 to £7,300

Support planning

Number of observations: 6
Mean: £21,310
Median: £13,880
Standard deviation: £24,280
Range: £2,530 to £67,940

Review process

Number of observations: 4
Mean: £5,300
Median: £5,880
Standard deviation: £2,040
Range: £2,530 to £6,930

Financial administration

Number of observations: 7
Mean: £6,110
Median: £5,050
Standard deviation: £5,420
Range: £390 to £15,000

Information set-up

Number of observations: 6
Mean: £6,870
Median: £2,570
Standard deviation: £8,220
Range: £580 to £18,500

Overall additional expenditure for the development of systems – (Costs associated with implementing personal budgets)

Number of observations: 8
Mean: £37,600
Median: £37,200
Standard deviation: £19,050
Range: £16,250 to £70,550

Cost of specific activities for the development of systems

Assessment process

Number of observations: 2

Jones et al (2011)

Mean: £10,580
Median: N/A
Standard deviation: £5,410
Range: £6,750 to £14,400

Budget-setting

Number of observations: 3
Mean: £4,240
Median: £3,310
Standard deviation: £2,720
Range: £2,110 to £7,300

Support planning

Number of observations: 5
Mean: £25,070
Median: £21,000
Standard deviation: £25,360
Range: £5,520 to £67,940

Review process

Number of observations: 3
Mean: £6,230
Median: £6,750
Standard deviation: £1,070
Range: £5,000 to £6,930

Financial administration

Number of observations: 5
Mean: £5,540
Median: £1,860
Standard deviation: £6,290
Range: £390 to £15,000

Information set-up

Number of observations: 5
Mean: £7,640
Median: £2,110
Standard deviation: £8,940
Range: £580 to £18,500

Workforce development (N=11)

The average cost that would have been required to meet the training needs of the workforce was £13,050 across all pilot sites (Median: £7,400). Eight of these sites reported an average mean cost of £15,880 that was additional to what would have incurred with personal health budgets (Median: £9,220)

Overall additional expenditure for the development of support planning

Number of observations: 8
Mean: £18,470
Median: £13,450
Standard deviation: £15,770
Range: £2,220 to £43,300

Cost of specific activities for the development of support planning**Peer support**

Number of observations: 3
Mean: £13,650
Median: £3,000
Standard deviation: £19,010

Jones et al (2011)

Range: £2,350 to £35,590

Private and voluntary sector

Number of observations: 4

Mean: £5,910

Median: £5,500

Standard deviation: £3,720

Range: £2,220 to £10,420

Marketing materials for in-house services

Number of observations: 3

Mean: £8,570

Median: £3,600

Standard deviation: £9,560

Range: £2,530 to £19,600

Overall additional resource for the development of support planning (Costs associated with implementing personal health budgets)

Number of observations: 6

Mean: £21,850

Median: £21,380

Standard deviation: £16,730

Range: £2,220 to £43,300

Cost of specific activities for the development of support planning

Peer support

Number of observations: 3

Mean: £13,650

Median: £3,000

Standard deviation: £19,010

Range: £2,350 to £35,590

Private and voluntary sector

Number of observations: 4

Mean: £5,910

Median: £5,500

Standard deviation: £3,720

Range: £2,220 to £10,420

Marketing materials for in-house services

Number of observations: 2

Mean: £11,600

Median: N/A

Standard deviation: £11,320

Range: £3,600 to £19,600

Overall additional resource for market development (Overall resource use)

Number of observations: 3

Mean: £5,750

Median: £2,190

Standard deviation: £6,770

Range: £1,500 to £13,550

Cost of specific activities for market development

Procurement

Number of observations: 2

Mean: £2,580

Median: N/A

Standard deviation: £1,580

Jones et al (2011)

Range: £1,460 to £3,700

Contract re-negotiation

Number of observations: 2

Mean: £2,430

Median: N/A

Standard deviation: £2,920

Range: £370 to £4,500

Transitional arrangements

Number of observations: 2

Mean: £2,860

Median: N/A

Standard deviation: £3,530

Range: £370 to £5,350

Overall additional resource for market development (Costs associated with implementing personal health budgets)

Number of observations: 1

Mean: £13,550

Cost of specific activities for market development

Procurement

Number of observations: 1

Mean: £3,700

Contract re-negotiation

Number of observations: 1

Mean: £4,500

Transitional arrangements

Number of observations: 1

Mean: £5,350

Variations in set-up costs (Overall cost to implement personal health budgets)**2 or less health conditions**

Number of observations: 9

Mean: £160,240

Median: £141,400

Standard deviation: £59,570

Range: £91,710 to £248,300

3 or more health conditions

Number of observations: 11

Mean: £135,810

Median: £119,070

Standard deviation: £50,360

Range: £96,560 to £248,100

Variations in set-up costs (Costs associated with implementing personal health budgets)**2 or less health conditions**

Number of observations: 9

Mean: £95,290

Median: £80,690

Standard deviation: £53,060

Range: £35,000 to £170,00

3 or more health conditions

Number of observations: 11

Mean: £91,640

Jones et al (2011)

Median: £82,6700

Standard deviation: £34,670

Range: £45,660 to £173,750

Variations in set-up costs (Overall cost to implement personal health budgets)**Location/type of authority implementing the pilot project****Metropolitan**

Number of observations: 4

Mean: £118,700

Median: £120,850

Standard deviation: £20,750

Range: £91,710 to £141,400

Unitary

Number of observations: 8

Mean: £143,390

Median: £129,430

Standard deviation: £51,030

Range: £91,560 to £232,280

London

Number of observations: 3

Mean: £155,380

Median: £110,700

Standard deviation: £89,390

Range: £97,140 to £258,300

Shire

Number of observations: 5

Mean: £169,590

Median: £162,630

Standard deviation: £61,510

Range: £96,160 to £248,100

Variations in set-up costs (Overall cost to implement personal health budgets)**Location/type of authority implementing the pilot project****Metropolitan**

Number of observations: 4

Mean: £48,950

Median: £44,440

Standard deviation: £16,890

Range: £35,000 to £71,960

Unitary

Number of observations: 8

Mean: £101,640

Median: £82,860

Standard deviation: £33,210

Range: £78,950 to £169,260

London

Number of observations: 3

Mean: £111,570

Median: £97,140

Standard deviation: £52,720

Range: £67,570 to £170,000

Shire

Number of observations: 5

<p>Jones et al (2011)</p> <p>Mean: £104,400 Median: £96,160 Standard deviation: £51,410 Range: £45,660 to £173,750</p> <p>Ongoing costs or savings of implementing the project Four of the sites anticipated a cost reduction in terms of assessment and support planning as a result of introducing personal budgets. One other site thought that the implementation of personal health budgets would lead to cost reductions within the project management structure, due to collaborative working with the local authority.</p> <p>Nine sites, however, reported on-going costs in terms of staff time, advocacy costs and the use of review panels.</p> <p>** Twelve of the pilot sites projected that the project management resource would be required for two years to ensure successful implementation. An average of £146,040 would be required to implement the initiative within the two year period, taking account of the level of resource that would be incurred without implementing personal health budgets</p>
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<p>Kremer (2006)</p> <p>Study aim(s): To describe the impact of personal budgets on health and social care professionals, and informal carers</p> <p>Quality assessment: Low</p>
<p>Population: NR</p> <p>Country: Netherlands</p> <p>Sample size: N=Unclear</p>
<p>Study methods:</p> <p>Study design: Methods not recorded</p> <p>Sample selection: NR</p> <p>Data collection: NR</p> <p>Evaluation/intervention:</p> <p>In Control: A partnership of central and local government and the independent and voluntary sectors. It aims to put disabled people in control of their own lives through the power of self-directed support. This involves giving people control of a personalised budget.</p>
<p>Results:</p> <p>Number of budget holders in 1996 Persons in care – 4,000/5,401 (74.1%) Mentally retarded persons – 1,400/5,401 (25.9%) Psychologically retarded persons – 1/5,401 (<0.01%) Physically disabled persons – 0/5,401 (0%)</p> <p>Number of budget holders in 1998 Persons in care – 7,118/10,344 (68.8%) Mentally retarded persons – 3,101/10,344 (30.0%) Psychologically retarded persons – 125/10,344 (1.2%) Physically disabled persons – 0/10,344 (0%)</p> <p>Number of budget holders in 2000 Persons in care – 16,282/22,618 (72.0%) Mentally retarded persons – 6,195/22,618 (27.4%)</p>

Kremer (2006)

Psychologically retarded persons – 141/22,618 (0.6%)

Physically disabled persons – 0/22,618 (0%)

Number of budget holders in 2002

Persons in care – 34,544/48,039 (71.9%)

Mentally retarded persons – 11,197/48,039 (23.3%)

Psychologically retarded persons – 2,203/48,039 (4.6%)

Physically disabled persons – 95/48,039 (0.2%)

State expenditure on care in 2002

Nursing homes – €4,190.7m

Residential homes – €3,180.7m

Home care – €2,076.0m

Personal budget (care and nursing) - €212.2m

State expenditure on care in 2003

Nursing homes – €4,291.5m

Residential homes – €3,211.2m

Home care – €2,082.2m

Personal budget (care and nursing) - €212.2

State expenditure on care in 2007 -estimate

Nursing homes – €4,605.9m

Residential homes – €3,211.7m

Home care – €2096.4

Personal budget (care and nursing) - €212.2

Impact of personal budgets on professionals

One motive for introducing personal budgets was to change the power relationship between the client and the professional. Clients who chose personal budgets were dissatisfied with regular home care, which was riddled with continuous turnover of personnel and the inflexibility of working hours.

Budget holders are very content with the care they receive. One study reported that most budget holders say that the care they buy is of very good quality. Recipients of regular public care, however, are also very content with the quality of care. The major difference between both groups is that the former feel they have a real voice in what kind of help is given, who comes to help, and at what time.

Home helps are hardly ever seen as professionals; at best, they can be considered as semi-professionals. A survey of Sting's (the organisation in charge of the regulation of home care workers in the Netherlands) members who worked for budget holders shows that these care workers are very satisfied. They say the quality of care they can give now is much higher than when employed by a care organisation as they can develop their own views on what needs to be done as well as the freedom and independence that goes with the job.

Personal assistants employed via direct payments sometimes feel obliged, like family carers, to undertake certain tasks or duties which may be beyond their skills or which may go against their professional standards. It is difficult for home helpers because the client has the monopoly on the quality of care and clients do not always understand their role as employers.

A survey of home helps shows that professionals themselves are concerned about their professional development. Some of them would like to improve the quality of care but lack opportunities to do so: they cannot consult other professionals or train and educate themselves as the Dutch state is no longer in charge of professional impetus under personal budgets. The definition of quality of care is in the hands of consumers rather than in those of the home helps. This consequently undermines the professionalism of home care.

Impact of personal budgets on the family

What has further weakened the professionalism of home care is budget holders employ family members as home helps. But care workers also compete with informal carers, who are often women. When a budget

Kremer (2006)

holder can employ his own wife, this refutes the notion that care is a profession.

Initially, married people were not allowed to have a labour contract but this changed owing to pressure from the organisation for informal carers. A study shows that more than half of budget holders employ informal carers. One study reports care users seem very content with this solution. They appreciate the quality of care and they like the fact that their daughter is paid and contracted, although some others have difficulties understanding why their long-standing care relationship should have money attached to it.

The interests of the care receiver are not necessarily in the interests of the caregiver but many informal caregivers feel valued and recognised. One potential problem, however, that can arise from informal care giving is that care givers may feel reluctant to exercise their social rights such as annual leaves.

Secondly, caregivers may feel a stronger moral obligation because of the existing personal budget contractual agreement. As a result, informal carers may therefore care too much and become overburdened. One study reports that 50 percent of caregivers said they were overburdened as they live in the same house with the care receiver.

Other problems have to do with loss of income and labour market prospects for the caregiver. To some extent, personal budgets can push informal carers out of the labour market as there is less flexibility to get involved in paid employment. The Dutch government however is wary of the monetarisation of informal care because they are afraid of the 'dead weight loss'; where people are paid although they would still care if this were not the case. The government believes this has a huge budgetary impact. This has resulted into ongoing debate about limiting the personal budget to exclude payments for informal care.

Laragy and Otmann (2011)

Study aim(s): To present a case study and analyse the findings using Bronfenbrenner's four system levels to identify what factors were effective in the program's implementation.

Quality assessment: Low

Population: Families of people with disabilities and managers of agencies managing people with disabilities

Country: Australia

Sample size: Developmental phase - N=8 (Five family members, one agency manager and two senior managers)

Follow-up phase - N=9 (Parents of people with disabilities and two senior managers)

Study methods:**Study design:**

Exploratory case study.

Limitations: The small sample size used contained families who self-selected and were strong advocates of service system reform, so they may not be representative of the larger sample.

Sample selection:

Families interested in joining the Individual Support Packages program and managers of the agencies managing the program; convenient sampling

Data collection: Developmental phase - Observation of family meetings and semi-structured face-to-face interviews

Follow-up phase - Semi-structured telephone interviews

Evaluation/intervention:

Facilitators of individual budgets:

Laragy and Otmann (2011)

Framework for the introduction and implementation of personal budgets

Results:

Model of funding, satisfaction, and social participation outcome ratings from family members in follow-up interviews:

Four families self-managed all their funds; they all had a high satisfaction with the choices they made, high satisfaction with level of control, and a high increase in social participation with the exception of one family with medium increase in social participation.

Of the two families who had self-managed a part of their funds and had a case manager managing the remainder, one of them had both high level of satisfaction with choice, and level of control, and high increase in social participation. The other family however had medium satisfaction both with satisfaction of choice and level of control, and no increase in social participation as a result of increased impairments.

The 7th family had all their funds managed by a case manager. They had both a high level of satisfaction with choice and level of control of choice but no increased social participation

System level findings for families using individual funding and case managers (Families' responses)

Micro-system

There was an increased control over choice of what funding what used for, which was highly valued. Outcomes also improved especially social participation of the disabled persons. Support from other families was essential and isolation increased over time

Enhanced levels of control resulted in more appropriate activities and higher levels of satisfaction. The self-esteem of families was also enhanced because they did not have to continually seek approval from a case manager.

"I want control ... to set priorities and be responsive to changing circumstances ... to know how much money I have and what I can spend until the end of the year" – Parent self-managing all funds

The families however needed more information and support than was available to make decisions and families feelings of isolation grew despite considerable peer support.

Meso-system

At this level, the range of options increased but access to information and support was critically important. Accessing information was time consuming and frustrating for the families however person-centred planning training encouraged creative thinking and innovative outcomes.

Organisation staff did not understand individual funding and gave contradictory advice. The need for flexibility conflicted with the organisation's requirements that support workers have a minimum 3-hr shift. The families were willing to pay 10% for administration and accounting fees and not have responsibility of being an employer of support workers.

All the families appreciated having the authority to decide whether to self-manage their funds or remain with traditional case-managed services. Self-managed families were glad they could carry over funds from one month to another as this gave them the opportunity to put money aside for emergencies as well as new opportunities.

The peer network that was supposed to replace the coordinator of the program never eventuated and as such majority of families were left wanting more support, especially in times of change or crisis. No self-managed family exercised the option of purchasing case management support because there were limited funds available to purchase supports and the informal groups were insufficient to prevent increasing feelings of isolation.

All self-managing families had to pay a compulsory 10% administrative charge for the management of their funds, provision of a monthly account and employment of support workers when required. They were nevertheless not willing to pay additional case management fees.

Access to information was critically important for all families and this included knowing policies and

Laragy and Otmann (2011)

procedures that determined how funds could be spent, the amount of allocated funding, the monthly balance, and services and social opportunities. Gaining this necessary information was however quite difficult especially for families that were self-managing.

"I would like it to be easier to access information – it takes a lot of time – I start with [government department], I use the [agency], and most importantly I use the grapevine" - Parent self-managing all funds

Planning was also identified as important. Families highly valued the person-centred planning seminars which introduced families to innovative strategies. Although formal planning processes were used initially, over time all self-managing families found them too restrictive and consequently, developed simpler processes.

"... [they] introduced me to the idea of looking outside the square."

The decisions of families to self-manage were determined largely by previous experiences with case managers, whether positive or negative.

"... the case manager has been the key to getting funding ... the case manager has been important, essential, in accessing resources and getting on the lists" - Parent using a case manager

"My experience of case managers was that they gave to the neediest. They thought we were okay and did not need lots of help ... (they were) responding to the squeaky gate." - Parent self-managing all funds

"We have had lots of things we would never have thought of when we depended on the case manager." - Parent self-managing all funds

Successful self-management was dependent upon having good working relations with agency administrative staff who understood the program's philosophy. Sometimes accounts were not paid by administrative staff who did not understand the parent's authority to make decisions and to negotiate more flexible working conditions with support workers.

"Top management understand family governance principles, but this understanding is not shared by lower managers and many staff 'still do not get it'." - Parent self-managing all funds

Exo-system

Government policies and guidelines provided increasing support for individual funding. Services were not always available when needed. There was increased opportunity to purchase supports and services better suited to personal needs, especially from outside the disability sector.

The individual funding program resulted in increased access to a range of supports and services. Though financial resources were limited, there was considerable improvement in the range of activities undertaken and outcomes achieved. For instance, one family, receiving a relative high level of funding, organized social activities to replace their family member's attendance at a disability "day centre".

Macro-system

Families were committed to individual funding principles and practice. The analysis of this level revealed that insufficient financial resources restricted the individual funding program's implementation in accord with its stated principles and policies. The coordinator's position could not be continued and six of the seven families spoke of insufficient resources to meet their needs

System findings for families using individual funding & case managers (Managers' response)

Micro-system

There was high client satisfaction because of increased control and flexibility. Support workers were sometimes preferred negotiating working conditions and hours directly with client rather than through the organisation because of positive relationship and flexibility.

A small proportion of the support workers, particularly migrant women, found it difficult to refuse any request when negotiating directly with clients.

Staff were initially sceptical and only became supportive over time when the success of the program became apparent.

The managers were also concerned about the conflict of interest between the families' needs for maximum

Laragy and Otmann (2011)

flexibility when employing support workers and workers' rights. Families found the agency's legal workplace agreement of a minimum 3-hr shift for support workers unnecessarily restrictive.

Meso-system

Provision of information and monthly accounts was difficult as well as facilitating peer support groups. Recruiting support workers was easier than expected because of their satisfaction working directly for one client. Vulnerable support workers need working conditions to be protected.

Provision of necessary information and support services was a serious challenge. Families were unaware of certain free support services and provision of necessary funds was particularly problematic for the managers.

Exo-system

There was insufficient funding resulting in inadequate infrastructure to support individualized funding users. Families in crisis had no access to additional funds and provision of a monthly account was a challenge because government funding was received in a mixture of individual and "block" allocations.

The agency's contingency fund held for people using case managed services was not available for those who self-managed all their funds. It was not always achievable for the latter group of families to set aside funds for emergencies.

Macro-system

Government was responsible for the implementation of individual funding principles and practices and there was inadequate government support to implement individualized funding policies.

Maglajlic et al (2000)

Study aim(s): The study focused on several issues: how to provide effective information; what sorts of support could direct payments purchase; how could it be accessed; how could users handle the money; how could it all be evaluated?

Quality assessment: Low

Population: people with intellectual difficulties, mental health service users and those with physical disabilities

Country: England (Tower Hamlets)

Sample size: 10 service users, 10 staff and 10 carers

Study Methods:

Study design: Qualitative

Sample selection: Not detailed

Data collection: Semi-structured interviews

Evaluation/intervention: Direct payments

Conducted in 1997-1998 and focus was early implementation of direct payments. Low sample size and may not have been representative.

Results: Some common themes emerge from all three disability groups. People are disappointed and cynical about the performance of the Tower Hamlets social services department. Most of their experiences of services have been negative although they

value greatly many face to face staff like keyworkers. They view any change with suspicion. They want direct payments accountable to them, through the various voluntary bodies.

People at all levels, users, carers and junior staff have hardly any knowledge about recent community care developments and especially direct payments. The current information systems are not working. Some overall information strategies are desperately needed. The various stakeholders in services feel uninvolved and without any sense of ownership. Nevertheless, these groups are cautiously enthusiastic about what

Maglajlic et al (2000)

direct payments might offer them. They see the possibilities for much more control and flexibility and, in some cases, an escape from the local authority swamp. However, they are anxious about the various practicalities.

Pearson (2010)

Study aim(s): To explore some of the key problems that will need to be addressed if poor uptake of the direct payments policy is to be reversed and direct payments are to be made available as a mainstream service option for all disabled people.

Quality assessment: High

Population: All persons involved in direct payment planning.

Country: Scotland

Sample size: NR

Study methods:

Study design: Qualitative

Reporting of methodology is incomplete.

Sample selection: All persons involved in direct payment planning in two Scottish local authorities.

Data collection: Semi-structured interviews

Evaluation/intervention:

Direct payments:

Barriers to implementing

Results:

Barriers to implementing direct payments

Resistance has centred on an anti-market discourse, whereby direct payments have been viewed by some senior policy planners as part of a broader drive to privatize social care services.

A pervading ignorance surrounding the principles of independent living that underpin direct payments found in many of the social work staff responsible for accessing information to potential users.

Despite a substantive training drive led by the local authority in conjunction with the local centre for independent living (CIL), planning staff have become increasingly aware of shortcomings in social workers' knowledge of direct payments. As the main local authority planner commented:

"They [social workers] don't really seem to understand them yet. When people are getting them [direct payments] it tends to be more out of desperation because they're seen as difficult cases and existing services can't meet their needs. ('East Scotland', main local authority planner)"

"Staff are finding it difficult to take on board that direct payments are just another way of delivering services'."

Lacklustre response to direct payments can be attributed to three related problems:

-At an organizational level, direct payment legislation emerged a year after fundamental restructuring of the local authority. As such, the shift to unitary status was said by senior planners to have limited impetus for policy planning and saw social service budgets cut substantially. Reorganization also signalled the end of what had been the main regional campaigning group of disabled people.

-This led to a second and on-going problem in that whilst disability activism in the area had been historically fragmented and low key, local authority restructuring seemed to have accentuated the problems faced in

sustaining interest and representation of disability issues. As the main local authority planner suggested, this “made services particularly susceptible to cuts’.”

-Direct payments have been continually viewed by a number of local authority and trade union officials as part of a wider strategy of ‘backdoor privatization’. This position was reiterated by the CIL representative:

“There’s still this real fear of backdoor privatization—not from the immediate planners— but the elected officials higher up. You keep asking yourself ‘why is there no progress? And you keep coming back to the same thing’. (‘West Scotland’, CIL representative)”

Rabiee et al (2009)

Study aim(s): To report the experiences and outcomes of early individual budget users two to three months after being offered an individual budget

Quality assessment: Mid

Population: Disabled people using individual budgets and carers

Country: United Kingdom

Sample size: N=14

Study methods:

Study design: NA

Sample selection: Adult users of individual budgets (with physical/sensory impairments, learning difficulties, mental health problems, and older people) and carers; service users and proxies.

Limitations: The interviewees were selected by staff in the pilot sites – so individuals selected for interview may not be representative of other individual budget holders. The experiences of the respondents may not be typical of those offered an individual budget later on. At the time of the interview, only seven of the fourteen interviewees were actually receiving an individual budget.

Data collection:

Semi-structured interviews

Evaluation/intervention:

Individual budgets:

Bring together a variety of income streams from different agencies to provide a sum for an individual, who has control over the way it is spent to meet his or her care needs

Results:

- Previous support arrangements

Two interviewees were new referrals and thus unable to make any such comparison. Six interviewees had previously received direct payments. Among most of the remainder, previous support arrangements consisted largely of personal assistants or carers coming into the home on a regular basis.

While some interviewees were reasonably happy with these arrangements, others complained about the lack of flexibility, consistency and unreliability of carers. Direct payments were also criticized for being too restrictive, as interviewees believed they could only be used to pay for personal care only and not for any other support needs.

Interviewees’ first priority in planning to use their individual budgets was generally personal assistance, through directly employed care workers, agency staff or informal carers. They also planned to spend their individual budgets on transportation to get out and about, go to meetings and be more involved in their communities; equipment, such as tele-care equipment; short periods of respite care at times that suited users and their families; and other things that mattered to them that would not have been funded under previous support arrangements

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Early experiences of individual budgets

Assessment and support planning

Most interviewees had found the self-assessment forms user-centred. Individual budgets' self-assessment and support planning were felt to be more about what they could and wanted to do. The processes were also felt to be holistic and encouraged people to think creatively about what they wanted to achieve

“It was a way of me being in charge...I was able to say what I thought was best for me ...they're ... beginning to realize that the users are the experts ... to be able to use the money in creative ways is fantastic”

Interviewees with fluctuating conditions found that the flexibility of individual budgets allowed them to use their allocated resources over a year and this reassured them that support would be available as and when they needed them.

“ ... I feel like there is less pressure on me to use my hours, ... 'cos I'll probably need more than ... what I've got when I'm ill but a lot less when I'm well. So I'm going to save them up and ... when I'm ill I can have someone sort of wait on me all the time then”

A few interviewees found the individual budget self-assessment form simpler than other self-assessments. Some others however reported difficulties with completing it. They found a number of questions difficult to understand or open to interpretation – e.g. 'substantial' was entirely subjective; and frequent could mean once a day, once a week or once a month. Some others found it difficult to answer certain questions, as more than one answer applied to them – there was concern that giving wrong answers could impact on the level of their individual budget.

Interviewees valued the involvement of other people, including other family members, friends, social workers and inclusion workers, particularly in completing the individual budget self-assessments. People with fluctuating conditions however reported problems with both self-assessment and planning their support arrangements, because they found it difficult to predict the level of support they would need at any given time – as their condition changed, sometimes unexpectedly, so their support needs could change significantly too. Two interviewees said they found it helpful to do two care plans – one for a 'good day' and one for 'a bad day' – in order to derive an average.

In three of the pilot sites, interviewees' self assessments had been completed and support plans devised with the help of family, friends, social workers, care managers or inclusion workers. Four of the interviewees on these sites reported having help from a broker to help work out how much support they could afford to purchase from different services. The fourth site had a series of workshops about support planning, involving representatives from most of the organisations involved with individual budgets, and people already using individual budgets who could mentor others.

A few interviewees reported that the support planning process had improved transparency in communication between themselves, their carers and professionals.

“ ... in the previous assessments ... it wasn't an open process ... no time did they ... come back to us and say ...'do you agree with this piece of work, do you need to change it?'” – Parent of a child with learning disability

All interviewees thought that the most important aspect of the individual budgets was that they offered more choice and control. A few of the interviewees had decided to spend their individual budget on paying for support to enable them to go to college; those with previous experience of direct payments stated that they could not have spent their direct payments like this.

For most interviewees, the individual budget was, or was expected to be, more or less the same as the value of their previous support arrangements, although some felt that their individual budgets were higher because they were able to do more with it. In four cases, the overall value of interviewees' support was expected to increase, as they had at the same time been made aware of other funding streams they were eligible for.

A few interviewees said they expected individual budgets to shift the balance of powers between users and service providers and in the long term, better quality support. Those who expected the value of their individual budgets to be lower than the value of previous support arrangements felt this would potentially

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reduce their choice and control over decisions and the outcomes that mattered to them.

A number of interviewees admitted they were not clear about what an individual budget was and how it differed from a direct payment or conventional support arrangements. There was also a lack of understanding about the different options for holding the budget and a few interviewees were not clear about what the individual budgets could or could not be used for. Two people reported receiving contradictory advice from care managers about what the individual budgets could be used for. Several people thought the assessment and support planning process were unduly lengthy. However most people expected this to become quicker and smoother once the scheme was established.

Using individual budgets

Interviewees who had previously used direct payments reported that their individual budget was easier to manage, as it did not require such onerous record-keeping.

“I couldn’t see how Social Services could change from ‘We’re in charge’ to trusting us, you know ... I was very cynical”

All interviewees stated that one of the most positive aspects of the individual budgets was their flexibility both in terms of what they could be spent on as well as when they were spent. For example, they were able to ask paid carers to come at times that suited the user, and they could get things done more quickly. They could also pay their carers more flexibly on the basis of what they were asked to do rather than how long it took them to do it.

A few users said they could go through periods where they needed minimal support, but needed a lot of support at other times. One interviewee who had to leave university because her support needs could not be met described how her individual budget has enabled her return.

“I didn’t think I’d be able to go back to university without it ... ‘cos ... when I’m ill, I need the carer to come round in the morning and get me up and get me dressed ... otherwise I wouldn’t ...”

The freedom to employ one’s own carer was appreciated by interviewees but the significance of this varied according to individual circumstances. Several of them saw it as an opportunity to maintain consistency and continuity, or to hire some trusted person like a family member or friend. Others saw it as an opportunity to employ different carers for different tasks. For example, one young person said she would rather pay a friend to accompany her on social outings and an older carer to take care of her personal needs. However, several interviewees did not want the extra effort of advertising for and recruiting their own staff and would have recruited through an agency.

Interviewees’ views on how much extra burden the management of the individual budget would be for themselves and their families. Those who did not anticipate needing the help of others to manage their individual budgets, including proxies, said they had experience of being self-employed and were familiar with tax and national insurance issues. However, they all emphasized that other people without this experience could struggle and some thought they might not be able to cope with these responsibilities if their condition deteriorated.

Where the support needs were high and the level of individual budget was low than the value of previous support arrangements, this could have placed additional burdens on family members because the implicit expectation of more unpaid informal care would be required.

“... designed to cut social budgets and ‘dump’ more onto informal carers ... if I was ... doing the work I’m doing for daughter, ... I could actually get paid for it” – Informal carer/Proxy

Parent carers managing a son/daughter’s individual budget were anxious about what would happen to their support arrangements if they were suddenly taken ill. Interviewees who had used a broker to manage their direct payments prior to the individual budgets continued using the same broker as it will help them keep track of how their money was spent. One interviewee who had withdrawn from the individual budget pilot thought did so partly because he thought he was expected to hire his own paid carers, and neither he nor his family members wanted to take on the responsibility of recruiting and employing somebody.

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Experienced and/or anticipated outcomes of using an individual budget

A few users mentioned that, prior to receiving an individual budget, they were virtually housebound as their care arrangements had covered personal care only.

“ ... personal care ... is all very well ... it is very needful but ... you can still be incredibly isolated ...with the individual budget, ... it's allowed me to pay for a driver and all ... when I need it ...” – Interviewee

Many interviewees reported that their previous reliance on informal carers had created a degree of dependency; and this sometimes having to wait for long until a family member was free to help them. Interviewees who had previous experience of direct payments said that both schemes helped them become less reliant on family members. A few interviewees noted that being able to use their money to buy gifts, as means of saying ‘thank you’ has resulted in relationships with family members reverting from predominantly care-giving to kinship relationships.

Many interviewees talked about how using the individual budgets had already enhanced their sense of identity and self-esteem, and that it is helping them regain their identity as ‘an individual’ and not as ‘a disabled person’.

“ ... My appearance is really important to me ... I can't put on make-up, I can't do my hair and things like that ... I've been able to pay for somebody to do that for me”

While none of the interviewees reported a negative outcome, some of them were concerned about the future. A few people were anxious about the sustainability of individual budgets. Some were anxious about what would happen if their circumstances changed after their support plan had been agreed – would individual budgets be enough to accommodate those changes? Some others were worried about the individual budgets being misused by users, their families or social care agencies and wanted to know how this could be prevented. One interviewee was concerned that the scheme might not be able to meet the higher costs of providing support in remote areas where local services were not available or paid carers had to travel longer distances.

Factors enhancing the impact of individual budgets

One-to-one support with the assessment and planning processes

All interviewees emphasized the importance of professional support during the assessment and support planning process. However, the process was difficult for some of them because in the past they had been told by professional what they could and could not have, and now needed help to learn how to plan their own support. A few people thought that one-to-one mentoring, apart from being used in the assessment and support planning process, should be extended to cover training on the financial management of individual budgets.

Carers of people with learning difficulties felt that it was essential to have an advocate involved in the assessment and support planning, to explain the self-assessment form; ensure that the individual's views were correctly represented; and challenge users' low expectations.

On-going help with managing an individual budget

Interviewees thought the effectiveness of individual budgets would be determined by how much they could enhance an individual's quality of life. However, several people questioned the extent to which individual budgets were accessible to different groups of people. Interviewees expected individual budgets to work well for more able people, with straightforward support needs, who did not require high levels of family assistance to plan and manage their support.

However for people with high-level or complex support needs and little family support, individual budgets would only work if free advocacy or brokerage services were available. Interviewees thought that the appropriateness of the individual budget option depended on the interplay of people's abilities; the level of support they needed; the extent of formal and informal priorities and preferences.

In general, interviewees felt that individual budgets might not work for older people, who could find it confusing and/or difficult to use the budget flexibly; for people without informal support; for people needing highly structured routines; and for people with cognitive impairments or low levels of mental capacity, who could easily be taken advantage of.

Riddell
<p>Study id: Riddell et. al. (2006)</p> <p>Study aim(s): To examine the implementation of direct payments policies in the UK.</p> <p>Quality assessment: High</p>
<p>Population:</p> <p>Key informants involved in the development of direct payments policies and their implementation; Individual officers responsible for direct payments in purchasing authorities; All local authorities.</p> <p>Country: UK</p> <p>Sample size: Interviews: N= 21 Survey: N=102</p>
<p>Study methods:</p> <p>Study design: Qualitative</p> <p>Sample selection: NR</p> <p>Data collection: Semi-structured interviews and surveys.</p> <p>Evaluation/intervention:</p> <p>Direct payments: Implementation, facilitators and barriers.</p>
<p>Results:</p> <p>Implementation:</p> <p>The mean average number of direct payments per authority was then 44.4 but there was considerable variation, both between localities and between countries. There were 19 authorities with no reported direct payments users.</p> <p>Of the 59 authorities reporting more direct payments than the mean average, there was a local support organisation. There was a positive association between the take-up of direct payments and the presence of a local support organisation described as 'user-led'.</p> <p>By 2003, England had established twice the rate of take-up per 100,000 adult population compared with other parts of the UK. Whilst there have been rapid increases in all parts of the UK since then, this differential was still evident in 2005. See Table 15 below.</p>

Table 15: Direct payment users in each country/province of the UK between 2000/1 and 2003: number and rate per thousand people with long-term limiting illness or disability (LTID)

Country/province	Population	% LTID	2000/1: number (rate) per '000 with LTID	2002/3: number (rate) per '000 with LTID	2003: number (rate) per '000 with LTID
England	50 million	18	4900 (0.54)	6300 (0.70)	9700 (1.00)
Scotland	5 million	20	207 (0.20)	392 (0.40)	571 (0.57)
Wales	3 million	23	No data	185 (0.26)	No data
Northern Ireland	1.5 million	23	33 (0.09)	49 (0.14)	128 (0.37)

Riddell

Results (continued):

Factors explaining the historically uneven geographical take-up of direct payments in the UK:

- The presence of a strong disability advocacy base;
- Adequate funding for policy development;
- The political culture of national, regional and local government;
- Local markets for the supply of social care;
- The role of local champions within purchasing authorities;
- The existence of appropriate infrastructure (specifically, but not exclusively, user-led direct payments support schemes).

There have been difficulties in monitoring and ensuring equity between different user groups.

Despite the extension of eligibility, there remain more recipients with physical or sensory impairments than for all other groups, but there is considerable variance between localities. There were fewer direct payments to people with mental health problems than to any other group.

There is enormous variation between and within user groups and regions in the intensity or size of direct payments packages.

Payment rates were consistent across different user groups, but there was considerable variation across the UK. Rates paid by local authorities in Northern

Ireland and Wales were markedly lower than in England and Scotland.

Direct payments were widely welcomed for the positive outcomes that could be achieved by disabled people and for the new creative options they provided to care managers and purchasers.

All of the interviewees said that direct payments gave users greater choice, control and flexibility, and there were many innovative examples of how they could be used to promote independent living. However, there were substantial differences in the degree of flexibility and choice available to users in different localities.

Responsibility for the implementation of direct payments within purchasing authorities varied greatly, with evidence of an increase in the number of dedicated direct payments officers in all parts of the UK. However, English authorities were far more likely to have designated officers compared with Scotland, Wales and Northern Ireland. The availability of development funding from central government had a significant impact on this.

Policy guidance from UK and devolved governments was broadly welcomed but street level bureaucracy and the local interpretation of national guidelines was a significant factor in successful implementation. Specific examples were given of needs for clarification from central government (e.g. in relation to capacity and consent for disabled children and young people).

There was evidence of difficulty in recruiting personal assistants in several areas (including half of Welsh authorities). There were several examples of specific local recruitment difficulties in more affluent areas and commuter belts (e.g. where casual and part-time domestic support work was available) and in localities where service sector or retail employers had recently established new large-scale job opportunities (e.g. new call centres or supermarkets).

In the majority of areas, the employment of relatives continued to be viewed with some caution whether they lived in the same household or not. However, the employment of relatives was seen as one way to tackle difficulties in recruitment affecting particular communities (e.g. within some urban black and minority ethnic communities and some sparsely populated rural communities).

The majority of support organisations were contracted to provide a wide range of services and roles (from promoting interest in direct payments, to the provision of advice and guidance, staff recruitment and payroll

services).

Authorities with the greatest numbers of direct payments users had generally developed a productive synergy with local disability groups over many years.

Facilitators Aiding factors identified as important (England and Scotland) – See Table 16 below and Table 17 – Barriers.

Table 16: Facilitators: Aiding factors identified as important (England and Scotland)

Factor	% English Local Authorities (N = 109)	% Scottish Local Authorities (N = 23)
Effective support scheme	89%	87%
Training and support for front line staff	86%	87%
Leadership within the local authority	81%	82%
Positive attitude of staff	80%	91%
National legislation, policy and guidance	82%	68%
Accessible information for service users and carers	78%	87%
Demand from service users and carers	78%	96%

Table 17: Barriers: Hindering factors identified as important (England and Scotland)

Factor	% English Local Authorities (N = 109)	% Scottish Local Authorities (N = 23)
Users' and Carers' concerns about managing direct payments	68%	66%
Staff resistance to direct payments	65%	22%
Lack of people to work as personal assistants	63%	63%

Rosenberg et. al.(2005)

Study aim(s):

Examined Family Care managers' and Interdisciplinary Team members' perspectives on various aspects of implementing a self-directed supports service provision and focused on factors facilitating implementation and barriers to implementation of self-directed supports.

Quality assessment: Mid

Population: Family Care managers and Interdisciplinary Team members

Country: USA

Sample size: NR

Rosenberg et. al.(2005)**Study methods:**

Study design: Qualitative

Sample selection:

Participants were recruited for participation by a contact person on staff at each Care Management Organization (CMO). The interviewers asked contact people at each CMO to select managers and IDT members to participate in the focus group interviews.

Data collection:

Semi-structured focus group interviews.

Evaluation/intervention:

Self-directed support (as an option within the 'Family care' program):

Implementation, facilitators and barriers.

Results**Initial implementation issues:****In the context of shift to Family Care:**

During the shift to Family Care, SDS was often not the highest of priorities.

"I think leadership both here . . . and at the state, recognized that while SDS was in the Family Care contract . . . [it] was not the highest priority. . . . We talked about it, and . . . we were starting to implement it a little bit. But it was never a priority for us, the same as it was a priority to get our claims system operating, so that we could pay our providers. As it was to get our IT system operating, so that we could figure out where our money was going, so we wouldn't go bankrupt." Care manager

SDS as a contract requirement

In some CMOs, it is unlikely that SDS would have been developed when it was, had it not been a contract requirement for Family Care.

"If we wouldn't have had Family Care, we probably wouldn't have done it. That was our impetus to do self-directed supports" Care manger

Reconciling SDS and managed care philosophies

A sense amongst staff that managed care and self-determination are philosophically in compatible from a fiscal perspective and from a control of services perspective. Firstly, increasing cost-effectiveness is probably the most important reason for switching to a managed care model. Fiscal eyebrows were raised by the fact that members could set the wages they paid their SDS workers at a higher rate.

"In a managed care environment, you're . . . being the most cost effective that you can. We have embraced that people have the right and the ability to hire their own staff [through SDS]. The question then is where is the cost effectiveness if [members] want to pay all of [their] staff \$10 an hour?" Care manager.

Secondly, the underpinning value of member control in SDS philosophically requires giving members full power over all aspects of the services they receive. These tensions between cost-containment and member choice, and between protection of health and safety and member choice, are inherent to an SDS model.

Legal issues

Liability was a barrier for initial implementation. The fear was that the CMO would be considered the employer of record and found liable in the case of accidents involving SDS members or employees.

Importance of previous experience with SDS-like services

Having previous experience with SDS-like services made a noticeable difference in the ease with which SDS was implemented in their county. CMOs that had some experience in member self-direction reported an easier transition to a functional SDS option.

SDS as part of a larger movement

Rosenberg et. al.(2005)

Understanding SDS as part of a national movement facilitated an embrace of SDS philosophy.

“Maybe the biggest change [in SDS since becoming a Family Care county] is consciousness that this is part of a national movement” Care manager

Supportive leadership, especially one person who takes a lead on SDS

The existence of one (or more) individuals with a passionate interest in SDS seemed to affect how eagerly SDS was embraced by a county. The impact could be felt especially strongly if the people excited about SDS were in positions of authority. In one CMO county, Interdisciplinary Team members reported that there had originally been a higher level manager in the county who was a strong advocate of SDS and because of that person the CMO was, “more likely to at least go through the motions of being interested in SDS.” Interdisciplinary Team members

By contrast, in another CMO, “I don’t think upper management has taken it on passionately. You can’t do more then. . . . You have to have the buy-in.” Care manager

Intellectual shift from traditional to self-directed model

Traditionally, state agencies that work in long-term care are accustomed to having a certain amount of control over service provision to care recipients. While SDS still falls within the rubric of state-supported services, and control remains largely with the state. Under SDS, the

CMOs must cede some amount of control to members.

“I think the part that people struggle with is the giving up of control, agency control. . . . We just have to let go, as hard as it is, we have to let [members] try [SDS]. . . . It’s really hard for people who’ve been with the agency and have had that control for so long to just say [to a member] ‘you know, if you want to do it you can do it, and we’ll help you as much or as little as you want” Care manager

Monthly vs. annual budgets

At the outset of SDS implementation in a CMO, each county struggled with decisions about the format SDS took. One of the key decisions was whether members who choose to self-direct will have a monthly or an annual budget. Only one CMO chose to operate SDS with an annual budget for members, and this resulted in some notable differences. Care managers in this county discussed the issue of hours that are “banked,” or left unused by the member, either intentionally in exchange for some other service or good, or unintentionally when actual service usage is less than what had been expected. This issue did not surface as a major theme in the other CMOs, because monthly budgets do not result in a considerable number of banked hours.

Choosing an annual budget has a number of advantages. Annual budgets offer greater member control over resources for members who want this, as well as a greater flexibility for members to obtain goods and services.

There are also drawbacks to annual budgets. First, annual budgets require ongoing monitoring throughout the year to ensure that use of resources is roughly in the target range. This can be confusing to members and time consuming for care managers. Secondly, care managers find themselves in a quandary when members spend either significantly more or less than their budgeted amounts.

State workgroup

When Family Care began, a group with 1-2 representatives from each CMO was formed to work on implementing SDS in the five Family Care CMO’s. In general, the CMO interviewees reported that the state SDS workgroup for Family Care was extremely useful, especially during the implementation phase. The CMOs found that the SDS workgroup allowed for across fertilization of ideas, the development of training materials and protocols, and the sharing of documents.

“Everyone got together and sat around the table and tried to hash through guidelines and protocols. One of the CMOs described what they are doing in terms of setting up annual individualized budgets, and what happens if there is money left over or not enough at the end of the year. . . . We could take it back and decide, ‘Do we think this is something that would work within our program?’” Care manager

Member involvement in early implementation

Rosenberg et. al.(2005)

Most, but not all, CMOs reported that members had been involved during initial SDS policy development. Usually member input was sought via CMO workgroups. Members on the workgroup helped the CMO staff to “get our heads around the philosophy of self-determination,” while managers at another CMO found that members “looked at [SDS] through advocates’ eyes more than we would have.” In a few counties, members actively helped develop policies for SDS.

Ongoing Issues

Staff training

In nearly every interview, interdisciplinary teams and managers alike noted that additional SDS training would be useful to staff. Training is essential for the initial implementation of SDS, and staff tends to appreciate trainings.

“Training about what SDS is has been useful . . . so we can know what the vision is, what we should be doing, what we can be working toward and striving for.” Care manager

Initial trainings, though essential, are of only limited benefit, because trainees are unable to absorb all of the information about SDS until they have used the system in practice.

“I think (the SDS process) is overwhelming until you’ve actually gone through it a few times. Then it’s like, ‘Oh, I get it.’ I had to ask [my supervisor] a lot of questions when I first got here.” Care manager

Member training and SDS provider training

Except for one CMO, all counties felt that their current member training was inadequate, and wanted additional member training. This concern is reasonable, since without member training, members may make mistakes as employers. In one CMO, a care manager reported that a member had suspended an SDS worker inappropriately. This care manager also expressed concern that a member could be held liable for such mistakes.

The bulk of member training on hiring, firing, training, and supervising employees was falling on the IDTs. Interviewees at other CMOs echoed the concern that member training was a drain on IDT time. In the one county where member training did not arise as a concern, nearly everyone uses a co-employment agency, rather than a fiscal intermediary. This suggests that member training may be especially important when fiscal intermediaries are used.

Setting budgets

Deciding upon the number of hours of service and rates of pay to SDS providers in individualized budgets is tricky for CMO staff. Interviewees also discussed inconsistency across care managers in setting budgets, as well as balancing care manager and member input.

“We’re in the process of developing guidelines and we’re really not sure about consistency over teams. . . . When you’re looking at the same needs, one budget may be higher than another person We have bands of identified pay rates based on the services they’re providing But it’s really at our discretion, what people are being paid. I find it very challenging to try to establish those rates for people.” Care manager

Staff time required

In nearly all of the counties, interviewees expressed that those members who self-direct require more care management time than members who do not. Caseloads were often too large to give SDS members as much time as they would like.

Paperwork

One reason that SDS requires additional staff time is because it often demands more paperwork than non-SDS services. Paperwork is an issue for members using a fiscal intermediary, especially because co-employment agencies handle the majority of the paperwork themselves for the members who chose to use their services. SDS paperwork for members who choose fiscal

intermediaries includes not only regular care plans and service authorizations, but also background check forms, W-4 forms, and other related paperwork. Each time a member hires anew worker, paperwork must again be completed. One of the CMOs seems to have successfully overcome some of the paperwork issues by removing most SDS paperwork from care managers.

Rosenberg et. al.(2005)

“Support staff do the paperwork. It’s minimal work for the case managers.” Care manager

Issues unique to target populations

Some CMOs have care managers that specialize in one or two target groups, and in other CMOs, each care manager works with all three target groups (frail older adults, adults with developmental disabilities, and adults with physical disabilities). Problems arise, according to those interviewed, when members do not have informal supports or guardians who can help them self-direct their care. “Monitoring provider liability, performance, and general behaviour” are important extra care management responsibilities for clients with developmental disabilities using fiscal intermediaries, because these members “are vulnerable and can be easily manipulated.”

Consistency across IDTs within a CMO

Care managers within the same CMO do not always make decisions about SDS care plans that are consistent with one another.

“In talking to these staff at [a CMU serving a similar population] you find out that people [there] are interpreting procedures differently, interpreting guidelines differently.” members who have networked with one another sometimes confront their care managers about other people who they perceive to have similar needs, but who have been authorized to receive a different number of hours. “I don’t think there is good . . . consistency between the teams [for arriving at a] number of hours and a salary. . . . I often get challenged: ‘why can’t my worker get as much as the lady down the hall’s worker?’” Care manager

A worksheet should be put in place for helping care managers devise budgets with members.

Paying family

Under what circumstances should CMOs authorize family members to be compensated to care for a member who is self-directing services?

“Some of us hesitate to pay family members. . . .Do we pay them? Do we not pay them? What do we expect of them when they’re living with the member? That’s a hard area for all of us.” Care manager

At the root is a complex interplay between cultural norms regarding the expectations of family members to care for one another, questions about what should constitute monetarily remunerated work, the economic needs of low-income families, and state and county fiscal constraints.

“I remember a specific conference . . . this guy at the conference said, ‘who is going to provide the best care other than a loving family member?’ And that really was what sent the message home. And he was right. . . . I started to look at things differently.” Care manager

There is concern about maintaining the integrity of family as an informal support:

“I think it’s everyone’s responsibility to provide care to family members living at home. But if they think they can get paid to do that, then you are destroying informal supports” Care manager

Meeting needs for backup

In some CMOs, finding adequate backup in the event that a member’s SDS workers cannot work as scheduled is an ongoing challenge for members. The issue is much more serious for personal care than for supportive home care, because personal care is usually a more urgent need that cannot be postponed until a more convenient time.

Vulnerability of members

Interviewees frequently expressed concern about keeping members who are using SDS safe, since care managers do not have the same tight level of oversight and control when members direct their own care. This issue highlights the tension between a member’s right to exert control over his or her services, and staff’s responsibility to ensure members’ health, safety, and quality of care.

“Sometimes people choose individuals to care for them who might not always be the best individuals to have in their lives.”Care manager

Sometimes members care deeply about directing their own care, as well as about the individuals (friends or

Rosenberg et. al.(2005)

family) that they have chosen to hire as their SDS workers.

“I had a member who didn’t feel comfortable complaining or asking the worker to do things a different way, because it was a friend. The friend wasn’t always coming at the same time [each day], or maybe not at the same day every week. [The member] felt she was working the time in, depending on her schedule. . . . If she wasn’t doing a good job, [the member] didn’t feel comfortable telling her. [The member] didn’t want to jeopardize the friendship.”Care manager

Members who cannot independently self-direct

In some situations, interviewees worried about the use of SDS by members with questionable capability to direct their care competently with their current level of support. “In order to be truly self-directed, the member has to have someone in their life” who can give them attention, outside of the care manager.

“Self-directed can be a hassle when the member does not pay attention to [how much money he/she is] utilizing. It technically shouldn’t be our job to watch that.

I think they don’t understand what the responsibility [of SDS] is. . . . The case managers are the ones that end up managing and guiding and helping them through it. ... What I question is, should some of the people who are on SDS **really be on SDS?**”**CMO staff person**

Financial impact

Most interviewees expressed that SDS was neither clearly expensive nor clearly a cost-saving mechanism. In most cases, management and care managers reported that cost played little or no role in the frequency with which SDS is used.

Benefits

SDS allowed for more privacy:

“With one fairly independent member, having a family member allows for more privacy than having a complete stranger coming in.” IDT staff member

This contributes to supporting the dignity of members in the face of dependence on receiving very personal cares like bathing, and help with toileting or feeding.

SDS also offers members, as employers, the opportunity to call the shots where they often have limited control. For those members who are able to take on this responsibility, it can make the difference between feeling dependent on larger systems for their day to day needs and feeling autonomous.

“I had one member who told me that when he went to sign the time sheets for the fiscal agent he felt like a man. It was really powerful. Instead of being needy, he was an employer!” IDT member

SDS allows members increased flexibility in scheduling.

For example, SDS can enable scheduling for early mornings or late evenings, times that are typically very difficult for an agency to accommodate. When members wish to alter the care schedule, SDS permits easy changes.

“The member can call the person in the morning and say, ‘Can you come later?’ Or vice versa,” Social worker

Cost savings as a possible benefit of SDS. Staffing members with complex needs through agencies has traditionally been expensive.

Perhaps the most important benefit identified was an increase in overall member satisfaction with care. “Members are much happier knowing that they know who’s coming in, when, and what they are going to do. They’re satisfied.” CMO staff member

Lessons Learned and Recommendations

Provider choice

Large provider networks that offer members as much choice as possible for all services are crucial. The larger the network, the more likely it will be that members will be able to exert control over self-directed

Rosenberg et. al.(2005)

and agency-directed services alike.

When there is competition among providers, providers are more apt to cater to member requests for scheduling, personnel, etc. in order to maintain business. (i.e.: Having at least one strong fiscal intermediary and at least one strong co-employment agency within the county was noted by staff as being very important.

Staff training and monitoring

Staff across CMO's reported that it is crucial that CMO training of IDTs extend beyond the initial training. Staff reported that initial training is certainly essential, but ongoing training for IDTs is also important because:

SDS is used infrequently by some staff, and staff get rusty in managing SDS cases

As IDTs become more competent in working with SDS, they tend to have increasingly sophisticated questions about the SDS system

SDS policies and the programmatic environment shift regularly as CMOs and the state work to streamline SDS.

CMOs should involve members in training opportunities as much as possible.

SDS should be discussed in regular staff meetings at CMOs.

CMO infrastructure

Having one or more management staff and care managers (if possible) at each CMO designated as lead contacts for SDS was consistently reported by staff as crucial.

It is essential that the person chosen to be a lead for SDS be passionate about member self-determination and have time to dedicate to SDS.

Paperwork for IDTs should be streamlined.

Nurses' roles in SDS should be clarified.

Policy development

Staff across CMO's expressed the importance of having policies regarding payment of family members (and guardians) that are clear, consistent, and well-conceived.

These policies should be developed with input from all stakeholders, including members and advocates, the state, care managers, CMO managers, and community groups.

Policy development should include members to the greatest extent possible.

Policies or guidelines regarding raises for SDS workers should be developed to ensure that members can offer their employees raises, as appropriate.

SDS innovation

Staff interviewed expressed the importance of having SDS expand to additional services, such as transportation and respite care.

CMOs should continue developing innovative forms of SDS. Staff interviewed had many excellent ideas such as SDS for cooperative housing, debit cards for meals, alternatives to adult day care, and daily living skills for people with disabilities.

It was also suggested by many staff that it would be extremely helpful to develop strategies for SDS members to network with one another.

Member training

Staff reported that it is crucial to have extensive SDS training and educational resources for members.

Ideally, resources should include a video for members, materials for members who learn differently, materials for blind and deaf members, and culturally appropriate materials.

SDS training for members should take advantage of community resources and co-employment agencies

Rosenberg et. al.(2005)
available locally to CMOs.
Member training needs to include extensive, easily understandable information about legal issues such as wage and hour law, and appropriate grounds for reprimanding or firing workers.
Role of the state CMO's reported that it is crucial for the state to allow maximum flexibility to implement innovative strategies for SDS.
State assistance developing educational materials for members due to the extensive expertise and funds needed to create materials such as videos, Braille materials, and materials in languages besides English.
Crucial that the state play a key role in working with the
CMO's in developing data systems. A number of CMOs reported that adapting their IT systems to meet state specifications for data collection is exceedingly difficult.
Early implementation Staff stressed that in early implementation the state needs to provide extra technical assistance to CMOs without previous SDS experience.
CMOs need to designate one or two dedicated staff people who feel passionate about SDS to spearhead the implementation process, and ensure the staff have time in their schedules to devote to SDS.
Staff interviewed recommended strongly that the state maintain a workgroup for SDS across multiple counties so that all counties can benefit from input and exchange of ideas from other CMOs.

Scourfield (2005)
Study aim(s): To examine the key issues surrounding the employment of personal assistants (PA).
Quality assessment: Mid
Population: N/A
Country: N/A
Sample size: N/A
Study methods:
Study design: Narrative review
Sample selection: N/A
Data collection: N/A
Evaluation/intervention:
Direct payments: key issues surrounding the employment of personal assistants (PA)
Results:
Potential demand, recruitment and employment issues:
There are a number of variables - not least the ease or otherwise of recruiting suitable staff – that will influence the rate of future uptake. It is therefore difficult to make an accurate forecast about demand.
If councils in England were able to achieve targets of 150 per 100000 set in 2003, then the number of people receiving direct payments would increase approximately six-fold to about 60000. Assuming that in the next five years, demand for DPs rise to 10 percent of those eligible for services, then this translates to about 150000 people. This in turn suggests that tens of thousands of Pas would be needed.
To date, very little research has been carried out into the recruitment and employment of PAs. A shortage of reliable and competent PAs could lead to unrealistically high expectations, being frustrated and enhance

risk of abuse. The question is how can it be ensured that such a workforce is competent, trustworthy and able to meet the needs of a diverse and vulnerable group.

There are several ways that someone with a DP can recruit a PA. The three most common are: to become a direct employer; to use a 'third party scheme' through an organization; or to use a care agency.

Recruiting from an agency is probably less likely to offer the flexibility and control afforded by more individualised recruitment strategies.

Recruitment is hampered by the low rates of pay that potential employers are forced to offer because of the level of DP given to them.

Matosevic et al. Found that, 'Most respondents had experienced difficulties in recruiting suitable care staff (75%) and nearly a third rejected at least half of their applicants' [Matosevic T, et al. (2001) Domiciliary providers in the independent sector, PSSRU Discussion paper 1605, Nuffield institute for health and personal social services research unit]. The three biggest problems cited were: unsuitable applicants (37.5%); competition from other providers (30.4%); and insufficient applicants (26.8%).

The issue of training is potentially problematic. Most employees like to train their personal assistants themselves. Many personal assistants want to have more formal training in key aspects of their job, especially when it is necessary to carry out specialised procedures.

There are practical issues such as who pays, who organises and provides it and how to make it accessible to all those who require it as well as who decides about what, if any, training is needed: the employer, the PA, 'professionals' or regulatory bodies.

The appeal of becoming a PA is more likely to be based on performing a socially necessary job than on factors of pay and conditions as it is a relatively low paid and low-status work with potentially unsocial hours.

There are suggestions that certain localities might be harder to recruit in than others. Regional and/or rural-urban differences in recruitment might be expected to correspond to the specific employment characteristics in those areas.

Social Care Institute of Excellence (2009)

Study aim(s): To provide a research briefing on the implementation of individual budget schemes in adult social care

Quality assessment: High

Population: Adult social care

Country: UK and international literature

Sample size: NA

Study methods:

Study design: Literature review

Search strategy and inclusion criteria not specified.

Results:

"The international evidence to date is based on many relatively small examples, but given the right level of support, user views are very positive and they report improvements.

- All schemes are still working to balance safeguarding and registration of the workforce with individual choice and control. There are emerging risks to be overcome at the level of the organisation and the individual.
- There are both advantages and disadvantages for carers and families. Support arrangements are needed to

ensure successful implementation.

- Older people and people with complex needs may need greater time and support to help them get the most from individual budget schemes, particularly the cash direct payment option.
- Brokerage and support is needed but the support infrastructure is not yet sufficiently well developed in the UK. Emerging evidence indicates that support is more successful when it is independent of the service system. Support brokers should provide a task-focused service and be trained and regulated.
- Early studies of personal assistants (PAs) paint a mixed picture of poorer pay and conditions but higher job satisfaction.
- Most schemes share the same goals of improving freedom of choice, independence and autonomy and using public funds more efficiently.
- Schemes still vary to take account of national context, but central government leadership is always a vital component.
- All schemes have taken time to embed and have needed strong local leadership and investment in targeted training and support for frontline staff.
- In the UK, IBSEN claims that individual budgets have 'the potential' to be more cost effective and there is improved satisfaction for people who use services.
- Reliable evidence on the long-term social care cost implications is not yet available. This is an area which needs urgent attention to sustain confidence. There is emerging international evidence that self-directed care can lead to health gains and consequent efficiency gains'.

Spalding et al. (2006)

Study aim(s): to describes publicly funded, self managed home care programs at federal, provincial and territorial levels across Canada.

Quality assessment: Low

Population: Key informants involved in implementing 16 self managed home care programmes

Country: Canada

Sample size: NA. Focus was on Canada in 2000-2005

Study methods:

Study design: Canadian literature 2000-2005, a review of government websites, and a series of semi-structured telephone interviews with key informants at federal, provincial and territorial levels

Sample selection: purposive, 67 telephone calls

Data collection: telephone interviews

Evaluation/intervention: self managed home care

Results:

Currently, it is almost impossible to answer basic questions about the costs and outcomes of self managed care programs alone, or in comparison to conventional home care programs.

Because existing Canadian evidence tends to focus on novel initiatives for specific target groups using a variety of methods and approaches, it is difficult to know to what extent it can be generalized.

Spandler and Vick (2006)
<p>Study aim(s): To draw on findings from the pilot evaluation to provide a preliminary understanding of how applicable the independent living philosophy is to mental health and what opportunities direct payments offer for service users.</p> <p>Quality assessment: High</p>
<p>Population: Direct payments recipients</p> <p>Country: England</p> <p>Sample size: N= 27</p>
<p>Study methods:</p> <p>Study design: Qualitative</p> <p>Sample selection: All service users who were actively using direct payments during the pilot were invited to take part in an interview.</p> <p>Data collection:</p> <p>Semi-structured interviews</p> <p>Evaluation/intervention:</p> <p>Direct payments:</p> <p>Implementation and the views of recipients.</p> <p>Benefits and barriers.</p>
<p>Results:</p> <p>Implementation:</p> <p>There was significant diversity in the ways direct payments were being used.</p> <p>Approximately half of the recipients were using direct payments to employ personal assistants (PAs) although this was less than is usual in other care groups.</p> <p>Workers were employed to help with social, emotional and practical support outside the home, domestic support, personal care, practical support and childcare.</p> <p>Recipients used payments to pay for transport, educational fees, leisure activities, and for their own choice of respite care. Five people used direct payments to collectively pay for a creative arts worker to facilitate a regular arts group in a community centre.</p> <p>Many direct payment packages in mental health were relatively small. The majority of payments (83%) were for ongoing support, rather than one-off payments, although one-off payments still appeared to be higher than for other recipient groups. Most packages (56%) were for less than 10 hours assistance per week, the most common between 5 and 10 hours (38%).</p> <p>The majority of referrals were made by social workers and community psychiatric nurses (CPNs). CPNs were as successful as social workers in enabling access. Self referrals did not usually proceed to a successful agreement in that only 1 out of 14 self-referrals resulted in an agreed package.</p> <p>Take up was slow. The length of time it took to process and set up direct payment packages, particularly if recipients employed their own PAs, meant that most recipients only started using direct payments in the last year of the national pilot.</p> <p>Benefits</p> <p>Recipients identified significant benefits, particularly in relation to choice and control, independence, autonomy and increasing access to, and enjoyment of social, cultural and physical activities, as well as improving their feelings about themselves in relation to the world around them.</p> <p>Regardless of someone's 'impairment' they should be able to do the things that other (non-disabled) people</p>

Spandler and Vick (2006)

take for granted, with the provision of assistance.

“There are some things that I couldn’t do, like I can’t go in to a busy shopping centre ... although I would like to, but if I have got somebody with me, then I will do it, I don’t like to go to crowded places on my own. It’s just not so much for the company, but I just feel scared of what might happen to me, and I have had quite a lot of panic attacks and agoraphobia as well. So I use it for shopping and to do a new course.”(Interview 3)

Whilst finding a suitable PA was sometimes difficult, when mental health recipients were able to recruit, they reported significant benefits in being able to select staff that they could trust and feel comfortable with (this often included selecting people with whom they could share common interests and hobbies).

Advanced directives or statements can be developed so the service user can determine in advance the support or treatment they would (or would not) like in the event of lessened capacity due to a mental health crisis.

The befriending aspect of the support that PAs were able to provide is significant.

“I get exhausted sometimes, so she helps me with housework and we go out shopping for food ... If I get a letter off anyone and if it’s official, she will sort it out ... she comes to Doctor’s appointments with me ... I go and see a friend, we go for a walk, you know, different things ... If the weather is nice we might go to [a country park] and we then we have dinner out, because I have got an eating disorder, so that’s part of the care plan.”(Interview 7)

Another significant element of independent living is the importance of people with disabilities being able to be less dependent on friends and family to provide support.

“I used to go places with my daughters and although [they’re] great ... it can be stifling at times ... they are very protective ... it doesn’t help me because I think they used to decide and sometimes I don’t want to go there ... Whereas having a PA I can say ‘I want to go to London next Saturday, can you come with me?’ This gives you that bit of independence that you can go and do something. All right you’re taking somebody with you, but it’s on a different relationship ... The dynamics are different and you’re the one that is in control ... so it’s like being on my own in a way and having that freedom.” (Interview 18)

Greater independence can relieve a sense of guilt that service users often experienced when having to call upon unpaid carers to support them.

“It’s given me a lot more control over what I do and given me more independence from my family so don’t rely on them as much and just knowing that I’ve got someone to support me during the day, it means I can do some of the things I want to do. It’s made things a lot easier for me, things usually my mum would have done with me. I can do a lot more leisure activities and actually have a social life.” (Interview 15)

Direct payments sometimes formalised already existing caring relationships which could be under considerable strain because of the lack of financial compensation.

“I don’t feel so guilty about calling upon my mother to help out because I know she is being paid and that my mother can come out to me, because she is being paid direct payments and isn’t doing the other job that she was doing before.” (Interview 12)

Direct payments enabled clients to take part in ‘ordinary’ activities which were non-stigmatising and not mental health focused, professionalised or medicalised.

“I try to find more things in the community and get away from mental health for a bit and into more everyday life. I don’t want to be stuck in the mental health system and think this is all there is, that’s all I am worth, like I’m not worthy of interesting hobbies, like anyone else. I am an individual, but I am not treated as an individual, I am treated as a mental health case.” (Interview 1)

Benefits relate to the emerging concept of ‘recovery’ in the mental health field. Themes that should be part of a recovery agenda:

Being believed in and encouraged; taking personal responsibility for one’s own life; acting to rebuild one’s

Spandler and Vick (2006)

own life; developing valuable relationships and roles; changing other people's expectations; gradually gaining a sense of greater well-being and; developing a new meaning and purpose in life. These encompass a number of aspects of a person's life which many recipients reported having improved following setting up support through direct payments.

Recipients reported a growth in self-worth and this is particularly significant given that mental health service users often argue that the experience of using psychiatric services can contribute to low self-esteem, confidence and self-worth.

What is crucial for recovery is having assistance to be able to pursue one's own self-defined goals and aims.

"I think it's a coming together in a logical way of what I was trying to do on my own and struggling to do on my own ... all these obstacles are now going, so I am getting a clearer way forward, it's meant a lot to me ... I think independent living is all about getting your life back and organising your life. It means really claiming what you have lost, after disasters, traumas, everything that's happened to you and reclaiming it bit by bit." (Interview 1)

Barriers

There were a number of difficulties in the application of direct payments that may limit the possibilities of independent living.

First, resource limitations and restrictive eligibility criteria for community care services generally may limit the opportunity for service users to access and use direct payments. Second, the evaluation suggested that only a very small number of mental health professionals had really grasped the principles of direct payments and independent living and were generally promoting it as a positive option to service users. Furthermore, there was some evidence that professionals were using highly selective criteria in determining who would be offered direct payments. These included being more likely to offer direct payments to clients who had a 'significant other' who could help them manage payments or to those who were considered as being more trustworthy and as having a stable lifestyle.

Direct payment packages in mental health often did not include additional costs for setting up, support with administration and contingency monies. As mental health needs often fluctuate, it may be necessary to provide for a greater level of flexibility in payments to allow for self-directed support during crises.

Perceived and actual difficulties with employing PAs were often experienced as a barrier to access, take up and successful use of direct payments. Recipients experienced difficulties recruiting workers for such short hours and at particular times (such as evenings and weekends). Furthermore, where recipients did employ workers, the term 'personal assistant', which often conveys a focus on personal care, didn't necessarily capture the variety of complex tasks that PAs may be required to do and the negotiation of complex needs and relationships.

Some recipients reported difficulties arising in actually making decisions, especially if there were constraints and pressures limiting their ability to make choices. Such difficulties emerge most acutely when clients attempted to employ their own PAs. There were some accompanying disadvantages around losing a certain amount of security and occasionally greater uncertainty, at least in the short term as increasing 'choice' is accompanied by responsibilities, constraints and consequences. Many mental health service users may feel that their capacity for exercising choice and control has been undermined by their experience of mental distress and long-term use of mental health services.

The process may be a long and difficult learning process both for professionals, in giving up, and service users in taking, more control, reaffirming the point that 'control and choice' are not all or nothing fixed points but rather a process.

"It's been a long learning curve. I now know that it's about what I want. I didn't grasp the fact that this was about me – me to choose – I didn't have any concept of it at all. It's taken me all these months to grasp that I needed to know what I wanted." (Interview 21)

A robust support infrastructure needs to be developed to enable service users to access and use them. This may involve investment in and development of initiatives such as user controlled trusts and circles of support. Local authorities and mental health services need to ensure not only that the implementation of

Spandler and Vick (2006)
direct payments is underpinned by the principles and philosophy of the independent living movement but that the whole social care system (not just direct payments) should be informed by these principles.
Limitations: The evaluation was only able to report on relatively short-term and early reported benefits for the small numbers of people who took part due to the long time that it took to actually implement the direct payments. Small sample size.

Stainton et al (2009)
Study aim(s): To assess the cost and resource implications associated with direct payments compared with traditional services, including an analysis of the factors which affected the relative cost and resource requirements of direct payments.
Quality assessment: High
Population: Disabled persons receiving direct payments. Adult Social Work teams Country: Wales Sample size: Direct payment users: N=23 Adult Social Work teams: N=88
Study methods: Study design: Qualitative and quantitative (descriptive). Sample selection: Participants were recruited through the Independent Living Support (ILS) scheme in two different local authorities (LA). Data collection: Micro-costing and gross costing with estimates of the direct costs based on rates of payment and estimates of other care services derived from the derivation of unit costs from expenditure data. In-depth interviews, file reviews and questionnaires. Evaluation/intervention: Direct payments: cost and resource implications associated with direct payments compared with traditional services
Results: Cost comparison with conventional services: The comparison of costs and resources, which did not include significant costs for traditional local authority services but included the cost of the DP support scheme, found that DP was cheaper than traditional in-house service provision and relatively cost neutral when compared with independent sector provision. User satisfaction was significantly greater with DP than traditional service delivery methods. Where both in-house and independent sector alternatives were available, it is clear that DP was substantially less costly than in-house services. Where independent sector alternatives only was available (no in-house services were available), DP was roughly equivalent in cost to average independent sector rates.

Stainton et al (2009)

Savings associated with DP:

Users' more flexible and creative use of funds: User creativity in managing staff frequently resulted in an increase in hours per pound when compared with LA or independent agencies.

The flexibility of DP also generally allows care to be more closely tailored to fluctuating needs, hence increasing efficiency.

The administration costs of DP (billing, collecting and accounting) were reduced.

Care managers reported that less frequent ongoing contact was necessary once DP was set up, although initial set-up was reported as being more time consuming.

Limitations: It is difficult to arrive at any definitive comparison of the cost of DP and conventional services due to the multiplicity of variables involved. For example, the rate paid by local authorities for DP and for in-house or independent sector providers will have an immediate bearing on any comparison. Even more complex is the issue of 'on costs', such as audit costs, or opportunity costs, such as case manager time, which in turn may be affected by the complexity and size of the care package.

Several costs not taken into account in this study can adversely affect the cost of DP. The discussion was limited to ongoing costs rather than costs involved in the initial set-up and training for DP and support schemes.

Sikma and Young (2003)

Study aim(s): To evaluate the Self-Directed Care (SDC) programme with regard to consumer satisfaction, service quality and safety.

Quality assessment: High

Population: Consumers of SDC as well as their individual providers (IP) and case managers (CM).

Country: USA

Sample size: Survey:

SDC consumers: N=125

IPs: N=69

CM: N=29

Focused interviews:

SDC consumers: N=30

IPs: N=30

CM: N=24

Study methods:

Study design: Cross-sectional (descriptive) and Qualitative

Sample selection: All eligible SDC consumers in the Washington state.

Data collection: Survey questionnaire, focused interviews, and review of existing databases, complaint logs and reports, and departmental field notes.

Evaluation/intervention:

Self-directed care:

Evaluation of the implementation of a new SDC program.

Sikma and Young (2003)

Results

Satisfaction with SDC:

Consumers reported high levels of satisfaction with the program, emphasizing the freedom afforded to them through SDC and the opportunity to take control of important aspects of life and daily care. There was consistent evidence of improved autonomy, self-determination, and choice across assessment approaches.

Satisfaction survey: Benefits of SDC:

Very satisfied or moderately satisfied= 94.7% of consumers

Consumers

Positive about program: 25%

Can meet needs: 22%

Promotes independence, control,
choice, freedom, and responsibility: 10%

Improves quality of life: 10%

Can stay at home: 10%

Values relationship with individual providers: 9%

No response: 6%

Less expensive option: 5%

Provides caregiver training: 2%

Relieves family members: 2%

Case managers

Promotes independence, control, choice, freedom, and responsibility: 27%

Generally satisfied: 20%

Lower liability concern: 12%

Can stay at home: 10%

No response: 5%

Less expensive option: 5%

Meets needs: 5%

Good option to offer: 5%

Improves quality of life: 2%

Individual providers

Can stay at home: 18%

No response: 18%

Promotes independence, control, choice, freedom, and responsibility: 15%

Generally satisfied: 11%

Caregiver training: 9%

Flexibility of work hours: 9%

Client–individual provider relationship: 7%

Sikma and Young (2003)

Meets needs 4%

Improves quality of life 3%

Focused interviews:

Three salient phases for SDC:

1. Deciding to self direct: Consumers identified powerful motivations to enrol in the program, primarily to be able to take charge of their own care, to stay at home, and to meet care needs.

2. Implementing SDC: Consumers described their roles as directing the care and expressing their own voice. Several contextual factors promoted consumer satisfaction during implementation, including convenient access to needed supplies (e.g., catheters and dressings), pharmacy support (particularly home delivery and appropriate packaging of medications), and professional support from registered nurses and physicians in problem solving and assisting with training IPs.

3. Living with SDC: The major themes reflected quality of life and satisfaction with staff.

Quality of life

Better timing and ability to control routine and freedom to choose: 13%

Better family relations: 6%

Get it done the way you like it: 4%

Get to live at home: 4%

Get out more: 3%

Stress of staffing is worth it: 1%

Satisfaction with staff

Clients are highly confident in the ability of individual providers to provide care once a match has been found: 20%

Some experience stress over ensuring consistent staff coverage: 5%

Value relationships with individual providers: 2%

Several contextual factors contributed to consumer satisfaction with the outcomes of the program:

-Quality of relationships with IPs

-Case manager support and facilitation of the process

-IP compensation

-Predictability of needs

-Proximity of IP to consumer, which affects accessibility and travel time.

The following are quotes from consumers about the effects of SDC on their lives:

"[SDC] put me in charge. I say when to do what, how to do it, and you know, if you don't want to be bothered, then nobody can force you to be bothered."

"Well, I wanted help around the house, my wife would have to do all my care, and it's a tremendous drain on our relationship taking from a husband-wife to a patient-nurse type of relationship. . . . It frees my wife up to be able to be a mom to the kids, getting them ready for school instead of saying, "No, takes care of yourself." She has to get me up in the morning and, you know, makes me a much happier person when my kids are taking care of their needs instead of just me. Oh . . . and it gives, you know, the opportunity to do some of the things she used to be able to do and gives me the feeling that I'm not just a drain on my family all the time. . . . I can get on with helping out as part of the family instead of just sucking the life out of them

Sikma and Young (2003)

all.”

Service Quality and Consumer Safety:

There was no evidence of problems with quality of care or consumer safety. From all perspectives, SDC improved quality of care by expanding options, providing a more comprehensive approach to care and better individualization of care (timing and tailoring to personal need), and improving medication management.

The vast majority of consumers indicated that they felt safe with SDC, and IPs expressed feeling safe because the consumer was directing the care.

Satisfaction survey: Concerns about SDC:

Consumers

No response: 44%

Nonspecific concern: 28%

All needs are not met: 10%

Case manager control or imposition: 5%

Recruiting, hiring, and retaining
caregivers: 4%

Case managers

Burden of extra work: 15%

Client ability to self-direct: 14%

Does not change anything: 14%

General concern: 12%

Role of case manager: 9%

Greater liability: 8%

Individual provider lack of ability: 8%

No response: 5%

Case managers need training: 2%

Risk of injury to client: 4%

Needs are not met: 3%

Family stress: 3%

Inadequate caregiver pay or benefits: 2%

Recruiting competent staff: 2%

Individual providers

Adequacy of pay and benefits: 39%

No response: 22%

Burden of extra work: 11%

Nonspecific concern: 4%

Consumer Abuse or Neglect

Five allegations of abuse or neglect were reported to Adult Protective

Services for SDC consumers; two were substantiated. One involved physical abuse by a live-in IP; the other was a case of neglect related to reporting to work under the influence of alcohol and lack of responsiveness to the calls of the consumer.

Staffing Issues—IPs

Consumers reported that SDC requires adequate, competent staff and actively managed the process of getting staff (recruiting and selection), keeping staff (retention), training staff, and supervising

and monitoring staff. Consumers valued their relationships with their IPs and were highly motivated to ensure ongoing coverage. There was

a range of need for staff, with some consumers having intermittent or circumscribed needs (such as catheter irrigation or dressing changes) and others requiring more extensive staff coverage (frequent medications and

Sikma and Young (2003)

assistance with activities of daily living).

Ongoing supervisory issues included retention, finding relief and covering for absences, coordinating schedules, and managing personnel. Consumers experiences with finding and supervising staff:

“I think the hardest drawback or worst drawback is finding competent help. It’s a long search; we went through 10 or 12 people before we found the two we have, and one is really good, and the evening worker is pretty good.”

“Find a family or a good friend you can count on for back-up because you never know when your daily caregiver isn’t going to show up. You’d have some sort of emergency back-up that you know will be there.”

IPs were challenged by a number of factors:

-Emotional stress: feeling of unrelieved responsibility, the emotional toll of providing care, interpersonal frustration, and burnout.

-Work hours: being on call, having difficulty finding respite or temporary relief, and feeling obligated to donate time when a visit exceeded the authorized time due to unpredictable needs.

-Compensation: Both IPs and consumers viewed compensation as inadequate, with low hourly pay rates and a lack of benefits (health care coverage, disability insurance, travel time and mileage reimbursement, and labour and industry insurance).

-Occupational risks: for injury during heavy lifting and transferring and for body substance exposure with inadequate protection.

The vast majority of IPs talked about respecting the points of view of the consumers and accepting their direction. The following quotes

from IPs are representative:

“I build relationships with the people, and I really value those relationships. They, you know, it’s really important to me, and that’s a benefit.”

“I would just say be nice to the client and take their lead and do things their way . . . I’ve never had a problem with it. I figure if that’s the way they want me to do it, that’s not the way I would it in my own home, but if that’s the way they want me to do it, it’s their house. Just always remember you are in the client’s home; defer to the client. They usually know what they want.”

In general, case managers recognized that the consumer held responsibility for hiring and evaluating staff members:

“The bottom line is if the client feels confident, who are we to say “No,” and I may personally not think that person is capable of, you know, doing it, but if the client thinks so and the outcomes are okay, I guess it’s time to butt out on that one.”

Case Manager Issues

Case managers were motivated to implement SDC by several factors:

-Supporting the desires of consumers

-Supporting consumers to

stay at home

-Recognizing and respecting the capacity of consumers to decide and direct their own care.

Particular questions from case managers included:

- Clarification of their role in assessing ongoing ability of consumers to self-direct

- How to deal with fluctuating abilities

– Confusion about their options for problem solving.

Sikma and Young (2003)
Case managers recognized core responsibilities including: -Providing information -Developing, managing, and monitoring the service plan.
Limitations: NR.

Timonen et al (2006)
Study aim(s): To understand the rationale and impact of cash-for-care programmes on the broader care regime, and the benefits and problems of the new arrangements
Quality assessment: Low
Population: Stakeholders in cash-for-care programmes Country: Ireland, United Kingdom, Finland and Netherlands Sample size: N=Unclear
Study Methods: Study design: Case study Sample selection: Senior civil servants with extensive knowledge of the background and policy processes associated with the introduction and operation of the cash-for-care programmes; senior health and social services administrators involved directly with the monitoring and implementation of the programme; representatives of national organisations with a special interest in domiciliary care services for older people; and academics/policy analysts. Data collection: In-depth, semi-structured interviews Evaluation/intervention: Direct payments: payments given to individuals so that they can organise and pay for the social care services they need, rather than using the services offered by their local authority.
Results Key aspects of cash-for-care programmes for older people Ireland: Home-care grants Financing Tax financed. Until recently, discretionary sums have been dedicated by individual health boards, but ear-marked budgets now becoming available Regulation Began in 2001. Currently at the discretion of individual health boards; more definite national guidelines emerging. As yet, no firm legislative footing Reach Some 550 recipients in 2004, but likely to increase to around 5,000 in 2006/2007 Strengths of scheme Contributes to development of community care that to date has relied on informal care (with institutional care as a last resort). Gives older people care choices Main criticisms Insufficient dedicated funding; limited availability and area differences; inadequate controls; unregulated homecare market; and funds cannot be paid to family members

Timonen et al (2006)

United Kingdom (England): Direct payments

Financing

Funded from tax revenue by central government; funds channelled from existing local authority budgets

Regulation and legislation

Available to older people since 2000. Local authorities obliged to offer direct payments to all those eligible since 2003 but take-up varies greatly by local authority

Reach

6,000 recipients in England in 2003/2004 (0.04% of 65+ years and 0.6% of community care recipients). Substantial growth likely after recent commitment to raise funding

Strengths of scheme

Care management services and direct payment support services in place

Main criticisms

Funding arrangements precarious; difficult to engage carers; onerous audit and administrative demands; sparse information; no guidelines and much local variation in funding

Finland: Palvelu-Seteli (Service vouchers)

Financing: Tax-financed

Regulations and legislation

Entitlement to vouchers, but not obligated (generic services can be demanded). Began in 2004 (pilot projects in the 1990s)

Reach

Numbers growing, but not intended to expand beyond 10% of all home-care recipients

Strengths of scheme

Broadening choice; some evidence of employment creation

Main criticisms

Limitations in scope; low uptake. Older persons do not have a right to vouchers (but do have a right to in-kind services)

The Netherlands: Personal budgets

Financing

Long-term care insurance (AWBZ - Algemene Wet Bijzondere Ziektekosten) financed through payroll contributions – 13% of income up to a ceiling of €30,000. No upper limit. Income-related co-payments up to a maximum of €6,978.40.

Regulation and legislation

Introduced in 1995. Strongly regulated. Independent agencies deal with assessment of need, pay and working conditions. Trades union have a role in supporting and training care assistants.

Reach

Approximately 30,000 older people (aged 55+ years) among personal budgets holders (0.8% of the 65+ years population)

Strengths of scheme

Some unpaid care has been substituted by paid care. Gives choice to older people. Acknowledges family contribution to care. Entitlement to personal budgets is based on a genuine choice between personal budgets and direct services

Main criticisms

Some funding moved out of the AWBZ to municipalities; fear that entitlement will be undermined; system holds family carers (living with the older person) responsible for many household and caring tasks

Timonen et al (2006)**Key factors influencing the creation and design of cash-for-care programmes/Rationale for introduction:****Ireland**

To compensate for gaps in service provision; efficiency and cost considerations; and shift in preference from institutional to home care

United Kingdom (England)

To promote clients' choice; promote clients' autonomy; and to compensate for gaps in service provision

Finland

To compensate for gaps in service provision; and to create more jobs

The Netherlands

To promote clients' choice; promote clients' autonomy; create more jobs; and shift in preference from institutional to home care

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