

Campbell Systematic Reviews

2008:1

First published: 23 January, 2008

Last updated: 23 January, 2008

Personal Assistance for Older Adults (65+) Without Dementia

Paul Montgomery, Evan Mayo-Wilson, Jane Dennis



THE CAMPBELL COLLABORATION

Colophon

Title	Personal assistance for older adults (65+) without dementia
Institution	The Campbell Collaboration
Authors	Montgomery, Paul Mayo-Wilson, Evan Dennis, Jane
DOI	10.4073/csr.2008.1
No. of pages	52
Last updated	23 January, 2008

Citation	Montgomery P, Mayo-Wilson E, Dennis J. Personal assistance for older adults (65+) without dementia. Campbell Systematic Reviews 2008:1 DOI: 10.4073/csr.2008.1
Co-registration	This review is co-registered within both the Cochrane and Campbell Collaborations. A version of this review can also be found in the Cochrane Library
Keywords	

Contributions	Evan Mayo-Wilson (EMW) wrote the background and methods with Paul Montgomery (PM) and Jane Dennis (JD). JD developed the search strategy with EMW and PM. EMW and PM conducted data extraction. EMW wrote the results and discussion with PM and JD.
Support/Funding	Centre for Evidence-Based Intervention, University of Oxford, United Kingdom Unit for Disabilities Issues, The National Board of Health and Welfare (Socialstyrelsen), Sweden The Institute for Evidence-Based Social Work Practice, The National Board of Health and Welfare (Socialstyrelsen), Sweden
Potential Conflicts of Interest	This review was funded by a grant from the Swedish government, the Unit for Disabilities Issues and the Institute for Evidence-Based Social Work Practice, the Swedish National Board of Health and Welfare (Socialstyrelsen). The reviewers have no known conflicts of interest.

Corresponding author	Evan Mayo-Wilson Centre for Evidence-Based Intervention University of Oxford Barnett House 32 Wellington Square Oxford OX1 2ER United Kingdom Telephone 1: +44 1865 280 339 E-mail: evan.mayo-wilson@socres.ox.ac.uk
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The Campbell Collaboration
P.O. Box 7004 St. Olavs plass
0130 Oslo, Norway
www.campbellcollaboration.org

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Mayo-Wilson E
Dennis J



The Campbell Collaboration Social Welfare Group

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Title

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Reviewers

Montgomery P, Mayo-Wilson E, Dennis J

Dates

Date edited: 26/02/2008

Date of last substantive update: 14/11/2007

Date of last minor update: 14/11/2007

Date next stage expected 15/11/2010

Protocol first published: Issue 4, 2007

Review first published: Issue 1, 2008

Contact reviewer

Evan Mayo-Wilson
Departmental Lecturer
Centre for Evidence-Based Intervention
University of Oxford
Barnett House
32 Wellington Square
Oxford
UK
OX1 2ER
Telephone 1: +44 0 1865 280 339
Facsimile: +44 1865 270 324
E-mail: evan.mayo-wilson@socres.ox.ac.uk
URL: <http://www.spsw.ox.ac.uk/>

Contribution of reviewers

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Internal sources of support

Centre for Evidence-Based Intervention, University of Oxford, UK

External sources of support

Unit for Disabilities Issues, The National Board of Health and Welfare (Socialstyrelsen), SWEDEN
The Institute for Evidence-Based Social Work Practice, The National Board of Health and Welfare (Socialstyrelsen), SWEDEN

What's new

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Text of review

Synopsis

Personal assistance is paid support of at least 20 hours per week for people with impairments. This review investigated the effectiveness of personal assistance versus any other form of care for older adults (65+). An exhaustive literature search identified 4 studies that met the inclusion criteria, which included 1642 participants. They suggested that personal assistance may be preferred over other services; however, some people prefer other models of care. This review indicates that personal assistance probably has some benefits for some recipients and their informal caregivers. Paid assistance might substitute for informal care and cost government more than alternative arrangements; however, the relative total costs to recipients and society are unknown.

Abstract

Background

There is a high prevalence of impairments among people 65+, and the elderly population is increasing in the West. Many countries offer personal assistance, individualised support for people living in the community by a paid assistant other than a healthcare professional for at least 20 hours per week.

Objectives

To assess the effectiveness of personal assistance for older adults with impairments, and the impacts of personal assistance on others, compared to other interventions.

Search strategy

Electronic databases including CENTRAL, MEDLINE, EMBASE, CINAHL, PsycINFO, ERIC, Dissertation Abstracts International and a variety of specialist Swedish databases were searched from 1980 to June 2005; reference lists were checked; 345 experts, organisations, government bodies and charities were contacted in an attempt to locate relevant research.

Selection criteria

This review included older adults (65+) living in the community who require assistance to perform tasks of daily living (e.g., bathing and eating) and participate in normal activities due to permanent impairments. Controlled studies of personal assistance in which participants were prospectively assigned to study groups and in which control group outcomes were measured concurrently with intervention group outcomes were included.

Data collection & analysis

Titles and abstracts were examined by two reviewers. Outcomes data were extracted. Because they made different comparisons, studies were not combined for meta-analyses. Studies were assessed for the possibility of bias. Results and potential sources of bias are presented for included studies.

Main results

Four studies involving 1642 participants made three eligible comparisons: (i) personal assistance versus usual care, (ii) personal assistance versus nursing homes, and (iii) personal assistance versus 'cluster care'. One was an RCT, three were non-randomised. Personal assistance was generally preferred over other services; however, some people prefer other models of care. This review indicates that personal assistance probably has some benefits for some recipients and caregivers. Paid assistance probably substitutes for informal care and may cost government more than alternatives; however, the total costs to recipients and society are currently unknown.

Reviewers' conclusions

Research in this field is limited. Personal assistance is expensive and difficult to organise, especially in places that do not already have services in place. When implementing new programmes, recipients could be randomly assigned to different forms of assistance. While advocates may support personal assistance for myriad reasons, this review demonstrates that further studies are required to determine which models of personal assistance are most effective and efficient.

Background

Definition of impairments

The International Classification of Impairments, Activities, and Participation (ICIDH-2) refers to *impairment* as loss or abnormalities at the level of body, body part or organ. People may have

difficulty performing particular *activities* as a result of impairments, and a person's *participation* in education, social life, work, and other areas may be limited as a result of interactions among impairments, activities, and environment ([WHO 2003](#)). Except with reference to studies using specific definitions of other terms, this review follows the classification in ICDH-2, which does not include the terms *disability* or *handicap*.

This review includes non-demented older adults (65+) with physical impairments (e.g., paralysis) and both physical and intellectual impairments (e.g., impairments resulting from stroke). It is part of a series of reviews; working-age adults and children are considered in reviews registered with the Cochrane and Campbell collaborations.

Prevalence of impairments

As is likely to be true in any developed country, the incidence of 'disability' in the U.S. is highest among adults between 18 and 65 years, but the rate of impairment among working age adults is much lower than the rate among older adults (17% versus 50%; [CDC 2001](#)). People over 65 are twice as likely as people between 45 and 65 and four times as likely as people between 18 and 44 to have impairments ([Kaye 1996](#)). Overall rates of impairments are strongly influenced by the relative size of the older-adult population ([Kaye 1996](#)).

Impairments that interfere with activities of daily living are highly prevalent among older adults and increase with age. While intellectual impairments are likely to be associated with physical impairments in all populations, moderate to severe intellectual impairments are unlikely to occur without associated physical impairments in this population. Similarly, severe physical impairments are likely to be associated with intellectual impairments.

As far as possible, this review uses internationally accepted definitions of impairments and refers to impacts that are likely to occur across cultures. However, most epidemiological studies have been conducted in the United States and Western Europe and therefore readers should consider the applicability of these data to other settings.

Consequences

Limited participation in activities may negatively impact older adults' life expectancy, quality of life, health and family functioning.

Proponents of the *social model of disability* regard activity restrictions as caused by societal and structural barriers and stress the need for their removal ([Abberley 1987](#); [Oliver 1990](#)). In addition to structural and environmental changes (e.g., making buildings accessible), the social model emphasises changes in public attitudes towards impairments to encourage increased participation and improved self-esteem. In this paradigm, independence is defined not as doing things alone but as making decisions for oneself and exerting control over how help is provided ([Morris 2001](#)).

Older adults with impairments require varying degrees of support, which is often provided by their families and friends. Consequently, carers may withdraw from work and social life ([Ko 2002](#)). Since women live longer than men, most recipients of assistance are female (65%) and less than a quarter receive paid assistance ([LaPlante 2002](#)). More than 20 billion hours of assistance are provided each year in the U.S., estimated to be worth \$200 billion at 1996 prices ([LaPlante 2002](#)). As Western populations continue to age, the amount of formal and informal care required will likely increase in amount and value.

Interventions

Increased participation (inclusion in activities of daily life) may have positive effects on the social functioning, mental and physical health of older adults.

There are many ways to increase participation by older adults with physical and intellectual impairments. For example, building codes may require that people who use assistive devices can access shops and meeting places. Clinicians and policymakers can work together to influence policy, discourse, and planning and to apply the social model in support of older adults ([Colver 2005](#)); however, broad interventions may not be sufficient to meet all needs. Older adults with severe impairments require tailored interventions. Assistive devices, skills training, physical therapy, education, and human support help people control their lives and engage in normal activities.

Personal assistance

Personal assistance is paid support given to older adults with impairments in various settings to enable them to participate in mainstream activities. Assistants might help with bathing, dressing, moving around during the day, shopping, etc. Personal assistance may aim to improve mental and physical health, but it differs from services by professional healthcare providers (e.g., nurses) with whom users have very different relationships. Personal assistance is designed for people with permanent impairments and differs from rehabilitative services and from services provided for fixed periods of time in that it is indefinite and ongoing.

Some form of personal assistance is now available (often by statutory right) in all Nordic countries, most Western European countries, Australia, parts of Asia, the U.S. and Canada. The naming of personal assistance may vary from country to country, which is often related to legislative categories rather than types of interventions. Rules about who may be a personal assistant also vary. For example, some countries allow users to employ family members (e.g., spouses) while others do not. Advocates of personal assistance argue that personal assistants should be chosen, trained and managed by users or their representatives. However, the organisation of services and the degree of user control varies around the world and may be affected by the administration of payments, employment laws, etc.

Compared to other interventions, personal assistance may have unique benefits and potential drawbacks. High staff turnover rates, low wages, and lack of training are potential problems ([Keigher 2000](#)). When it is possible to do so, many people prefer to use assistive devices to complete activities of daily living rather than receive help in performing those tasks ([Verbrugge 1997](#)). Compared to other ways of compensating for particular activity limitations, personal assistance may create unnecessary dependencies for some older adults ([Agree 2003](#)).

Even if personal assistance is clearly preferred over other services by working adults with physical impairments, other recipients may be more susceptible to abuse and less able to manage employees. Groups that are underrepresented in the public discourse about the rights of people with impairments may prefer other services. Direct payments for personal assistance may not be ideal for people who have difficulty finding an assistant, administering their services, negotiating or giving instructions ([Pijl 2000](#)). 'Many people requiring personal assistance in one form or another do not want and/or are incapable of assuming complete control over service delivery' ([Nosek 1991](#)).

There have been non-systematic reviews of studies of personal assistance services for people with

different types of impairments, for example spinal cord injury ([Hagglund 2004](#)). However, traditional reviews have failed to locate many evaluation studies and have not offered a definitive account of international research on personal assistance. A recent report by the Swedish National Board of Health and Welfare (Socialstyrelsen) highlighted the need for a sensitive and exhaustive search for trials and a systematic synthesis of existing studies ([Socialstyrelsen 2005](#)).

Objectives

To assess the effectiveness of personal assistance programmes for older adults with impairments, and the impacts of personal assistance on partners, families and carers, compared to other interventions.

Criteria for considering studies for this review

Types of studies

Randomised controlled trials, quasi-randomised controlled trials and nonrandomised controlled studies of personal assistance compared to other forms of support or to 'no-intervention' (which may include unpaid care) in which participants were prospectively assigned to study groups and in which control group outcomes were measured concurrently with intervention group outcomes.

Types of participants

Older adults (65+) living in the community who require assistance to perform tasks of daily living (bathing, eating, getting around, etc.) and to participate in normal activities due to permanent impairments.

Older adults living outside their own homes (e.g., in nursing homes) were excluded. Studies in which the majority (51% or more) of participants had been diagnosed as suffering from dementia at baseline were excluded as their reasons for receiving assistance and goals might differ from other older adults.

Types of interventions

In consultation with experts and the reference group, the reviewers sought to determine what minimal amount of assistance could be offered and still follow the personal assistance model for this population. Twenty hours of assistance is the minimum required to qualify a person for personal assistance in several countries with national schemes.

This review defines personal assistance as individualised support for people living in the community by a paid assistant other than a healthcare professional for at least 20 hours per week, which is provided for an indefinite period of time (i.e., *not* rehabilitation or respite care).

Comparisons could have included, either singly or in combination, informal care (which might be delivered by partners or other family members), institutionalisation, service housing (cluster housing), on-demand services, night patrols, transportation services, and other alternatives to personal assistance. 'No-treatment' and 'waiting list' groups were eligible even if other services

received were not described. Studies examining different forms of personal assistance (e.g., assistance organised by users compared to assistance organised by others) were included. These were treated as separate comparisons.

Types of outcome measures

Primary outcomes

- 1) Global quality of life, both (a) generic measures (e.g., the Short-Form Health Survey; [Ware 1992](#)) and (b) impairment specific measures. Though well-validated measures for the general population were considered, a review of global health measures found that 'very few measures have been validated specifically for cognitively impaired respondents' ([Riemsma 2001](#)).
- 2) User satisfaction. Direct reports were preferred, though proxies were eligible if users were unable to communicate.
- 3) Participation, including social life, membership in community groups, sexual participation, ability to engage in spontaneous activities, time outside the home, and mobility.

Secondary outcomes

- 1) Unmet needs, particularly the inability to perform activities of daily living.
- 2) Health outcomes, including direct measures of muscle strength, disease, injuries, nutrition, abuse or pain and indirect measures such as hospitalisation, emergency room visits or need for institutionalisation.
- 3) Functional status measured using either generic or impairment-specific tools. Measures might have included the FIM Instrument ([Heinemann 1993](#); [Linacre 1994](#)) or an index of activities of daily living ([Katz 1963](#); [Sheikh 1979](#)).
- 4) Outwardly directed challenging behaviour (e.g., the Cohen-Mansfield Agitation Inventory; [Cohen-Mansfield 1986](#)).
- 5) Psychological outcomes, including dementia, psychological disorders (e.g., anxiety and depression), challenging behaviour, self-harm, suicide and substance abuse. For example, measures might have included the Geriatric Depression Scale ([Yesavage 1982](#)), the Mini-Mental State questionnaire ([Folstein 1975](#); [Tombaugh 1992](#)), or the PAS-ADD ([Moss 1998](#); [Prosser 1998](#)).
- 6) Impact on others, including family (spouse and child) employment, satisfaction, and quality of family life. For example, measures might have included the Dysfunctional Behaviour Rating Instrument ([Molloy 1991](#)), the Short-Form Health Survey ([Ware 1992](#)) or the General Health Questionnaire ([Goldberg 1979](#)).
- 7) Direct and indirect costs, both immediate and long-term.

Outcome intervals

Outcomes were grouped by length of follow-up.

Search strategy for identification of studies

As we anticipated many relevant documents would be unpublished, a three-part search strategy was undertaken in order to maximise chances of capturing all relevant literature.

I. Electronic search

Databases were searched for published and unpublished studies. All electronic searches were limited to research reported since 1980 because scoping for this project, including a review of relevant laws and policy documents and contacts with international experts, found that widespread

personal assistance programmes began in the mid 1990s. Experts have noted that personal assistance was available in some form before the introduction of programmes in the 1990s, but they and the reviewers believed it was unlikely that any relevant trials were conducted before 1980.

No language restrictions were imposed on any results from any search attempts, although most databases were searched in English. Latin American and Caribbean Health Sciences Literature (LILACs) were searched using Spanish and Portuguese terms and Scandinavian databases were searched in appropriate languages.

No filters based on methodology were applied because test searches indicated that such filters might eliminate relevant studies.

The authors worked with a reference group of users, clinicians, policymakers, and analysts ([Jackson 2005](#)) to develop this protocol and search strategy. The group recommended a highly sensitive search (one that was likely to capture all relevant reports) rather than a more specific one (a search that would identify fewer irrelevant papers).

The following databases were searched electronically:

Biomedical databases

Cochrane Central Register of Controlled Trials (CENTRAL) (Issue 2, 2005)

MEDLINE (1980 - June 2005)

CINAHL (Cumulative Index to Nursing and Allied Health Literature) (1982 to June 2005)

EMBASE (1980 - June 2005)

LILACs (Latin American and Caribbean Health Sciences Literature) (1982 to July 2005)

Social sciences databases

ASSIA (Applied Social Science Index & Abstracts) (1987 - July 2005)

IBSS (International Bibliography of the Social Sciences [IBSS] on Bath Information and Data Services [BIDS]) (1980 to June 2005)

C2-SPECTR (The Campbell Collaboration's Social, Psychological, Educational and Criminological Trials Register) (N.d. to June 2005)

Dissertations Abstracts A (Dissertation Abstracts International A: The Humanities and Social Sciences) (N.d. to June 2005)

EconLit (1980 to June 2005)

ERIC (Educational Resources Information Center) (1980 to June 2005)

PsycINFO (1980 to June 2005)

Sociological Abstracts (1980 to June 2005)

SIGLE search (System for Information on Grey Literature in Europe) (1980 to June 2005)

Scandinavian databases (searched to August 2005)

Artikelsök

DIVA

Handicat

Hicat

LIBRIS

LIBRIS Uppsök

SveMed+

Danbib

Medline was searched via Ovid using the following terms:

- 1 Home Care Services/
- 2 Activities of Daily Living/
- 3 Personal Health Services/
- 4 (personal adj2 assist\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 5 (personal adj2 care\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 6 exp Homemaker Services/
- 7 independent living.mp.
- 8 direct assistance.mp.
- 9 direct payment.mp.
- 10 attendant care.mp
- 11 in home.mp
- 12 Caregivers/
- 13 (allowanc\$ or fee or fees or financ\$ or fund\$ or money\$ or monies\$ or pay\$ or paid or remunerat\$ salar\$ or wage\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 14 state-support\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 15 state support\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 16 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
- 17 12 and (13 or 14 or 15 or 16)
- 18 16 or 17 (25461)
- 19 limit 16 to yr=1980-2005

Similar terms were used to search other databases; see attached for selection of other search strategies used ([Table 01](#), [Table 02](#), [Table 03](#), [Table 04](#), [Table 05](#), [Table 06](#), [Table 07](#)).

Scandinavian databases were searched using index terms or free text terms, depending on the database's functionality, including:

- ADL (Svenska MeSH)
- Assistansreformen
- Assistenter: handikappade
- Dagliga livets aktiviteter
- Funktionshindrade (Svenska MeSH)
- Handikaplagstiftning
- Handikappolitik
- Handikappreformen
- Lagen om assistansersättning
- Lagen om stöd och service till vissa funktionshindrade
- Lagstiftning Handikappade
- LASS LSS LSS-insatser
- Personer med funktionshinder - hem och bostäder (Svenska ämnesord)
- Personer med funktionshinder - vård och omsorg (Svenska ämnesord)

Personlig assistant
Personlig assistans (Svenska ämnesord)
Personliga assistenter: handikappade
Psyiskt funktionshindrade (Svenska MeSH)
Psyiskt utvecklingsstörda (Svenska MeSH)
Psykiatireformen
Rörelsehindrade (Svenska MeSH)

II. Personal communications

Appropriate government departments, non-governmental organisations, non-profit groups, advocacy groups, user groups, and experts in the field were contacted. These approaches and any replies were documented by the authors. Additionally, impairment-oriented email lists (list-servs) were approached requesting assistance in locating studies. Lists of these can be found in the Campbell version of this review at: <http://www.campbellcollaboration.org/SWCG/titles.asp>

The reviewers contacted authors of all included and excluded studies to request details of ongoing and unpublished studies.

III. Reference lists

Reference lists from previous reviews and from all included and excluded studies were searched.

Relevant websites, including those maintained by users, governments, other agencies, and academics were searched.

Methods of the review

Trial selection strategy

A highly sensitive search for this review was conducted concurrently with the searches for five related reviews covering different types of impairments and age groups. Based on their titles or abstracts, one reviewer (EMW) eliminated most citations. Two reviewers (EMW and PM) reviewed remaining citations and articles were reviewed if one author felt a paper might be relevant.

Data management

Data collection

Data extraction was conducted independently by two authors (EMW and PM).

The following data were collected for all trial arms:

- 1) Descriptive data, including participant demographics (age, gender, types and extent of impairments, living arrangements, social and economic status);
- 2) Intervention characteristics (including delivery, duration, and within-intervention variability);
- 3) Other interventions received; and
- 4) Outcome measures listed above (including multiple measures of outcomes where available).

The following data were collected for all studies:

- 1) Programme differentiation, i.e. differences in the services received by participants in different arms ([Dane 1998](#); [MRC 2000](#)), including crossover between groups; and
- 2) Context.

Methodological quality

Two reviewers (EMW and PM) independently assigned each included study to a quality category described in the Cochrane Handbook ([Higgins 2005](#)) where:

- (A) indicates adequate concealment of the allocation (for example, by telephone randomisation, or use of consecutively numbered, sealed, opaque envelopes);
- (B) indicates uncertainty about whether the allocation was adequately concealed (for example, where the method of concealment is not known);
- (C) indicates that the allocation was definitely not adequately concealed (for example, open random number lists or quasi-randomisation such as alternate days, odd/even date of birth, or hospital number); and
- (D) indicates that random allocation was not used.

Studies in all quality categories were considered for inclusion in the review and meta-analyses.

Though well-designed nonrandomised studies sometimes come to the same conclusions as randomised trials, nonrandomised studies are most likely to arrive at different conclusions about an intervention's effects when groups are different at the outset ([Deeks 2003](#)). Therefore, the pre-treatment assessment and the allocation of participants is described in the Table of Included Studies to identify differences between intervention and control groups that may have existed at baseline.

Existing scales for measuring the quality of controlled trials have not been properly developed, are not well-validated and are known to give differing (even opposing) ratings of trial quality in systematic reviews ([Moher 1995](#)). At present, evidence indicates that 'scales should generally not be used to identify trials of apparent low quality or high quality in a given systematic review. Rather, the relevant methodological aspects should be identified a priori and assessed individually' ([Juni 2001](#)).

The following components are considered in the Description of Studies and Table of Included Studies:

- 1) Allocation bias (Was group assignment determined randomly or might it have been related to outcomes or the interventions received?);
- 2) Performance bias (Could the services provided have been influenced by something other than the interventions being compared?);
- 3) Detection bias (Were outcomes influenced by anything other than the constructs of interest, including biased assessment or the influence of exposure on detection?);
- 4) Report bias (Were the outcomes, measures and analyses selected a priori and reported completely? Were participants biased in their recall or response?);
- 5) Attrition bias (Could deviations from protocol, including missing data and dropout, have influenced the results?) ([Delgado 2004](#); [Juni 2001](#)); and
- 6) Outcome validity (Were the outcome measures objective, validated for the population, reported directly by the user or obtained through official records, etc.?).

Multiple arms

If two or more eligible intervention groups were compared to an eligible control, thus requiring that the reviewers choose a single intervention group for comparison, the service that best followed the goals of personal assistance (e.g., services that gave users maximum control) was included. If a single eligible intervention group was compared to multiple eligible control groups, 'no-treatment' controls were chosen over other groups for comparison. For studies that did not have a no-treatment

condition, the most commonly available intervention was chosen to maximise the external validity of the results.

Missing data

Contact authors of all included studies were contacted to supply unreported data (e.g., group means and standard deviations (SDs), details of dropouts, and details of interventions received by the control group). Other authors were contacted if necessary. If a study reported outcomes only for participants completing the trial or only for participants who followed the protocol, authors were contacted and asked to provide additional information.

Data synthesis

Outcome data

The studies included in this review made different comparisons and the reviewers concluded that meta-analysis was not appropriate. RevMan 4.2 would have been used to perform the calculations where applicable as described in [Table 08](#), 'Table of archived methods for use in future updates'.

Where possible, we calculated the relative risk (RR) and 95% confidence interval for dichotomous outcomes. All RRs reported herein were calculated by the reviewers.

Description of studies

Results of the search

After removing duplicates electronically, 58,431 citations were retrieved for this and related reviews. Based on their titles or abstracts, one reviewer (EMW) eliminated most citations. Two reviewers (EMW and PM) reviewed 14,712 citations. Full-texts were reviewed for 130 citations identified through electronic databases (often because we could not access abstracts or other information that would allow us to exclude a citation).

Additionally, staff at the CDPLPG contacted by email or letter the 300 research organisations/charities listed at the website of the Independent Living Institute (Sweden) (<http://www.independentliving.org/donet/>) between November 2005 and January 2006, and a further 31 other organisations and experts/practitioners in the field of disability were contacted following leads supplied by some of those who responded to this first call. In June 2006, relevant government offices of 14 countries wherein personal assistance was known to be common (UK, Denmark, Italy, Switzerland, Sweden, France, Austria, Finland, Belgium, USA, Hungary, Federal Republic of Germany, Norway). 66 responses were received and forwarded to EW and PM. This process is documented in Appendices within the Campbell version of this review, available at <http://www.campbellcollaboration.org/SWCG/titles.asp>

Ten prospective studies were considered for inclusion in this review; four were included.

A flowchart of the process of trial selection was made in accordance with the QUORUM statement ([Moher 1999](#)) and is included in [Figure 01](#).

Excluded studies

Six controlled prospective studies involving 9844 older adults were excluded from this review.

Four randomised controlled trials involving 9294 eligible participants were excluded because the

amount of assistance received was not sufficient for inclusion in the review. This included two Cash and Counseling sites in Arkansas and Florida, which were evaluated much like the NJ site. A third study examined if paid care leads to an absolute reduction in informal caregiving or to a change in living situation ([Carcagno 1988](#)). Finally, [Weissert 1979](#) compared three interventions (homemaker services, day care, and homemaker services and both day care).

Two non-randomised studies involving a total of 650 participants were excluded. [Hughes 1984](#) investigated the impacts of a 'home care' program; participants in the intervention group received 22 visits over a 9 month period. [Kuyvenhoven 1995](#) examined an intervention to reduce institutionalisation in which a majority of participants in the intervention group received some home-help, all users had to relocate to a housing project for older adults and it was impossible to disentangle the impacts of assistance from the impacts of moving to a specially designed community.

Included studies

Four included studies involving 1642 participants made three eligible comparisons: (i) personal assistance versus usual care ([Carlson 2007](#), [Sherwood 1983](#)), (ii) personal assistance versus nursing homes ([Braun 1987](#)), (iii) individual personal assistance versus 'cluster care' ([Feldman 1996](#)). One was a RCT ([Carlson 2007](#)), three were non-randomised.

Personal Assistance versus Usual Care

In the largest study ([Carlson 2007](#)), eligible Medicaid beneficiaries were randomly assigned to receive a monthly payment (personal assistance) in lieu of other Medicaid services or to receive usual care from 1999 to 2003. All participants or their representatives - 467 in the personal assistance group and 471 in the control group - completed a baseline survey (52% by proxy). Overall, 58% of participants were 65-79 years and 41% were over 80 years. Participants or their representatives were contacted by a counsellor who helped them develop a spending plan, provided advice and monitored services. Personal assistance participants received more paid care than control participants, who often paid for care out of pocket (38.8 versus 33.2 hours over two weeks). The amount and type of services purchased with cash assistance therefore qualified the intervention for inclusion in this review.

After assignment, the authors describe the intervention enrolment process as complex and discouraging; only 31% of participants received cash assistance within 3 months, 36% never received assistance, and 33% disenrolled during the following year (of whom, 76% withdrew before the assistance started). The average monthly payment at enrolment was \$1056; 66% of payments were managed by representatives. Of those still living in the community, 61% of the personal assistance group was receiving cash at 9 month follow-up. At 9 months, 94% and 82% of participants in the personal assistance and control groups reported receiving paid care in the previous two weeks ($p < 0.01$). They received 133 hours and 143 hours in total ($p = 0.28$), 39 and 31 of which was paid ($p < 0.01$).

Details presented here are based on published reports and available manuscripts (see: www.mathematica-mpr.com). As more information from this trial emerges, we hope to include it in updates of this review.

[Sherwood 1983](#) compared matched participants from Pennsylvania (US) counties with (101 older adults at pretest, 84 in the analyses) and without (101 at pretest, 86 in the analyses) the intervention.

Follow-up occurred approximately ten-months later. Personal assistance was available to participants 18 years or older who were 'judged to be incapable of independent living in the community, but do not require services that can be obtained only in a nursing home'. Participants were placed in a home with a provider who offered assistance in household tasks, activities of daily living and participating in activities. Client needs were reassessed annually. Most participants were older adults (82 and 80 years old and dependent in most activities of daily living), but some recipients were younger adults with mental health problems or intellectual impairments. Data for adults with intellectual impairments are reported in a related review; data for a handful of younger adults were not reported separately and we have not been able to obtain separate data about this group from the authors.

Though participants did not necessarily remain in their own homes, which would more closely represent the personal assistance model, participants did remain in the community (e.g., in a carer's home). Furthermore, 91% of homes were single family dwellings and most homes had only 1 to 3 clients. While exact figures regarding the amount of assistance received were not provided, 41% of assistants spent 4 to 8 hours caring per day and 38% spent more than 8 hours caring each day. The amount and type of services received qualified the intervention for inclusion in this review.

Personal Assistance versus 'Cluster Care'

[Feldman 1996](#) investigated personal assistance for Medicaid clients in New York City using non-equivalent sites and regression models to adjust for some of the known between-site differences. There was a 93% response rate to the baseline survey, which yielded data for 404 participants, 175 participants at 4 personal assistance sites and 229 clients at 7 'cluster care' sites.

All study participants had been receiving individualised personal assistance prior to entry. Participants in the personal assistance group continued to receive these services throughout the study. Participants in the comparison group were switched to cluster care by the provider. This was a lower cost service provided to people who lived near each other (e.g., in the same apartment building) by workers serving multiple clients. Cluster care reduced service hours, increased staff turnover, and led to gaps in assistance during the day.

In the intervention and comparison groups, participants were receiving 50.32 (SD=27.84) and 57.56 (SD=35.22) hours of home care per week at baseline, usually organised in 4, 8 or 12 hour blocks. Therefore, the group that continued to receive personal assistance met the threshold for inclusion. Most participants were both under 85 and female (82%). Follow-up occurred approximately 16 months after baseline.

Personal Assistance versus Nursing Homes

[Braun 1987](#) matched clients in three long-term care settings in Honolulu: nursing homes and two community settings. Participants were eligible for the study if they had been in their current setting for 3 months or longer; there were 100 eligible participants receiving personal assistance and 101 in nursing homes. From all eligible participants, the authors constructed 49 matched triads (147 total participants, 98 of whom are included in this review). Participants were 78 and 80 years old on average.

Participants in the community lived with a carer and received personal assistance for up to 24 hours per day supervised by a social worker. The amount and type of services received qualified the

intervention for inclusion in this review. The nursing home group was selected for comparison. Follow-up occurred three months after baseline.

Methodological quality of included studies

In the one included RCT, the risk of bias overall was low. In three non-random studies, there was some risk of bias, as described below and in [Table 09](#), [Table 10](#) and [Table 11](#). However, the results of the randomised and non-randomised studies are generally consistent, which somewhat mitigates these concerns.

Three studies were at high risk of allocation bias for reasons that are apparent in the Description of Studies and in the Additional Tables 9 through 11. Participants in two studies ([Feldman 1996](#), [Sherwood 1983](#)) were allocated by site. Neither controlled for clustering. Of the non-randomised studies, only [Feldman 1996](#) controlled for measured baseline differences. To control for pre-existing trends, [Feldman 1996](#) also created a time coefficient by regressing weekly home care hours prior to the intervention on time.

All studies appeared somewhat vulnerable to performance bias. Satisfaction with the intervention was a primary outcome of this review and insofar as satisfaction with one's care influences one's perception of other outcomes, it may be impossible to disentangle these variables. In [Carlson 2007](#), participants were probably unsatisfied with existing services and control participants may have been motivated to report negative outcomes. In [Sherwood 1983](#), intervention participants may have been motivated to report favourable outcomes, but little is known about the comparison group. In [Feldman 1996](#), cluster care participants upset with a change in service may have been motivated to report negative outcomes. In [Braun 1987](#), intervention participants may have been more likely to report favourable outcomes.

Most outcome measures in the review did not appear particularly vulnerable to detection bias; the direction of such effects could not be determined in any case. In all studies, short follow-up periods make it impossible to detect benefits or harms that occur as a result of continued use of personal assistance. Cost data in all studies should be interpreted with caution as these refer to charges to specific government programmes; no effort was made to estimate total costs in most studies.

Most studies appeared somewhat vulnerable to report bias as detailed in [Table 09](#), [Table 10](#) and [Table 11](#).

Studies included in the review were vulnerable to attrition bias and most did not correct this bias. In [Carlson 2007](#), the number of participants in different analyses at the same interval varies considerably; means are predicted using ordinary least squares regression or logit models. [Braun 1987](#) was somewhat vulnerable to this bias. [Feldman 1996](#) and [Sherwood 1983](#) were vulnerable to attrition bias as detailed in the relevant tables.

Included studies used a mix of objective outcomes and other measures. Some outcome measures were validated, but the studies also used many unvalidated measures (e.g., of wellbeing and satisfaction), parts of validated scales (e.g., a subsection of the Vigor, Intactness, Relationships, and Orientation scales), and single questions (e.g., about mobility). Furthermore, floor and ceiling effects limit the ability of many measures to detect change.

Results

Due to substantial differences across trials in intervention design, comparison groups, and assessment, no results were combined using meta-analysis. Results for each outcome are summarised below. For many outcomes, statistics were not reported completely (i.e. values were not accompanied by measures of variance and complete significance tests were not reported); study authors were unable to provide additional information despite repeated requests.

Primary outcomes

Quality of life

None of the studies used a validated measure of quality of life.

One study, [Carlson 2007](#), used a single question to measure satisfaction with the way participants were spending their lives. In the intervention and control groups, 47% and 25% ($p < 0.01$; $N = 680$) were 'very satisfied'.

In [Braun 1987](#), personal assistance recipients ($N = 45$) were more likely than nursing home residents ($N = 44$) to report that they were often happy ($RR = 1.69$ [$1.05, 2.74$]) and had somebody they could count on ($RR = 1.21$ [$0.95, 1.54$]).

User satisfaction

Overall, participants appeared satisfied with personal assistance, though the models tested were not universally superior to other models of care.

In [Carlson 2007](#), there were 'large' (at least 10% or at least half the size of the control group proportion or its complement) and significant relationships favouring the treatment group for satisfaction with: the paid caregiver (working age adults were pooled with older adults in the analysis); daily living assistance (e.g., eating and toileting); help around the house/community (excluding transportation); routine health care assistance; transportation assistance; and overall care arrangements. For several measures of satisfaction, there were not significant effects in favour of the treatment group: paid caregivers taking something without asking, paid caregiver giving unwanted help (working age adults were pooled with older adults in the analysis), and rude and disrespectful behaviour by a paid caregiver. In the treatment and control groups, 57% and 37% ($p < 0.01$) of participants were very satisfied with overall care arrangements.

Of those participants in [Carlson 2007](#) who dropped out of the intervention, the most common reasons for leaving were dissatisfaction with the amount of cash assistance, difficulty acting as an employer, and satisfaction with traditional agency care.

[Sherwood 1983](#) measured satisfaction in several ways. Differences between the intervention and comparison groups were not significant for the 'Good Place Scale' (4.70 versus 4.88; range 4 [most favourable] to 8 [least favourable]) or the 'Environment Satisfaction Scale' (10.82 versus 10.70; range 4 [least favourable] to 12 [most favourable]). Differences were significant but probably not meaningful for two single questions regarding feelings toward the living situation (1.15 versus 1.36, $p < .01$; range 1 [positive] to 3 [negative]) and relationships with other people (2.84 versus 2.68, $p < .01$; range 1 to 3 with unclear direction).

In [Feldman 1996](#), satisfaction with care was measured by averaging ratings of satisfaction with help

as related to each ADL/IADL activity. Our analysis indicates that participants at the personal assistance sites were not more likely than participants at cluster care sites to report they were 'very satisfied' at baseline (RR=0.97 [0.88, 1.07]). Based on a logistic regression including 14 other variables, the authors report that '[c]lients at cluster care sites, whether in cluster care or excluded from it, were significantly less satisfied with their care than clients at traditional sites. This result holds true for clients with fewer as well as with more limitations' (OR=0.29 [0.15, 0.56]).

In [Braun 1987](#), personal assistance recipients were less likely than people in nursing homes to report that they would rather live elsewhere (RR=0.35 [0.20, 0.60]) or that they worried about their future care (RR=0.54 [0.29, 0.99]). Caregiver ratings were consistent with the participant ratings, though caregivers underestimated participants' desire to live elsewhere.

Participation

Three studies measured participation, though these data were not yet reported for [Carlson 2007](#).

In [Sherwood 1983](#), participation outcomes were measured at post-test. There were no differences on nine self-reported outcome measures: religious attendance, contact with friends, visiting friends, having at least one close person, interest in family visiting, interest in informal group activities, interest in going for walks, interest in reading papers, and desire for more contact with friends. There were significant differences on four of them, one difference favouring the control group ('help other people') and three favouring the experimental group (participation in clubs, interest in clubs, and taking rides). There were no differences on two clinician-reported measures, the involvement scale and the number of outside friends. There was a significant difference in favour of the control group in the extent of outside interests.

[Braun 1987](#) reports that participants in intervention group improved in spending time outside the placement setting while participants in nursing homes did not. Caregivers reported that 41 (84%) and 5 (10%) participants saw their children daily or weekly (RR=8.20 [3.54, 18.99]).

Secondary outcomes

Unmet needs

In two studies, the personal assistance group experienced fewer unmet needs than the comparison group.

In [Carlson 2007](#), there were 'large' and significant relationships favouring the treatment group for unmet needs for help with ADLs, unmet needs for help with IADLs, unmet needs for help with transportation (e.g., to and from shopping and recreational activities), and unmet needs for help with routine health care (e.g., medication, checking blood pressure and doing exercises). For neglect by a paid caregiver, there was a 'modest' and significant relationship favouring the treatment group. In the treatment and control groups, 44% and 58% ($p<0.01$) of participants reported an unmet need with an activity of daily living.

[Sherwood 1983](#) reports that participants in the personal assistance group experienced significantly fewer unmet needs than participants in the control group, including overall unmet needs (1.26 versus 2.52, $p<.01$; range 1 [no need] to 5 [very high need]), though this was not true of unmet transportation and recreational needs (0.45 versus 0.60, n.s.; range 0 [no unmet need] to 3 [3 unmet needs]).

Physical health

Though not a goal of the intervention, most studies reported some data about mortality, which suggest that personal assistance had no comparative impact. Data on other health outcomes were mixed, suggesting personal assistance might have some beneficial impacts on health. There was no evidence of detrimental impacts.

Mortality

About 7% of participants in [Carlson 2007](#) died in each group. In [Feldman 1996](#), 14% of intervention participants and 15% of controls died. [Sherwood 1983](#) does not report mortality, but relatively similar rates of loss-to-follow-up (17% and 15%) suggest that differences were unlikely to be significant. Across three groups in [Braun 1987](#), 27 participants (31%) died.

Morbidity and Medical Care

In [Carlson 2007](#), several adverse health outcomes were measured. The control group was not superior to the intervention group on any measure. There were some differences favouring the intervention group, for example between the number of intervention and control participants who had a fall (13% and 20%, $p=0.01$) and whose contractures developed or worsened (18% and 27%, $p<.01$). Differences on other measures were not significant, including bedsores that developed or worsened (7% and 7%, $p=0.97$) and urinary tract infections (15% and 15%, $p=0.97$).

[Sherwood 1983](#) reported the average number of days that participants spent in institutional or community settings during the trial. 'Experimentals experienced about 1.2 days in the community for every one day spent in the community by controls.' From a figure in the report, we calculated that participants in the intervention group spent an average of 34 days in hospital or a long-term care setting while participants in the control group spent an average of 82 days in one of those settings.

[Braun 1987](#) reports that there were no significant differences in morbidity for 49 participants in: infections (respiratory, urinary tract, etc.), which were experienced 3 and 1 times leading to hospitalisation and 11 and 10 times *not* leading to hospitalisation; injuries (falls, fractures, bruises, abrasions), which were experienced 2 and 3 times leading to hospitalisation and 12 and 8 times without hospitalisation; rashes, which were experienced 4 and 3 times, and decubitus (skin) ulcers, which were experienced 3 and 5 times.

Abuse and Neglect

Across sites in [Carlson 2007](#), counsellors periodically contacted participants and representatives to detect abuse, fraud and neglect. 'There was no evidence from consumers, counsellors, or state program staff that participation in Cash and Counseling led to any adverse effects on consumers' health or safety' (Shore 2007).

Functional status

Direct measures of functioning suggest that personal assistance does not improve functioning. One study suggested that personal assistance may have a negative impact compared to agency-delivered care for some participants, though this could be a statistical artefact.

In [Sherwood 1983](#), functional status was measured at post-test through a clinical assessment of IADL and a two item self-reported mobility scale. Differences on the 'Community Survival Scale' (14.2 versus 13.93; range 5 [poor survival skills] to 20 [good survival skills]) and the mobility scale

(1.07 versus 0.87; range unclear) were not significant.

[Feldman 1996](#) measured functional status by combining self-reported scores on the ADL and IADL, which the authors report measured functional status with more sensitivity than either scale alone. Normalised scores were used to assess the degree to which clients ADL/IADL scores changed relative to other people with similar impairments at baseline. Controlling for baseline differences, the authors found no association between being at a cluster care site and normalised change in functional status (the unstandardised coefficient: $b = 0.13$, $SE = 0.13$, $p > 0.10$).

[Braun 1987](#) reports that personal assistance participants 'made significant improvement over time in more ADL items than did patients in the nursing home setting.' However, changes in total ADL scores were not different between groups, which both improved significantly (14.05 to 12.06 versus 14.21 to 13.16), nor were changes in mobility different between groups, which both improved significantly (6.78 to 4.98 versus 6.80 to 6.18).

Challenging behaviour

Most participants did not have intellectual impairments and challenging behaviour was not reported in any trial.

Mental health

Data about mental health outcomes were very limited.

[Sherwood 1983](#) measured psychological outcomes at post-test using unvalidated measures. Differences in personal adjustment were not significant (mean 2.3 versus 2.1; range 1 [no neurosis] to 5 [psychotic]) while differences in emotional health (mean 2.67 versus 2.44, $p < .05$; range 1 [very depressed] to 3 [even mood]) and how the future looks (mean 2.34 versus 2.76, $p < .05$; range 1 [very optimistic] to 5 [very pessimistic]) favoured the intervention group.

[Feldman 1996](#) measured depressive symptoms using a 20 item scale, the Center for Epidemiologic Studies Depression Scale (CES-D; [Sumpton 1987](#)). Though data were not included in the report, the authors indicate that cluster care did not affect depressive symptoms.

Most participants in [Braun 1987](#) reported that they often had a good appetite and slept well, differences were not significant between groups ($RR = 1.00$ [0.87, 1.16]; $RR = 0.98$ [0.80, 1.20]).

Impact on others

Only one study reported outcomes for informal caregivers and found benefits.

In [Carlson 2007](#), impacts on caregivers were measured through a caregiver survey administered 10 months after baseline. Results for caregivers of older adults and non-elderly participants were reported together ($N = 1042$). Personal assistance increased the amount of total assistance provided by the primary informal caregiver in the previous two weeks (123 hours versus 113 hours, $p = 0.06$), an effect due to the inclusion of the non-elderly group in these analyses. Consequently, these results are generally biased *against* personal assistance. Nonetheless, caregivers increased their satisfaction with overall care arrangements (52% and 32% were very satisfied, $p < 0.01$), decreased their emotional strain (42% and 49% experienced a great deal of strain, $p = 0.02$) and decreased feelings that caregiving limited their privacy (41% and 51%, $p < 0.01$) or free time (55% and 60%, $p = 0.06$). Personal assistance reduced financial strain (30% and 39% said caregiving caused a great deal of

strain, $p < 0.01$), reduced the chance that a person who wanted outside work would not seek employment due to caregiving (34% and 44%, $p < 0.01$), and reduced absenteeism (54% and 66%, $p < 0.01$). It further reduced the chance of experiencing a great deal of physical strain (42% and 32%, $p < 0.01$) and experiencing negative health outcomes due to caregiving (31% and 40%, $p < 0.01$).

Costs

Broad cost data were available for only one trial, which suggests personal assistance may save a small amount of money compared to treatment as usual. Data from three other trials provide little information about the true relative costs of personal assistance and other services.

Of the included studies, [Sherwood 1983](#) provides the most comprehensive estimate of the costs of personal assistance (Ruchlin 1983). Accounting for placements and government services, community support services and informal care, the authors report that personal assistance saved \$5.04 per participant per day compared to treatment as usual.

[Carlson 2007](#) reports that the program increased participants ability to receive care to which they were entitled, which increased costs to a single government programme, Medicaid. Notably, these estimates do not account for costs to other agencies, charities, family and friends or consumers. Estimated costs to Medicaid were \$20236 and \$19407 per client in the first year, \$20015 and \$17975 in the second year. [Braun 1987](#) also measured costs as Medicaid expenditures; in fiscal year 1986, charges were \$28 and \$74 per day for personal assistance and nursing home participants.

[Feldman 1996](#) reports that clients who were assigned to personal assistance received six more hours of assistance per week than clients assigned to cluster care, which led to a relatively higher cost *for the assistance itself* (the unstandardised coefficient for cluster care: $b = -720.4$, $SE = 395.35$, $p < 0.10$). Most of the difference came from clients in the cluster care group who actually received cluster care and who had five to ten limitations at baseline.

Discussion

This review identifies some evidence that personal assistance recipients may express greater satisfaction and fewer unmet needs than participants receiving other services, with possible benefits in participation and physical health. Further data would be required to draw conclusions about mental health and cost. One trial found evidence of benefits to caregivers. Across studies, follow-up periods were generally very short and this review does not provide information about the long term impacts of personal assistance.

Advocates of personal assistance emphasise the value of user control. One study found that personal assistance was preferred by participants, who appeared to enjoy the companionship and control over the timing of specific tasks and the organisation of their lives; however, reducing the amount of assistance and degree of user control had no significant impacts on objective outcome measures.

The amount of assistance delivered to participants in two studies was poorly described. [Braun 1987](#) did not provide these data and [Feldman 1996](#) only describes between-group differences; in these studies, the type of assistance received was equally unclear. No included or excluded study compared a very large amount of personal assistance (e.g., 90 hours per week) to another form of service. Large amounts of assistance are increasingly common in Europe, particularly in Scandinavia. As a result, the conclusions of this review may not extend to users with very severe

impairments or to more intense models of personal assistance. Though the amount and type of assistance received was better described in [Sherwood 1983](#), the study aimed to maintain recipients in the community but not their own homes. This model is a very different from both cluster housing, which was tested in one excluded study, and somewhat different from personal assistance delivered in participants' own homes.

Cost data from included studies are difficult to interpret and have limited generalisability. Most reported data should be interpreted in light of currently available services and their present costs, with the exception of the data from [Carlson 2007](#). Most data are not comprehensive and implications for different stakeholders may be quite different; the relative costs of personal assistance and other services may be contextually dependent, varying from country to country.

In broad terms, this review found some evidence that personal assistance substitutes for informal care and it did not find evidence that personal assistance reduces long-term institutional care. The substantial amount of paid assistance received by participants in the control group in [Carlson 2007](#) underscores the fact that people receive both unpaid and paid assistance without external intervention; 'despite the concentration in the literature on programs delivering personal assistance services, the reality is that the vast majority of persons with severe disabilities have no contact with formal programs' ([Nosek 1991](#)). These data suggest that providing personal assistance is likely to raise government or insurance costs by paying for work that users would otherwise hire themselves and by paying for time that people would otherwise spend providing assistance for free.

Even if personal assistance is not desirable for all older adults, some people and their carers clearly wish to try it. Of those, some eventually determine they prefer other services or become unable to manage personal assistance. For this reason, Nosek suggests that personal assistance be offered to some individuals on a trial basis for a limited time so that 'both consumers and providers of services could assess the feasibility of management arrangements and mutually define the parameters of management responsibilities' ([Nosek 1991](#)). When intervention participants can choose to return to treatment as usual rather than receive personal assistance, it may not be surprising that consumers select the option that leads to the best outcomes for them. Consequently, it is difficult to separate the benefits of personal assistance *per se* and the benefits of consumer choice.

Reviewers' conclusions

Implications for practice

There have been relatively few controlled studies of personal assistance for older adults who require a great deal of assistance. Existing evidence suggests that personal assistance is generally preferred over other services by consumers and their representatives *who agree to participate in research*; however, some people prefer other models of care. This review indicates that personal assistance probably has some benefits for some recipients, their friends and families. Paid assistance probably substitutes for informal care and may cost government more than alternative arrangements; however, the relative *total* costs to recipients and society are unknown. Decisions to provide or not to provide and to take-up or not to take-up personal assistance will be informed by personal values and preferences in addition to evidence of its effectiveness.

This review indicates that personal assistance is safe for older adults, though it may be difficult to manage. People who choose to receive personal assistance may prefer it to other services, particularly services over which users have little control. However, this review does not indicate that personal assistance would be superior to other services for people who are already satisfied with the assistance they receive. Personal assistance appears to benefit informal caregivers as well. Individuals considering personal assistance may wish to discuss their options with family and friends.

Implications for research

In 1986, Ratzka noted that 'there has been surprisingly little in the way of policy evaluation. The work that has been done in this area is restricted to gathering descriptive statistics on number of hours provided by one type of service, number of consumers, staff, and expenditures' ([Ratzka 1986](#)). While several studies have been conducted since the 1980s, few studies have compared directly personal assistance and other services and further evaluations are required to determine the relative merits of different ways of organising assistance.

Personal assistance is expensive and difficult to organise, especially in places that do not have such services in place already. In locations with personal assistance, recipients may resist being assigned to other services. Nonetheless, it would be possible to compare personal assistance to other services or to different forms of personal assistance in locations implementing new programmes. Similarly, new users might be assigned to new models of personal assistance in places with long-standing personal assistance services.

Services for older adults with impairments are organised differently around the world. While advocates may support personal assistance for myriad reasons, this review demonstrates that further studies are required to determine (i) what marginal benefits are gained from personal assistance (i.e. the added value compared to other services that exist today), (ii) at what total relative cost and (iii) which models of personal assistance are most effective and efficient.

Acknowledgements

We wish to thank Jo Abbott (Trial Search Coordinator of the Cochrane Developmental, Psychosocial and Learning Problems Group) for developing and conducting the search with JD; Julie Millener (Research Secretary of the CDPLPG) for coordinating the grey literature search and for support throughout; Maja Frederikson (IMS, Sweden) for conducting searches of Swedish databases; Anette Fomsgaard (Nordic Campbell Center, Denmark) for conducting searches of Danish databases; and Charlotte Couldrey for assistance retrieving articles. We thank Celia Almeida and Katinka Hodin for translating documents.

Input from a reference group chaired by Haluk Soydan and organised by the Swedish National Board of Health and Welfare (Socialstyrelsen) has been invaluable. We are particularly grateful to Knut Sundell, Director of IMS, for his support. Parts of this review dealing with personal assistance users, government policy, law, and service administration have been shaped by advice from Peter Brusén, Katarina Carlsson, Ulla Clevnert, Johan Glad, Carina Gustafsson, Kerstin Gynnerstedt, Elaine Johansson, Inger Ljung, Anders Printz, Lydia Springer and Karin Tengvald.

Thanks to Georgia Salanti (Cambridge University) for useful comments on the protocol in draft and to David Gordon (Townsend Centre for International Poverty Research, University of Bristol) for helping to identify background information.

Finally, thanks to Geraldine Macdonald (Coordinating Editor of CDPLPG), Jeff Valentine (Campbell Collaboration Methods Group) and anonymous peer reviewers for their feedback and support.

Potential conflict of interest

This review was funded by a grant from the Swedish government, the Unit for Disabilities Issues and the Institute for Evidence-Based Social Work Practice, the Swedish National Board of Health and Welfare (Socialstyrelsen). The reviewers have no known conflicts of interest.

Characteristics of included studies

Study	Methods	Participants	Interventions	Outcomes	Notes	Allocation concealment
Braun 1987	<p>Clients were selected from three settings to create matched triads. People receiving personal assistance were compared to those in nursing homes at baseline and three months. Participants were over 55 and had been in their current setting for 3 months or more.</p>	<p>There were 49 older adults receiving personal assistance and 49 in nursing homes. On average, they were 78 and 80 years old and dependent in most activities of daily living. Participants were mostly female (28 and 28). Some were living with family or friends (15 and 25) and many were widowed (23 and 20).</p> <p>In addition to other medical conditions, common problems included stroke (about 17 per setting), dementia (~16 per setting), and problems in vision speech or hearing (~10 per setting). They scored 14 on the Katz Index of ADL (Katz 1972), which ranges from 6 (independent in all items) to 18 (dependent in all items).</p>	<p>The personal assistance group received a variety of services that included assistance with activities of daily living, household tasks and transportation.</p>	<p>Personal assistance participants were more likely to be happy often and indicate they had somebody they could count on. They were less likely to indicate they would rather live elsewhere or that they were worried about their future care. They improved in spending time outside the house while nursing home residents did not. There were no significant differences in morbidity or total ADL scores.</p>		D

<p>Carlson 2007</p>	<p>Allocation was random. Participants were assessed by telephone at baseline and 9 months. Carers were assessed at 10 months.</p>	<p>Participants had to be current users of the state's personal care benefit. Overall, 79% were female, 59% white and 40% Hispanic (regardless of race). Few had attended college (17%) and many (43%) were in poor health. The majority (63%) lived with at least one other person and few (11%) lived in a rural area. Most participants were dependent in several ADLs; 67%, 66% and 87% were not independent in transferring, toileting and bathing; 74% expressed a need for more help with personal care.</p>	<p>Participants received a monthly allowance that could be used to hire caregivers. Intervention participants received approximately 19 hours of paid care per week compared to 16.6 hours of paid care per week in the control group. The intervention allowed people to hire relatives 'during a time when agency workers were in short supply'.</p> <p>Participants reported difficulty budgeting for the programme and completing paperwork; they were less likely than younger adult participants in a related trial to receive the intervention. Of those who received a payment in the 8th month of the study, 86% of participants used it to pay workers, using 81% for this purpose (data available for 267 participants). Of those who hired a worker in the first 9 months, 45% hired a worker who lived with</p>	<p>The intervention group was satisfied with the intervention and reported greater satisfaction with their lives overall. They experienced fewer unmet needs. Caregivers reported lower burden and greater satisfaction.</p>	<p>A</p>
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			the participant; 20% of participants tried to hire a worker but were unable to do so (data available for 402 participants).			
Feldman 1996	Participants in two non-equivalent groups were compared using regression-adjusted measures. All had been receiving individualised care (over 50 hours per week). Some were switched to 'cluster care'. Records were compared and interviews were conducted at baseline and 16 months.	<p>There were 175 participants at four sites who continued to receive personal assistance and 229 participants at 7 sites who were switched to cluster care. Participants were excluded if they could not be left alone, if they could not provide access to their apartment, or if they were psychotic.</p> <p>Participants lived in four of New York's five boroughs. Those receiving personal assistance were more likely to be black (62% versus 38%), less likely to be Hispanic (14% and 28%), and less likely to live with someone (17% and 28%). Most participants were widowed or divorced (65% and 68%). Of those in the personal assistance and cluster care groups, 3% in each group had 'total</p>	Participants in both groups received paid assistance. Those switched to cluster care received assistance that was organised in blocks of time and over which the users had less control.	Participants in the 'cluster care' group received less care at a lower cost and did not appear to suffer on any objective outcomes. However, they were dissatisfied with the service.		D

		paralysis', 74% and 58% had 'missing or weakened limbs', and 44% and 45% used a wheelchair. Of the 10 ADL/IADL measured, participants experienced limitations in 6.62 (SD=2.27) and 6.09 (SD=2.78).				
Sherwood 1983	Participants in Pennsylvania counties with the intervention were compared to matched participants in counties without the intervention. Participants were assessed at baseline and 10 months.	There were 101 older adults in the intervention group and 101 controls. Few details were provided about their characteristics. Most participants and assistants were white; 13% of program applicants and 30% of assistants were black.	Participants in the intervention group lived with an assistant, 41% of whom spent more than 8 hours per day giving assistance in household tasks, activities of daily living and participating in activities. Assistants provided help with laundry (97%), personal shopping (83%), cleaning clients' rooms (80%), transportation to social activities (77%), handling money (65%), grooming (49%), bathing (37%), dressing (26%), and preparing special diets (21%). Most did not work outside the home; they typically earned \$6,000 to \$7,000 excluding program payments.	Differences in satisfaction were inconsistent and unlikely to be clinically meaningful. Differences in participation were inconsistent. People receiving personal assistance reported slightly fewer unmet needs though no difference in functional status. Differences on unvalidated measures of mental health favoured the intervention group but were unlikely to be clinically significant. The authors claim personal assistance save \$5.04 per day per participant.		D

Characteristics of excluded studies

Study	Reason for exclusion
Carcagno 1988	Participants in the intervention group did not receive enough assistance. The study may have been ineligible for other reasons; the intervention and its implementation are not well-described in published reports.
Hughes 1984	Participants in the intervention group did not receive enough assistance.
Kuyvenhoven 1995	It was impossible to disentangle the impacts of assistance from the impacts of moving to a specially designed community.
Weissert 1979	Participants in the intervention group did not receive enough assistance.

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Additional tables

01 CENTRAL search strategy (Issue 2, 2005)

Search strategy

#1 HOME CARE SERVICES

#2 ACTIVITIES OF DAILY LIVING

#3 PERSONAL HEALTH SERVICES

#4 (personal near/2 assist*)

#5 (personal near/2 care*)

#6 exp HOMEMAKER SERVICES

#7 independent living

#8 direct assistance

#9 direct payment

#10 attendant care

#11 in home

#12 CAREGIVERS

#13 (allowance* or fee or fees or finance* or fund* or money* or monies* or pay* or paid or remunerate* or salar* or wage*)

#14 state-support*.

#15 state support*.

#16 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11

#17 #12 and (#13 or #14 or #15 or #16)

#18 #16 or #17

02 EMBASE via OVID 1980 to June 2005

Search strategy

- 1 *Home Care Services/ (4240)
- 2 *"Activities of Daily Living"/ (1920)
- 3 *Personal Health Services/ (6034)
- 4 (personal adj2 assist\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] (416)
- 5 (personal adj2 care\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] (1248)
- 6 exp Homemaker Services/ (11661)
- 7 independent living.mp. (743)
- 8 direct assistance.mp. (18)
- 9 direct payment.mp. (18)
- 10 *CAREGIVERS/ (1763)
- 11 (allowanc\$ or fee or fees or financ\$ or fund\$ or money\$ or monies\$ or pay\$ or paid or remunerat\$ salar\$ or wage\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] (137255)
- 12 state-support\$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] (239)
- 13 state support\$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] (239)
- 14 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 (21553)
- 15 10 and (11 or 12 or 13 or 14) (360)
- 16 14 or 15 (21674)
- 17 limit 16 to yr=1980-2005 (21456)

03 ASSIA and Soc Abstracts searched via CSA to June 2005

Search strategy
((personal assistance) or (personal care) or (home care)) or ((independent living) or (direct (pay* or assistance))) or (((care-giver* or caregiver\$) and (allow* or fee or fees or financ* or fund* or money or moneys or pay* or paid or remunerat* or salar* or wage*)))

04 C2-SPECTR searched June 2005

Search strategy
C2-SPECTR was searched in June 2005 using the terms: Personal care OR personal assistance OR home care OR direct payment OR direct assistance OR caregiver* OR care-giver*

05 EconLit searched via Silver Platter 1980 - June 2005

Search strategy
#12 ((home-care) or (personal-care) or (home care) or (independent living) or (personal assistance) or (independent living) or (direct assist*) or (direct pay*) or (personal care) or (caregiver* or care-giver*)) and (PY:ECON = 1980-2005)(324 records) #11 (home-care) or (personal-care) or (home care) or (independent living) or (personal assistance) or (independent living) or (direct assist*) or (direct pay*) or (personal care) or (caregiver* or care-giver*)(328 records) Searches and results below from: SIGLE 1980-2004/12 #10 independent living(84 records) #9 direct assist*(1 records) #8 direct pay*(56 records) #7 personal care(24 records) #6 caregiver* or care-giver*(36 records) #5 home-care(1 records) #4 personal-care(1 records) #3 home care(193 records) #2 independent living(84 records) #1 personal assistance(9 records)

06 PsycINFO searched via SilverPlatter 1980 to June 2005

Search strategy

Searches and results below from saved search history PA26June2005Final

#28 (personal assistance) or ((allowanc* or fee or fees or financ* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*) or (state support*)) and (("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*))) or ("Independent-Living-Programs" in MJ,MN) or ("Assisted-Living" in MJ,MN) or ("Home-Care-Personnel" in MJ,MN) or (explode "Home-Care" in MJ,MN) or (home care) or (independent living) or (direct assistance) or (direct pay*) or (personal care)(6427 records)

#27 (allowanc* or fee or fees or financ* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*) or (state support*)) and (("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*))(1108 records)

#26 allowanc* or fee or fees or financ* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*) or (state support*)(79580 records)

#25 ("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*)(14795 records)

#24 home care(3627 records)

#23 independent living(1348 records)

#22 direct assistance(41 records)

#21 direct pay*(32 records)

#20 personal care(406 records)

#19 personal assistance(100 records)

#18 "Independent-Living-Programs" in MJ,MN(246 records)

#17 "Assisted-Living" in MJ,MN(104 records)

#16 "Home-Care-Personnel" in MJ,MN(122 records)

#15 explode "Home-Care" in MJ,MN(2010 records)

#14 (personal assistance) or ((allowanc* or fee or fees or financ* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*) or (state support*)) and (("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*))) or ("Independent-Living-Programs" in MJ,MN) or ("Assisted-Living" in MJ,MN) or ("Home-Care-Personnel" in MJ,MN) or (explode "Home-Care" in MJ,MN) or (home care) or (independent living) or (direct assistance) or (direct pay*) or (personal care)(6427 records)

#13 (allowanc* or fee or fees or financ* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*) or (state support*)) and (("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*))(1108 records)

#12 allowanc* or fee or fees or financ* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*) or (state support*)(79580 records)

#11 ("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*)(14795 records)

#10 home care(3627 records)

#9 independent living(1348 records)
 #8 direct assistance(41 records)
 #7 direct pay*(32 records)
 #6 personal care(406 records)
 #5 personal assistance(100 records)
 #4 "Independent-Living-Programs" in MJ,MN(246 records)
 #3 "Assisted-Living" in MJ,MN(104 records)
 #2 "Home-Care-Personnel" in MJ,MN(122 records)
 #1 explode "Home-Care" in MJ,MN(2010 records)

07 SIGLE searched via SilverPlatter 1980 to June 2005

Search strategy

#12 ((independent living) or (direct assist*) or (direct pay*) or (personal care) or (caregiver* or care-giver*) or (home-care) or (personal-care) or (home care) or (independent living) or (personal assistance)) and (PY:SI = 1980-2005)(385 records)
 #11 (independent living) or (direct assist*) or (direct pay*) or (personal care) or (caregiver* or care-giver*) or (home-care) or (personal-care) or (home care) or (independent living) or (personal assistance)(388 records)
 #10 independent living(84 records)
 #9 direct assist*(1 records)
 #8 direct pay*(56 records)
 #7 personal care(24 records)
 #6 caregiver* or care-giver*(36 records)
 #5 home-care(1 records)
 #4 personal-care(1 records)
 #3 home care(193 records)
 #2 independent living(84 records)
 #1 personal assistance(9 records)

08 Table of methods archived for use in future updates

Issue	Method
Multiple measures	When a single study provides multiple measures of the same outcome, we will report all measures. For example, if a study includes two measures of quality of life (either measures completed by the same respondent or measures completed by different respondents), we will report both of them. If measures of an outcome are combined for meta-analysis, we will conduct multiple meta-analyses if multiple studies report multiple measures that can be combined in this way. If we conduct meta-analyses in which only one effect estimate can be used from each study, we will select one measure if it is more valid or reliable than the others. For example, if a single respondent completes both a validated scale assessing multiple domains of quality of life and an unvalidated visual analogue scale, we will select the validated scale. If a study includes several equally valid measures and only one effect estimate can be used for meta-analysis, we will calculate the average effect for this purpose (e.g. the average SMD or RR weighted by variance).
Multiple arms	If two or more eligible intervention groups are compared to an eligible control, thus requiring that the reviewers choose a single intervention group for comparison or inclusion in a meta-analysis, the most intense service or the service that best follows the goals of personal assistance (e.g., services that give users more control) will be included in the meta-analysis. If a single eligible intervention group is compared to multiple eligible control groups, 'no-treatment' controls will be chosen over other groups for comparison and inclusion in meta-analyses. For studies that do not have no-treatment condition, the most common intervention in clinical practice will be chosen to maximise the external validity of the results.
Data synthesis (Outcome data)	Meta-analyses may be conducted to combine comparable outcome measures across studies. All overall effects will be calculated using inverse variance methods. Random-effects models will be used because studies may include somewhat different treatments or populations.
Continuous data	Mean differences, standardised mean differences (SMDs) and 95% CIs will be calculated for comparisons of continuous outcome measures.
Dichotomous data	Within studies, relative risks (RRs) and 95% confidence intervals (CIs) will be calculated for comparisons of dichotomous outcome measures. Dichotomous outcome measures may be combined by calculating an overall RR and 95% CI.
Continuous outcomes	Continuous outcome measures may be combined when means and standard deviations or complete significance testing statistics are available, unless statistical tests assuming normality would be inappropriate. For example, for scales beginning with a finite number (such as 0), effect estimates will not be combined unless a mean is greater

	<p>than its standard deviation (otherwise the mean would be very unlikely to be an appropriate measure of the centre of the distribution). If continuous outcomes are measured identically across studies, an overall weighted mean difference (WMD) and 95% CI may be calculated. If the same continuous outcome is measured differently across studies, an overall standardised mean difference (SMD) and 95% CI may be calculated (Higgins 2005). SMDs will be calculated using Hedges g.</p>
Types of analyses	<p>Studies in which participants are analysed as members of the groups to which they were originally assigned (intention-to-treat analysis), studies that include only those participants who were willing or able to provide data (available-case analysis), and studies that analyse participants who adhered to the study's design (per-protocol analysis; Higgins 2005) will be analysed separately. Studies in which the reasons for excluding participants from analyses can not be determined from relevant reports or through contact with the authors will be considered with per-protocol analyses.</p>
Homogeneity	<p>The consistency of results will be assessed using the I-squared statistic (Higgins 2002; Higgins 2003). If there is evidence of heterogeneity (Q-statistic p less than or equal to 0.1 coupled with an I2 value of 25% or greater), the authors will consider sources according to pre-specified subgroup analyses and sensitivity analyses (below) but will not report an overall estimate of effect size. If heterogeneity remains within these subgroups, the review will report the results on a trial-by-trial basis, in a narrative summary.</p>
Subgroup analyses	<p>Large numbers of subgroups may lead to misleading conclusions and are best kept to a minimum (Counsell 1994; Oxman 1992; Yusuf 1991). If possible, this review will include separate effect estimates for the following subgroups:</p> <ol style="list-style-type: none"> 1) Organisation of services 2) Place of residence 3) Acquisition of impairment 4) Amount of assistance
Assessment of bias	<p>Sensitivity analyses will investigate the influence of lower quality studies (i.e., those rated C and D on allocation concealment) on the results of the review. To investigate the possibility of bias, including publication bias, funnel plots will be drawn (Deeks 2005; Egger 1997; Sterne 2001). In the event of asymmetry, the reviewers will seek input from methodologists, including the Cochrane and Campbell Collaboration Methods Groups, on appropriate analyses.</p>
Graphs	<p>When meta-analyses are performed, data will be entered into RevMan in such a way that the area to the left of the line of no effect indicates a favourable outcome for personal assistance.</p>

09 Potential Sources of Bias - Braun 1987

Category	Sequence generation	Allocation conceal	Blinding	Missing data	Selective reporting	Other
Description	<p>Unlike the populations from which they were drawn, the matched groups were not statistically different on age, orientation, ADL score, or mobility. The groups were similar in sex (28 participants per group were female), ethnicity (e.g. 22 and 21 participants were white), and marital status (e.g. 23 and 20 participants were widowed). They were less similar in living arrangement prior to entry (15 and 25 participants lived with family or friends),</p> <p>People in nursing homes had greater cognitive impairment as measured by a subsection of the Vigor, Intactness, Relationships, and Orientation (VIRO) scale (Kastenbaum 1972) and they were slightly more dependent in activities of daily living. All of the nursing home participants entered those settings through a hospital.</p>	Allocation was not concealed.	Participants, providers and researchers were aware of group assignment.	Included carer assessments for all participants and participant reported outcomes for all those who could participate; 4 personal assistance and 5 nursing home participants were unable to respond. Missing cases were evenly distributed and unlikely to correspond to outcomes.	Some measures of variance were not reported, but most results are reported clearly and completely.	

				Morbidity data were collected through chart review and it is possible that these outcomes would be better detected and/or recorded in nursing homes relative to the other settings.		
Authors' judgement	The study was not random. Participants were matched.	Inadequate	Inadequate	Incomplete data were adequately addressed.	There appeared to be little vulnerability to report bias.	

10 Potential Sources of Bias - Carlson 2007

Category	Sequence generation	Allocation conceal	Blinding	Missing data	Selective reporting	Other
Description	The report implies that randomisation was conducted by a person not connected to the administration of the measures or intervention. Randomisation created balanced groups.	The report indicates that the generation of the allocation sequence was unconnected to its administration	It would have been impossible to blind participants or personnel. Many outcomes included questions that required assessors to know a participant's allocation and it would have been practically difficult to blind them.	Data are available online (www.cashandcounseling.org); however, in current published reports, many scales with four options were collapsed to create dichotomous outcome measures of the most extreme options and data for most outcomes are not reported numerically. Minimum detectable differences are reported. Participants were excluded from certain analyses if relevant conditions were met (e.g. paid caregivers acting as proxy respondents were not asked about consumer satisfaction with care). This was designed to prevent detection biases that would overestimate programme effects and might result in biases that underestimate program impacts (e.g. impacts on informal caregivers might be biased as a result of excluding those caregivers	Most results are not reported in detail (though simplified presentation of outcomes is understandable given the number of outcomes measured). Complete study data are available online, but we have not been able to reanalyse them. The authors indicate that reported outcomes are representative of other outcomes. We have not located reports of participation outcomes, which were measured and could have been included in this review.	

				<p>who became paid caregivers). The authors sent a 26 page survey to all participating consultants (who were also involved in trials of cash and counselling for younger adults) 18 months after enrolment began, which included many open-ended questions; 37 of 50 consultants responded. This may have increased the probability of detecting problems in the intervention group and strengthens the claim that consumer-directed personal assistance is safe.</p> <p>None of the main outcomes included all participants randomised. Some outcomes were measured through program records while others were measured through client interviews or interviews with proxies. Consequently, the number of participants in different analyses at the same interval varies considerably; outcome measures included 402 and 381 participants for service use, 248 and 255 for satisfaction with paid caregivers, 308 and 373 for</p>	
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				<p>unmet needs, 374 and 368 for adverse events, and 291 and 319 for overall satisfaction with care. At nine months, survey response rates in the intervention and control groups were 86% and 81%, 62% and 60% of which were completed by proxies (19% and 1% by paid caregivers). The authors report that they attempted to contact participants in the intervention group who disenrolled from the intervention, most of whom returned to agency-directed services. Means are predicted using ordinary least squares regression or logit models.</p>		
<p>Authors' judgement</p>	<p>Sequence generation was adequate.</p>	<p>Allocation was adequately concealed.</p>	<p>The nature of the intervention prevented blinding most individuals involved. Given the nature of the assessments, this probably introduced little bias.</p>	<p>Reasons for exclusion are well-documented and logically justified. Appropriate models appear to have been used to account for missing data. Criteria for including participants in particular analyses may have impacted the results, though the resultant biases were not consistent in direction. Incomplete outcome data were adequately addressed.</p>	<p>The data may be vulnerable to reporting bias, particularly with regard to participation outcomes.</p>	

11 Potential Sources of Bias - Feldman 1996

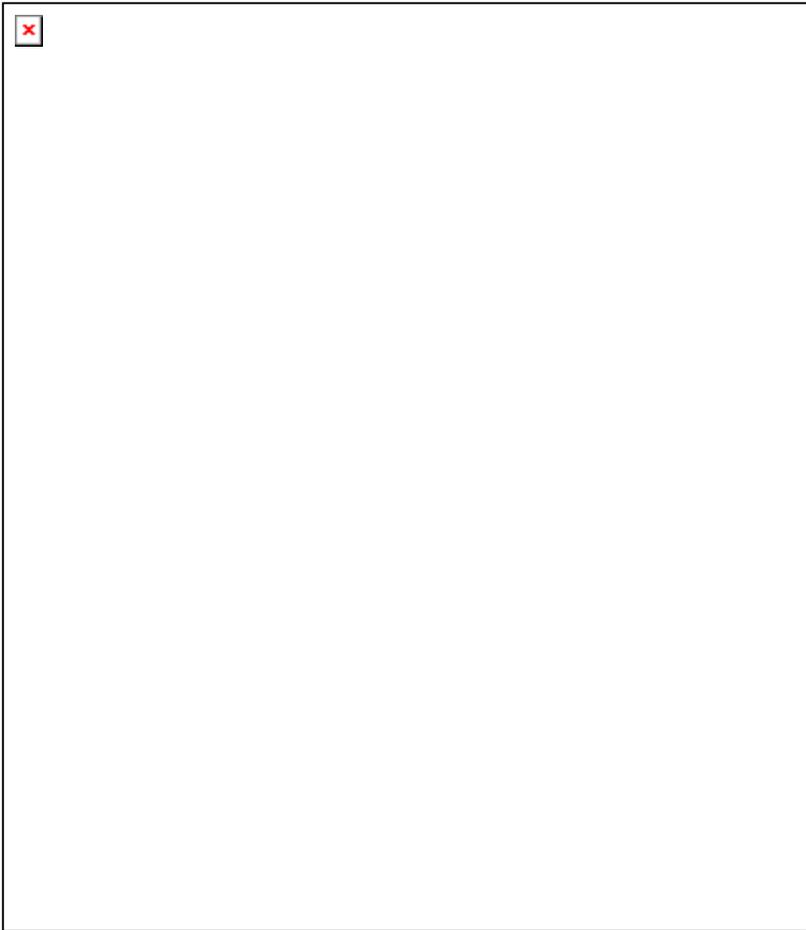
Category	Sequence generation	Allocation conceal	Blinding	Missing data	Selective reporting	Other
Description	Participants were matched and were similar on many baseline variables (including age, gender, marital status, number of children nearby, health status, and use of a wheelchair), but participants differed in race and ethnicity, problems with limbs, use of a walker, and use of a senior centre. The analyses controlled for measured differences and time trends.	Allocation was not concealed.	Participants, providers and researchers were aware of group assignment.	The authors completed follow-up interviews for 284 (70%) clients; 120 (30%) entered a long-term institution, moved or died during the study. Home care agencies were contacted for details about dropouts, but values were not imputed for these cases. No effort was made to account for missing cases.	The report is largely limited to summary statistics including regression coefficients and ORs for outcome measures; most raw data were not reported and it is difficult to independently interpret the clinical meaning of the data.	Assignment was by site. Analyses do not account for clustering.
Authors' judgement	The study was not random. Participants were matched.	Inadequate	Inadequate	Incomplete data were not adequately addressed.	There is some vulnerability to report bias.	Failure to account for clustering introduces a small risk of bias.

12 Potential Sources of Bias - Sherwod 1983

Category	Sequence generation	Allocation conceal	Blinding	Missing data	Selective reporting	Other
Description	The study was not random. The groups were different at baseline and matching participants from the pool of eligible participants was controlled by the researchers. The study reported little about the baseline characteristics of participants and their similarity on demographic variables or outcome measures.	Allocation was not concealed.	Participants, providers and researchers were aware of group assignment.	The authors report 'only sample members interviewed both at pretest and posttest were used in the analyses involving outcome variables derived from interview data' (84 intervention and 86 controls); values were not imputed for participants who died.	Though baseline data were measured, only post-test data are reported. The reviewers were unable to evaluate the effects of baseline differences on the results.	Assignment was by site. Analyses do not account for clustering.
Authors' judgement	Sequence generation was not adequate.	Inadequate	Participants, providers and researchers were aware of group assignment.	Incomplete data were not adequately addressed.	The report is vulnerable to report bias.	Failure to account for clustering introduces a small risk of bias.

Additional figures

Figure 01



Study selection flowchart

Notes

Published notes

This review is co-registered within both the Cochrane and Campbell Collaborations. A version of this review can also be found on the Campbell C2-RIPE Library.

Contact details for co-reviewers

Dr Jane A Dennis

Co-ordinator, Cochrane Developmental, Psychosocial & Learning Problems Group

School for Policy Studies

University of Bristol

8 Priory Road

Bristol

UK

BS8 1TZ

Telephone 1: +44 117 954 6782

Telephone 2: +44 117 954 6755

Facsimile: +44 117 954 6756

E-mail: j.dennis@bristol.ac.uk

URL: <http://www.bris.ac.uk/Depts/CochraneBehav/>

Secondary address:

86 Cranbrook Road

Bristol

UK

BS6 7DB

Telephone: +44 117 9446336

Dr Paul Montgomery

University Lecturer

The Centre for Evidence-Based Intervention

University of Oxford

Barnett House

32 Wellington Square

Oxford

UK

OX1 2ER

Telephone 1: +44 1865 280 325

Facsimile: +44 1865 270 324

E-mail: paul.montgomery@socres.ox.ac.uk

URL: <http://www.spsw.ox.ac.uk/cebi>