

Campbell Systematic Reviews

2008:2

First published: 20 February, 2008

Last updated: 6 May, 2008

Personal Assistance for Adults (19-64) with both Physical and Intellectual Impairments

Evan Mayo-Wilson, Paul Montgomery, Jane Dennis



THE CAMPBELL COLLABORATION

Colophon

Title	Personal assistance for adults (19-64) with both physical and intellectual impairments
Institution	The Campbell Collaboration
Authors	Mayo-Wilson, Evan Montgomery, Paul Dennis, Jane
DOI	10.4073/csr.2008.2
No. of pages	46
Last updated	6 May, 2008

Citation	Mayo-Wilson E, Montgomery P, Dennis J. Personal assistance for adults (19-64) with both physical and intellectual impairments. Campbell Systematic Reviews 2008:2 DOI: 10.4073/csr.2008.2
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	Unit for Disabilities Issues, The Swedish National Board of Health and Welfare (Socialstyrelsen), Sweden The Institute for Evidence-Based Social Work Practice, The Swedish 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 The Centre for Evidence-Based Intervention University of Oxford Barnett House 32 Wellington Square Oxford OX1 2ER United Kingdom E-mail: evan.mayo-wilson@socres.ox.ac.uk
-----------------------------	--

Campbell Systematic Reviews

Editors-in-Chief Mark W. Lipsey, Vanderbilt University, USA
Arild Bjørndal, Norwegian Knowledge Centre for the Health Services &
University of Oslo, Norway

Editors

Crime and Justice David B. Wilson, George Mason University, USA

Education Chad Nye, University of Central Florida, USA
Ralf Schlosser, Northeastern University, USA

Social Welfare Julia Littell, Bryn Mawr College, USA
Geraldine Macdonald, Queen's University, UK & Cochrane Developmental,
Psychosocial and Learning Problems Group

Managing Editor Karianne Thune Hammerstrøm, The Campbell Collaboration

Editorial Board

Crime and Justice David Weisburd, Hebrew University, Israel & George Mason University, USA
Peter Grabosky, Australian National University, Australia

Education Carole Torgerson, University of York, UK

Social Welfare Aron Shlonsky, University of Toronto, Canada

Methods Therese Pigott, Loyola University, USA
Peter Tugwell, University of Ottawa, Canada

The Campbell Collaboration (C2) was founded on the principle that systematic reviews on the effects of interventions will inform and help improve policy and services. C2 offers editorial and methodological support to review authors throughout the process of producing a systematic review. A number of C2's editors, librarians, methodologists and external peer-reviewers contribute.

The Campbell Collaboration
P.O. Box 7004 St. Olavs plass
0130 Oslo, Norway
www.campbellcollaboration.org

Personal assistance for adults (19-64) with both physical and intellectual impairments

Evan Mayo-Wilson
Paul Montgomery
Jane A Dennis



The Campbell Collaboration Social Welfare Group

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

Personal assistance for adults (19-64) with both physical and intellectual impairments

Review information

Authors

Evan Mayo-Wilson¹, Paul Montgomery¹, Jane A Dennis²

¹The Centre for Evidence-Based Intervention, University of Oxford, Oxford, UK

²School for Policy Studies, University of Bristol, Bristol, UK

Contact person

Evan Mayo-Wilson

The Centre for Evidence-Based Intervention
University of Oxford
Barnett House
32 Wellington Square
Oxford
OX1 2ER
UK

E-mail: evan.mayo-wilson@socres.ox.ac.uk

Dates

Assessed as Up-to-date:	14 June 2005
Date of Search:	14 June 2005
Next Stage Expected:	15 November 2010
Protocol First Published:	Issue 4, 2007
Review First Published:	Issue 2, 2008
Last Citation Issue:	Issue 2, 2008

What's new

Date / Event	Description
13 November 2008 Amended	Converted to new review format.

History

Date / Event	Description
29 November 2007 New citation: conclusions changed	Substantive amendment

Abstract

Background

There is a high incidence of impairments among working age adults, and their prevalence is increasing in the West. Many countries offer personal assistance in the form of 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 adults with physical and intellectual impairments, and the impacts of personal assistance on others, compared to other interventions.

Search methods

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

Adults (19-64) with permanent physical and intellectual impairments living in the community who require assistance to perform tasks of daily living (e.g., bathing and eating) and participate in normal activities. 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 and analysis

Titles and abstracts were examined by two reviewers. Outcome data were extracted. Because no two studies made the same comparison, studies were not combined for meta-analyses. Studies were assessed for bias. Results and potential sources of bias are presented for included studies.

Results

Two studies involving 1002 participants compared personal assistance versus usual care. Whilst personal assistance was generally preferred over other

services, some people prefer other services. Personal assistance may have some benefits for some recipients and may benefit caregivers. Paid assistance probably substitutes for informal care and may cost government more than alternatives; however, some evidence suggests it may reduce costs. The total costs to recipients and society are unknown.

Authors' 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, but its total cost relative to other services is unknown. When implementing new programmes, recipients could be randomly assigned to different forms of assistance (e.g. organised by individual users versus organised through a cooperative). While advocates may support personal assistance for myriad reasons, this review demonstrates that further studies are required to determine which models of assistance are most effective and efficient for particular people.

Plain language summary

Personal assistance for adults (19-64) with both physical and intellectual impairments

Personal assistance is here defined as 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 adults with both physical and intellectual impairments. A literature search identified 2 studies that met the inclusion criteria, which included 1002 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 may have 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.

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 ICIDH-2, which does not include the terms *disability* or *handicap*.

This review includes adults (19-64) with *both* physical impairments (e.g., paralysis) and intellectual impairments (which include 'learning impairments', 'learning disabilities', 'intellectual disabilities', 'mental retardation', and impairments resulting from acquired brain injuries or 'traumatic brain injury'). Intellectual impairments and physical impairments affect activities and participation differently. This is part of a series of reviews conducted with the Cochrane and Campbell collaborations; adults with physical impairments only are considered separately, as are children and older adults.

Prevalence of impairments

Previous reviews have identified inconsistencies in the measurement of impairments and activity limitations ([UN 1990](#)). In 2003, the European Year of People with Disabilities, a survey found that 16% of Europeans between 16 and 64 have a long-standing health problem or impairment and 5% of Europeans have a 'very severe' long-standing health problem or impairment ([Dupré 2003](#)), but variability in responses across nations suggested that people in different countries interpreted and responded to a standardised questionnaire differently ([Dupré 2003](#)).

As is likely to be true in any developed country, the incidence of impairment in America is highest among adults between 19 and 64 years, but the rate of impairment among working age adults is much lower than the rate among older adults (50% versus 17%; [CDC 2001a](#)). Though the working adult population is larger than the older adult population, most impairments are acquired with age. For example, the vast majority (82%) of Europeans with impairments or long standing health problems acquired their impairment after birth ([Dupré 2003](#)).

Population estimates in the U.S. and other censuses do not usually indicate the prevalence of severe impairments. People with severe intellectual impairments, particularly acquired impairments, often experience physical impairments. In the U.S., impairments are fairly common due to head or spinal cord injury (1%) and about 0.8% of working age adults experience 'mental retardation'. Americans who report difficulty with activities of daily living (8 million) represent only a quarter of those with some functional limitation (32 million; [CDC 2001b](#)). About 0.3% report difficulty eating ([CDC 2001b](#)); people who have difficulty eating are most likely require assistance and to have severe impairments ([LaPlante 2002](#)).

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

Impacts

Limited participation in activities may negatively impact 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.

Participation in activities may be limited for adults with both physical impairments and intellectual impairments when physical, social and attitudinal environments restrict their choice and involvement in activities in which they wish to take part. For example, about 11% of older working age Americans are unable to work and about 7% experience limitations in their work. Roughly 3% of younger working age Americans are unable to work and about 3.5% are limited in the amount or kind of work they can perform ([Kaye 1996](#)). Limited participation in activities may have negative impacts on other areas, including mental and physical health.

In the U.S., more than 13.2 million adults living in the community received assistance in activities of daily living (ADLs) or instrumental activities of daily living (IADLs) in 1996. Of those, most received help with only IADLs (which include items like using a telephone, preparing meals, and grocery shopping) and received 16.3 hours of assistance per week; people requiring assistance with ADLs received 57 hours of help per week.

Caring for a person with impairments can be stressful, particularly for relatives (often parents). Comorbid problems can also impact carers. For example, challenging behaviour often occurs in the context of learning impairments and mental health problems ([Moss 2000](#)) in addition to physical impairments.

Most recipients of assistance are female (65%) and less than a quarter receive paid assistance. 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](#)).

Interventions

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

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

Personal assistance

Personal assistance is paid support given 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. For example, personal assistance may be provided through agencies or through individual budgets.

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 adults (Agree 2003). People with learning impairments leaving institutions in favour of community living may prefer the latter, but they describe important positive and negative aspects of relocation ([Barber 1994](#)) that should be considered when designing and evaluating interventions. Furthermore, institutionalisation may reduce risk of mortality for people with intellectual impairments ([Strauss 1998](#)).

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 for adults (19-64) with both physical and intellectual impairments, and the impacts of personal assistance on partners, families and carers, compared to other interventions.

Methods

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

Adults (19-64) living in the community who require assistance to perform tasks of daily living (bathing, eating, getting around, etc.) due to varying levels of permanent physical and intellectual impairments (learning disability or acquired brain injury).

With the exception of people living in student accommodation (e.g. residential schools or dormitories), adults living in institutions for people with impairments were excluded.

People with physical impairments only and people with intellectual impairments only will be excluded because these impairments affect activities and participation differently.

Types of interventions

In consultation with experts and the reference group (see Acknowledgements), 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 include:

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

Secondary outcomes include:

- 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. Measures might include the Health of the Nation Outcome Scales for People with Learning Disabilities ([Roy 2002](#)).
- 3) Functional status measured using either generic or impairment-specific tools. Measures might have included the FIM Instrument ([Heinemann 1993](#); [Linacre 1994](#)), Barthel Index ([Mahoney 1965](#)) or the Patient Evaluation and Conference System ([Harvey 1981](#)).
- 4) Outwardly directed challenging behaviour. Measures might include items from

the externalising scale of the Behavior Problem Inventory ([Sturmev 1993](#)).

5) Psychological outcomes, including psychological disorders (e.g. depression), self-harm, pica (eating non-food substances), suicide and substance abuse. For example, measures might have included the PAS-ADD ([Moss 1998](#); [Prosser 1998](#)).

6) Impact on others, including family (e.g. parental) employment, satisfaction, and quality of family life.

7) Direct and indirect costs, both immediate and long-term.

Outcome intervals

Outcomes were grouped by length of follow-up.

Search methods 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 the 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)

MEDLINE

CINAHL (Cumulative Index to Nursing and Allied Health

Literature)

EMBASE

LILACs (Latin American and Caribbean Health Sciences Literature)

Social sciences databases

ASSIA (Applied Social Science Index & Abstracts)

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

C2-SPECTR (The Campbell Collaboration's Social, Psychological, Educational and Criminological Trials Register)

Dissertations Abstracts A (Dissertation Abstracts International A: The Humanities and Social Sciences)

EconLit

ERIC (Educational Resources Information Center)

PsycINFO

Sociological Abstracts

SIGLE search (System for Information on Grey Literature in Europe)

Scandinavian databases

Artikelsök

DIVA

Handicat

Hicat

LIBRIS

LIBRIS Uppsök

SveMed+

Danbib

Medline was searched 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\$ 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 [Table 1](#), [Table 2](#), [Table 3](#), [Table 4](#), [Table 5](#), [Table 6](#) and [Table 7](#)).

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)

Handikapplagstiftning

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

Psykiskt funktionshindrade (Svenska MeSH)

Psykiskt utvecklingsstörda (Svenska MeSH)

Psykiatrireformen

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 sent a letter requesting assistance in locating studies.

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.

Data collection and analysis

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 full articles were acquired and 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. 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; see also Moher 1995).

The following components are considered in the Description of Studies and in Additional Tables:

- 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 or their representatives 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 8](#), 'Table of archived methods for use in future updates'.

Results

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 independently. 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, JD and Julie Millener at the CDPLPG contacted by email or letter the 300 research organisations and 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 those who responded to this first call. In June 2006, we contacted 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.

Four prospective studies were considered for inclusion in this review; two were included.

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

Included studies

The included studies involved 1002 participants and compared personal

assistance with usual care ([Carlson 2007](#), [Sherwood 1983](#)). One was randomised ([Carlson 2007](#)).

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 - 456 in the personal assistance group and 458 in the control group - completed a baseline survey (78% by proxy, mostly parents). Most follow-up occurred nine months later.

Participants in the intervention group or their representatives were contacted by a counsellor who helped them develop spending plans, provided advice and monitored services. Personal assistance participants received more paid care than control participants, who often paid for care out of pocket (39 versus 29 hours over two weeks).

After assignment, the authors describe the intervention enrolment process as complex and discouraging; only 14% of participants received cash assistance within 3 months, 42% never received assistance, and 34% disenrolled during the following year (of whom, 91% withdrew before the assistance started). The average monthly payment at enrolment was \$1641. Of those still living in the community, 54% of the personal assistance group was receiving cash at 9 month follow-up. At 9 months, 76% and 64% of participants in the personal assistance and control groups reported receiving paid care in the previous two weeks ($p < 0.01$). They received 188 hours and 189 hours in total ($p = 0.88$), 39 and 29 of which was paid ($p < .01$). Of those who hired a worker in the first 9 months, 42% hired a worker who lived with them.

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

In [Sherwood 1983](#), personal assistance was provided to participants with intellectual impairments 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'. Groups comprised matched participants from Pennsylvania (US) counties with (44 at baseline, 43 in the analyses) and without (44 at baseline, 42 in the analyses) the intervention. Follow-up occurred approximately ten months later.

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 and these data are reported in a related review.

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 few 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.

Excluded studies

Two studies were excluded. This included two Cash and Counseling sites in Arkansas (AK) and New Jersey (NJ), which were evaluated much like the included Florida site (Carlson 2007). In AK, participants did not receive a sufficient amount of assistance. In NJ, most participants had physical impairments only and are included in a related review.

Risk of bias in included studies

In [Carlson 2007](#), the risk of bias overall was low; in [Sherwood 1983](#), there was some risk of bias, as described below and in [Table 9](#) and [Table 10](#).

Allocation bias

Participants in [Sherwood 1983](#) were allocated by site but the analyses do not account for clustering. The results may be unreliable for this and other methodological reasons, and the results were not corrected for clustering because we lacked necessary information, including cluster size and the interclass correlation coefficient.

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.

Detection bias

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 both 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 should be interpreted with caution as these refer to charges to specific government programmes.

Report bias

Both studies appeared somewhat vulnerable to report bias as detailed in Additional Tables 9 and 10.

Attrition bias

Both studies were vulnerable to attrition bias as detailed in the Additional Tables. 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. [Sherwood 1983](#) did not impute missing values.

Outcome validity

These 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).

In [Sherwood 1983](#), most data appear to have been collected by carers or agency staff. In [Carlson 2007](#), 83% and 82% of 9 month surveys were completed by proxies. The proportion of data collected by somebody other than the recipient is noteworthy because services for people with intellectual impairments can provide the 'illusion of client involvement, rather than the reality', particularly for people who have difficulty communicating verbally (Williams 2000).

Effects of interventions

Due to substantial differences between studies in intervention design, comparison groups, and assessment, no results were combined using meta-analysis. Results for each outcome are summarised below.

Primary outcomes

Quality of life

Neither study used a validated measure of quality of life. [Carlson 2007](#), used a single question to measure satisfaction with the way participants were spending their lives. In the intervention and control groups, 64% and 50% ($p < 0.01$) of participants or their representatives described the participant as 'very satisfied'.

User satisfaction

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

In [Carlson 2007](#), there were 'large' and significant relationships favouring the treatment group for satisfaction with: the relationship with the paid caregiver (working age adults were pooled with older adults in the analysis), daily living assistance (e.g. eating, dressing, toileting, transferring and bathing), 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: rude and disrespectful behaviour by a paid caregiver, paid caregivers taking something without asking (working age adults were pooled with older adults in the analysis), and paid caregiver giving unwanted help (working age adults were pooled with older adults in the analysis). In the treatment and control groups, 68% and 48% ($p < 0.01$) of participants were very satisfied with overall care arrangements.

[Sherwood 1983](#) measured satisfaction in several ways. Differences between the intervention and comparison groups were not significant for any measure, including the 'Good Place Scale' (4.39 versus 4.8; range 4 [most favourable] to 8 [least favourable]), the 'Environment Satisfaction Scale' (10.88 versus 9.27; range 4 [least favourable] to 12 [most favourable]), and a single question regarding relationships with other people (2.98 versus 2.85; range 1 to 3 with unclear direction).

Participation

Both 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 the three clinical assessment outcome measures ('Involvement Scale', outside friends, and outside interests) and there were no differences on two self-reported outcomes (attendance at religious services and 'Help Other People'). There were significant differences favouring the intervention group on two self-reported outcome measures (interest in reading papers and desiring more contact with friends).

Secondary outcomes

Unmet needs

In both studies, the personal assistance group reported fewer unmet needs than the comparison group.

In [Carlson 2007](#), there were 'modest' and significant relationships favouring the treatment group: unmet needs for help with ADLs (e.g. eating, dressing, toileting, transferring and bathing), unmet needs for help with IADLs (e.g. preparing meals, doing laundry, doing housework and doing yard work), and unmet needs for help with routine health care (e.g. medication, checking blood pressure and doing exercises). There was not a significant effect favouring the treatment group for unmet needs for help with transportation (e.g. to and from a physician's office, shopping, school, work, and social and recreational activities or neglect by a paid caregiver). In the treatment and control groups, 27% and 34% ($p=0.01$) of participants reported an unmet need with an activity of daily living.

In [Sherwood 1983](#), participants in the personal assistance group had fewer unmet needs than participants in the control group, including overall unmet needs (0.81 versus 2.55, $p<0.01$; range 1 [no need] to 5 [very high need]), though this did not apply to transportation and recreational needs (0.26 versus 0.29; range 0 [no unmet need] to 3 [3 unmet needs]).

Physical health

Though not a goal of the intervention, data suggest that that personal assistance had no comparative impact on mortality. Data on other health outcomes were

mixed, with some trends in favour of personal assistance. There was no evidence of detrimental impacts.

Mortality

In [Carlson 2007](#), about 2% of intervention participants died. Data for controls were not reported. [Sherwood 1983](#) does not report mortality directly, but relatively similar rates of loss-to-follow-up (1 and 2 participants) suggest that differences were unlikely to be significant.

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 (15 versus 18, $p=0.24$), whose contractures developed or worsened (9 versus 14, $p<0.05$) and in urinary tract infections (8 versus 12, $p<0.05$). Differences on other measures were not significant, including bedsores that developed or worsened (4 versus 6, $p=0.25$).

From a figure in [Sherwood 1983](#), we calculated that participants in the intervention group spent an average of 111 days in hospital or a long-term care setting while participants in the control group spent an average of 115 days in one of those settings.

Functional status

Direct measures of functioning suggest that personal assistance does not improve functioning. 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 were statistically significant for the 'Community Survival Scale' (12.12 versus 13.69; range 5 [poor survival skills] to 20 [good survival skills]) and the mobility scale (0.45 versus 0.17; range unclear).

Challenging behaviour

Measures of challenging behaviour were 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 significantly favoured the control group (mean 2.26 versus 2.57, $p<0.05$; range 1 [no neurosis] to 5 [psychotic]) while differences in emotional health (2.74 versus 2.79; range 1 [very depressed] to 3 [even mood]) and how the future looks (1.78 versus 1.56; range 1 [very optimistic] to 5 [very pessimistic]) were not significant.

Impact on others

[Carlson 2007](#) assessed impacts on caregivers through a caregiver survey administered 10 months after baseline. Results for caregivers of older adults and non-elderly participants were reported together. 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 attributable to the inclusion of the non-elderly group in these analyses. 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%, $p<0.01$).

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 [the intervention] led to any adverse effects on consumers' health or safety' (Shore 2007).

Costs

Some data suggest that personal assistance may save a small amount of money compared to treatment as usual, but there was little information about the true relative costs of personal assistance and other services.

[Sherwood 1983](#) provides a comprehensive estimate of the costs of personal assistance. Accounting for placements and government services, community support services and informal care, the authors report that personal assistance saved \$25.30 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. Estimated costs to Medicaid were \$27433 and \$24106 per client in the first year, \$24425 and \$21539 in the second year. Notably, these estimates do not account for costs to other agencies, charities, family and friends or consumers.

Discussion

Summary of main results

This review identifies some evidence that personal assistance recipients may express greater satisfaction and fewer unmet needs than participants receiving other services. Further data would be required to draw conclusions about impacts on health and cost. This review did not find evidence that personal

assistance reduces long-term institutional care. One trial found mixed effects on caregivers.

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. 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.

Applicability of evidence

This review included 1002 participants in two trials conducted in the U.S. More trials would be required to demonstrate if these results generalise to other countries and populations. In both studies, follow-up periods were short and this review does not provide information about the long term impacts of personal assistance.

Neither 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 somewhat different from personal assistance delivered in participants' own homes.

Cost data have limited generalisability. Data from Carlson 2007 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.

Research and service provision for people with intellectual impairments may both be limited. It has been noted that '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). For example, Askheim 2003 identified 24 users with intellectual impairments in Norway. Of those, 16 answered a survey. Askheim notes 'there are no exact official figures of how many intellectual[ly] disabled personal assistance users there are in Norway. Investigations after we did our survey show that the number is a little higher than 24.' As services like Cash and Counselling expand, which is similar to 'Direct Payments' in Britain and similar services that are expanding throughout Europe, there will be more users with intellectual impairments. The impacts of personal assistance for people with intellectual impairments should be further investigated.

Finally, participants with traumatic brain injury (TBI) were eligible, but no studies of people with TBI were included. People who acquire both physical and intellectual impairments in adulthood may differ from people with lifelong impairments; they may have families who are unaccustomed to their impairments and may react to sudden loss of functioning. Future studies might explore differences between people with recently acquired impairments and other recipients of personal assistance.

Quality of the evidence

The larger included study (Carlson 2007) has high internal validity and the second (Sherwood 1983) offers a plausible counterfactual scenario. Nonetheless, low uptake and non-response raise questions about the external validity of these results. Dropout may suggest that some people who wish to try personal assistance eventually determine they prefer other services or it may indicate that they 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 other models of support 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.

Finally, proxy interviews were used in place of direct communication for most participants. While assessments for people with intellectual impairments can provide the 'illusion of client involvement, rather than the reality' (Williams & Robinson, 2000), interviews with carers may not accurately represent the views of adults with intellectual impairments.

Authors' conclusions

Implications for practice

There have been relatively few controlled studies of personal assistance for adults with both physical and intellectual impairments who require a great deal of assistance. Existing evidence suggests that personal assistance may be 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 may have some benefits for some recipients, their friends and families; however, the relative total costs to recipients and society are unknown. 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.

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 personal assistance and other services directly, and further evaluations are required to determine the relative merits of different ways of organising assistance. 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 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 for particular people.

Acknowledgements

Special thanks to: 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 Professor Haluk Soydan and organised by the Swedish National Board of Health and Welfare (Socialstyrelsen) has been invaluable. We are particularly grateful to Knut Sundell and Karin Tengvald, Directors of IMS, for their 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 and Lydia Springer.

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.

Contributions of authors

EMW wrote the background and methods with PM and 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.

Declarations 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.

Differences between protocol and review

Published notes

This review is co-registered within the Campbell Collaboration.

Characteristics of studies

Characteristics of included studies

Carlson 2007

Methods	Allocation was random. Participants were assessed by telephone at baseline and 9 months. Carers were assessed at 10 months.
Participants	Participants had to be current users of the state's personal care benefit. Overall, 45% were female, 78% white and 21% Hispanic (regardless of race). Few (11%) lived in a rural area. Most participants were dependent in several ADLs; 52%, 64% and 78% were not independent in transferring, toileting and bathing; 54% expressed a need for more help with personal care.
Interventions	Participants received a monthly allowance that could be used to hire caregivers. Intervention participants received approximately 20 hours of paid care per week compared to 14 hours of paid care per week in the control group.

Outcomes	Quality of life User satisfaction Unmet needs Physical health Impact on others Costs
Notes	

Risk of bias table

Item	Judgement	Description
Allocation concealment?	Yes	A - Adequate

Sherwood 1983

Methods	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.
Participants	There were 44 adults in each group. Few details were provided about their characteristics. Most participants and assistants were white; 13% of program applicants and 30% of assistants were black.
Interventions	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.
Outcomes	User satisfaction Participation Unmet needs Physical health Functional status Mental health Impact on others Costs
Notes	

Risk of bias table

Item	Judgement	Description
Allocation concealment?	Unclear	D - Not used

Footnotes

Characteristics of excluded studies

Carlson 2007 (AK)

Reason for exclusion	Participants did not receive a sufficient amount of assistance.
-----------------------------	---

Carlson 2007 (NJ)

Reason for exclusion	Most participants had physical impairments only (and are included in a related review).
-----------------------------	---

Footnotes

Characteristics of studies awaiting classification

Footnotes

Characteristics of ongoing studies

Footnotes

Summary of findings tables

Additional tables

1 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

Footnotes

2 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)

Footnotes

3 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*)))

Footnotes

4 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*

Footnotes

5 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)

Footnotes

6 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)

Footnotes

7 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)

Footnotes

8 Table of methods archived for use in future updates

Issue	Method
Multiple measures	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 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.
Types of analyses	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.
Homogeneity	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

	<p>an I-squared 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>

Footnotes

9 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	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	

			<p>result of excluding those caregivers 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 older 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 thorough client interviews or interviews with proxies. Consequently, the number of participants in different analyses at the same interval varies considerably;</p>	<p>participation outcomes, which were measured and could have been included in this review.</p>	
--	--	--	--	---	--

				<p>outcome measures included 419 and 392 participants for service use, 204 and 200 for satisfaction with paid caregivers, 362 and 387 for unmet needs, 418 and 391 for adverse events, and 275 and 292 for overall satisfaction with care. At nine months, survey response rates in the intervention and control groups were 92% and 86%, 83% and 82% of which were completed by proxies (13% 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>		
Authors' judgement	Sequence generation was adequate.	Allocation was adequately concealed.	The nature of the intervention prevented blinding most individuals	Reasons for exclusion are well-documented and logically justified. Appropriate models appear to have been used to account for missing data. Criteria for including	The data may be vulnerable to reporting bias, particularly with regard to participation	

			involved. Given the nature of the assessments, this probably introduced little bias.	participants in particular analyses may have impacted the results, though the resultant biases were not consistent in direction. Incomplete outcome data were adequately addressed.	outcomes.	
--	--	--	--	---	-----------	--

Footnotes

10 Potential Sources of Bias - Sherwood 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' (43 intervention and 42 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.

Footnotes

References to studies

Included studies

Carlson 2007

Published and unpublished data

Brown RS, Dale SB. The research design and methodological issues for the cash and counseling evaluation. *Health Services Research* 2007;42(1):414-45.

* Carlson BI, Foster L, Dale SB, Brown R. Effects of cash and counseling on personal care and well-being. *Health Services Research* 2007;42(1):467-87.

Dale SB, Brown RS. How does cash and counseling affect costs? *Health Services Research* 2007;42(1):488-509.

Foster L, Dale SB, Brown R. How caregivers and workers fared in cash and counseling. *Health Services Research* 2007;42(1):510-32.

Schore J, Foster L, Phillips B. Consumer enrollment and experiences in the cash and counseling program. *Health Services Research* 2007;42 (1 S1):DOI: 10.1111/j.475-6773.2006.00679.x.

Sherwood 1983

Ruchlin HS, Morris JN. Pennsylvania's domiciliary care experiment: II. Cost-benefit implications. *American Journal of Public Health* 1983;73(6):654-60.

* Sherwood S, Morris JN. The pennsylvania domiciliary care experiment: I. Impact on quality of life. *American Journal of Public Health* 1983;73(6):646-53.

Excluded studies

Carlson 2007 (AK)

Carlson BI, Foster L, Dale SB, Brown R. Effects of cash and counseling on personal care and well-being. *Health Services Research* 2007;42(1):467-87.

Carlson 2007 (NJ)

Carlson BI, Foster L, Dale SB, Brown R. Effects of cash and counseling on personal care and well-being. *Health Services Research* 2007;42(1):467-87.

Studies awaiting classification

Ongoing studies

Other references

Additional references

Abberley 1987

Abberley P. The concept of oppression and the development of a social theory of disability. *Disability and Handicap in Society* 1987;2:5-19.

Askheim 2003

Askheim OP. Personal assistance for people with intellectual impairments. *Disability & Society* 2003;18(3):325-39.

Barber 1994

Barber JG, Cooper BK, Owen L. The short-term effects of relocation on the intellectually disabled. *Research on Social Work Practice* 1994;4(2):248-58.

CDC 2001a

Centers for Disease Control and Prevention. Prevalence of disabilities and associated health conditions among adults-United States, 1999. *JAMA* 2001;285(12):1571-2.

CDC 2001b

Centers for Disease Control and Prevention. Prevalence of disabilities and associated health conditions among adults-United States, 1999. *Morbidity and Mortality Weekly Report* 2001;50(7):120-5.

Colver 2005

Colver A. A shared framework and language for childhood disability. *Developmental Medicine and Child Neurology* 2005;47:780-4.

Counsell 1994

Counsell C, Clarke M, Slattery J, Sandercock P. The miracle of DICE therapy for acute stroke: fact or fictional product of subgroup analysis? *BMJ Clinical Research* 1994;309(6970):1677-81.

Dane 1998

Dane A, Schneider B. Program integrity in primary and early secondary prevention: Are implementation effects out of control? *Clinical Psychology Review* 1998;18:23-45.

Deeks 2003

Deeks J, Dinnes J, D'Amico R, Sowden A, Sakarovitch C, Song F, et al. Evaluating non-randomised intervention studies. *Health Technology Assessment* 2003;7(27):1-173.

Deeks 2005

Deeks J, Macaskill P, Irwig L. The performance of tests of publication bias and other sample size effects in systematic reviews of diagnostic test accuracy was assessed. *Journal of Clinical Epidemiology* 2005;58(9):882-93.

Delgado 2004

Delgado Rodriguez M, Llorca J. Bias. Journal of Epidemiology and Community Health 2004;58(8):635-41.

Dupré 2003

Dupré D, Karjalainen A. European Union. Luxembourg: EuroStat, 2003 (25 Nov).

Egger 1997

Egger M, Davey Smith G, Schneider M, Minder C. Bias in meta-analysis detected by a simple, graphical test. BMJ Clinical Research 1997;315(7109):629-34.

Harvey 1981

Harvey RF, Jellinek HM. Functional performance assessment: a program approach. Archives of Physical Medicine and Rehabilitation 1981;62(9):456-60.

Heinemann 1993

Heinemann AW, Linacre JM, Wright BD, Hamilton BB, Granger C. Relationships between impairment and physical disability as measured by the functional independence measure. Archives of Physical Medicine and Rehabilitation 1993;74(6):566-73.

Higgins 2002

Higgins J, Thompson S. Quantifying heterogeneity in a meta-analysis. Statistics in Medicine 2002;21(11):1539-58.

Higgins 2003

Higgins J, Thompson S, Deeks J, Altman D. Measuring inconsistency in meta-analyses. BMJ Clinical Research 2003;327(7414):557-60.

Higgins 2005

Higgins JPT, Green S, editors. Cochrane Handbook for Systematic Reviews of Interventions 4.2.5 [updated May 2005]. In: The Cochrane Library, Issue 3. Chichester, UK: John Wiley & Sons, Ltd, 2005.

Jackson 2005

Jackson N, Waters E. Criteria for the systematic review of health promotion and public health interventions. Health Promotion International 2005;20(4):367-74.

Juni 2001

Juni P, Altman DG, Egger M. Systematic reviews in health care: Assessing the quality of controlled clinical trials. BMJ Clinical Research 2001;323(7303):42-6.

Kaye 1996

Kaye H, LaPlante M, Carlson D, Wenger B. Trends in disability rates in the United States, 1970-1994. Disability Statistics Abstracts 1996;17:1-6.

Keigher 2000

Keigher S. The interests of three stakeholders in independent personal care for disabled elders. Journal of Health & Human Services Administration 2000;23(2):136-80.

LaPlante 2002

LaPlante MP, Harrington C, Kang T. Estimating paid and unpaid hours of personal assistance services in activities of daily living provided to adults living at home. Health Services Research 2002;37(2):397-415.

Linacre 1994

Linacre JM, Heinemann AW, Wright BD, Granger CV, Hamilton BB. The structure and stability of the Functional Independence Measure. Archives of Physical Medicine and Rehabilitation 1994;75(2):127-32.

Mahoney 1965

Mahoney F, Barthel D. Functional evaluation: The Barthel Index. Maryland State Medical Journal 1965;14:61-5.

Moher 1995

Moher D, Jadad AR, Nichol G, Penman M, Tugwell P, Walsh S. Assessing the quality of randomized controlled trials: An annotated bibliography of scales and checklists. Controlled Clinical Trials 1995;16(1):62-73.

Moher 1999

Moher D, Cook D, Eastwood S, Olkin I, Rennie D, Stroup D. Improving the quality of reports of meta-analyses of randomised controlled trials: the QUOROM statement. Lancet 1999;354:1896-900.

Morris 2001

Morris J. Impairment and Disability: Constructing an Ethics of Care That Promotes Human Rights,. Hypatia 2001;16(4):1-16.

Moss 1998

Moss S, Prosser H, Costello H, Simpson N, Patel P, Rowe S et al. Reliability and validity of the PAS-ADD Checklist for detecting psychiatric disorders in adults with intellectual disability. Journal of Intellectual Disability Research 1998;42(2):173-83.

Moss 2000

Moss S, Emerson E, Kiernan C, Turner S, Hatton C, Alborz A. Psychiatric symptoms in adults with learning disability and challenging behaviour. *British Journal of Psychiatry* 2000;177:452-6.

MRC 2000

MRC. A framework for development and evaluation of RCTs for complex interventions to improve health. Medical Research Council 2000.

Nosek 1991

Nosek M. Personal Assistance Services: A Review of Literature and Analysis of Policy Implications. Houston TX: Department of Physical Medicine and Rehabilitation, Baylor College of Medicine, 1991.

Oliver 1990

Oliver M. The politics of disablement. London: Macmillan, 1990.

Oxman 1992

Oxman A, Guyatt G. A consumer's guide to subgroup analyses. *Annals of Internal Medicine* 1992;116(1):78-84.

Pijl 2000

Pijl M. Home care allowances: Good for many but not for all. *Practice* 2000;12(2):55-65.

Prosser 1998

Prosser H, Moss S, Costello H., Simpson N, Patel P, Rowe S. Reliability and validity of the Mini PAS-ADD for assessing psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research* 1998;42(4):264-72.

Ratzka 1986

Ratzka A. Independent living and attendant care in Sweden: A consumer perspective: Monograph no. 34. New York: World Rehabilitation Fund, 1986.

Riemsma 2001

Riemsma R, Forbes C, Glanville J, Eastwood A, Kleijnen J. General health status measures for people with cognitive impairment: learning disability and acquired brain injury. *Health Technology Assessment* 2001;5(6):1-100.

Roy 2002

Roy A, Matthews H, Clifford P, Fowler V, Martin DM. Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD). *British Journal of Psychiatry* 2002;180:61-6.

Socialstyrelsen 2005

Socialstyrelsen. Personlig assistans. En inventering av forskningslaget (Swedish). [Personal assistance. An overview of research]. Stockholm: The Swedish National Board of Health and Welfare (Socialstyrelsen), 2005.

Sterne 2001

Sterne J, Egger M. Funnel plots for detecting bias in meta-analysis: guidelines on choice of axis. *Journal of Clinical Epidemiology* 2001;54(10):1046-55.

Strauss 1998

Strauss D, Shavelle R, Anderson TW, Baumeister A. External causes of death among persons with developmental disability: the effect of residential placement. *American Journal of Epidemiology* 1998;147(9):855-62.

Sturmey 1993

Sturmey P, Fink C, Sevin J. The Behavior Problem Inventory: A replication and extension of its psychometric properties. *Journal of Developmental and Physical Disabilities* 1993;5(4):327-36.

UN 1990

UN. Disability Statistics Compendium (Statistics on Special Population Groups). Department of International Economic and Social Affairs Statistical Office, United Nations 1990.

Ware 1992

Ware J, Sherbourne C. The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical Care* 1992;30(6):473-483.

WHO 2003

WHO. International classification of functioning, disability and health. Geneva: World Health Organization, 2003.

Yusuf 1991

Yusuf S, Wittes J, Probstfield J, Tyroler HA. Analysis and interpretation of treatment effects in subgroups of patients in randomized clinical trials. *JAMA* 1991;266(1):93-8.

Zarb 1994

Zarb G, Nadash P. Direct payments for personal assistance. Findings: Social Policy Research 1994;64.

Other published versions of this review

Classification pending references

Data and analyses

Figures

Sources of support

Internal sources

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

External sources

- 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

Feedback

Appendices