

# **Title**

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

## **Reviewers**

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## **Contribution of reviewers**

EMW wrote the background and methods with PM and JD. JD developed the search strategy with EMW and PM.

## **Internal sources of support**

None

## **External sources of support**

Unit for Disabilities Issues, The National Board of Health and Welfare (Socialstyrelsen), SWEDEN  
The Institute for Evidence-Based Social Work Practice, The National Board of Health and Welfare  
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## **What's new**

### **Dates**

Date review re-formatted: //

Date new studies sought but none found: //

Date new studies found but not yet included/excluded: //

Date new studies found and included/excluded: //

Date reviewers' conclusions section amended: //

Date comment/criticism added: //

Date response to comment/criticisms added: //

## **Text of review**

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# 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 will include adults (19-64) with physical impairments. Intellectual impairments and physical impairments affect activities and participation differently. Therefore, adults with both physical and intellectual impairments, children and older adults will be considered in other Cochrane and Campbell reviews.

## Prevalence of impairments

Around the world, about six hundred million people have impairments ([UN 1990](#)), most of whom live in the developing world. 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 18 and 65 years, but the prevalence 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 of Europeans with impairments or long standing health problems (82%) acquired their impairment after birth ([Dupré 2003](#)).

Gross rates of impairments in the United States (U.S.) have increased substantially in recent decades as a result of an aging population that is living longer and, more recently, as a result of higher reported levels of impairments among children and young adults ([Kaye 1996](#)). However, population estimates in the U.S. and other censuses do not usually indicate the prevalence of severe impairments. Among Americans over 18 years, arthritis and back problems are the most common types of impairments (18% and 17% respectively; [[CDC 2001b](#)]). Causes of severe limitations are less frequent, including head or spinal cord injury (1%), paralysis (0.8%) and missing limbs (0.7%; [[CDC 2001b](#)]). 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 2% of Americans between 18 and 65 years (3.5 million) report some difficulty with activities of daily living ([CDC 2001b](#)). About 0.3% of working age adults (0.5 million) 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.

## **Consequences**

A discourse of disability ethics has evolved to discuss concepts of independence, defined not as people with disabilities "doing everything" for themselves, but as having maximum control over how help is provided ([Morris 2001](#)).

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 physical impairments when physical, social and attitudinal environments restrict their 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 ([Kaye 1996](#)). 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. Most recipients are female (65%) and less than a quarter receive paid assistance ([LaPlante 2002](#)). More than 20 billion hours of assistance are provided each year in the U.S., estimated to be worth \$200 billion at 1996 prices ([LaPlante 2002](#)).

## **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 impairments. For example, building codes may require that people who use assistive devices can access offices and shopping malls. Clinicians and policymakers can work together to influence policy, discourse, and planning and to apply the social model in support of adults with physical 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, physical therapy, education, and human support help people control their lives appropriately and engage in normal activities.

## **Personal assistance**

### *Purpose*

Personal assistance is support given to people with physical impairments living in normal housing (e.g. apartments or family homes) to enable them to participate in mainstream activities in various

settings. Personal assistance is directed by users and is designed to promote independence and to reduce strain on families. Assistants might help with bathing, dressing, moving around during the day, shopping, etc. Personal assistance is provided by non-professionals; it 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.

#### *Funding and control*

Personal assistance may be purchased by governments, insurance providers, or individuals. It may be provided directly or indirectly through payments or vouchers.

Personal assistance differs from voluntary or charitable services, over which users do not have the same control. It also differs from respite care, which is temporary and aims to help carers rather than individuals with impairments.

#### *Amount and duration*

Personal assistance is designed for people whose participation in many normal activities would be impossible without help. While user needs should be assessed periodically, personal assistance is designed for people with permanent impairments. For example, the needs of a person with a recently acquired impairment might be different from the needs of a person who has had an impairment from birth and the needs of both might change; personal assistance would be designed to meet their unique needs and would develop with them. In this way, it differs from rehabilitative services and from services provided for fixed periods of time.

Receipt of personal assistance is dependent on the amount of help required by an individual. For example, personal assistance in Nordic countries is generally provided to people requiring at least 20 hours of help per week, though most users have severe impairments and both require and receive substantially more assistance.

#### *Provision*

Some form of personal assistance is now available (often by statutory right) in all Nordic countries, most Western European countries, Australia, parts of Asia, Canada, and the U.S. Services in different countries for different users are called by different names, which often relate to legislative categories rather than types of interventions.

Eligibility varies around the world. For example, countries that see services for adults as a 'right' may not be able or willing to provide comprehensive services for children and older adults. Services for people of different ages may be provided through different mechanisms.

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.

Differences in eligibility affect the number and types of people who receive support and these differences affect the amount and types of support individuals and their families receive. That is, the relative number of people receiving personal assistance and their characteristics vary across countries, insurance schemes, etc.

Advocates of personal assistance argue that personal assistants should be chosen, trained and managed by users. 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.

### **Previous studies**

Compared to other interventions, personal assistance may have unique benefits and potential drawbacks. Assistants may help people achieve more professionally, but having a personal assistant at work could be stigmatising. People with physical impairments might be relieved to have assistants, but assistants might interfere with family life and with users' need for privacy. Compared to other ways of compensating for particular activity limitations, personal assistance may create unnecessary dependencies for some people. People may prefer to use assistive devices to complete activities of daily living rather than receive help in performing those tasks ([Verbrugge 1997](#)).

Even if personal assistance is clearly preferred over other services by many working adults with physical impairments, groups that are underrepresented in the public discourse about the rights of people with impairments (e.g., people in rural areas and people with difficulties communicating) may prefer other services, particularly since these groups may be more susceptible to abuse and less able to manage employees. 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](#)).

While many personal assistants are managed by users or their representatives, the nature of personal assistance can make it difficult to separate the roles that individuals play in supporting people with impairments. For example, Askheim identified one mother of a child with intellectual impairments in Norway who acted both as the manager of her child's payments and as a full-time personal assistant ([Askheim 2003](#)). Similarly, partners of adults with impairments might have mixed roles. Policies that permit different care arrangements may have substantially different impacts.

As the personal assistance movement gained strength, 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](#)). Some research now suggests that personal assistance may meet otherwise unmet needs of people with impairments. Shortly after its introduction, a survey of direct payment recipients in the UK found that 40% had a need for additional hours of personal service while 80% of people receiving other services had a similar need ([Zarb 1994](#)). There have been non-systematic reviews 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 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 physical impairments, and the impacts of personal assistance on partners, families and carers, compared to other interventions.

# Criteria for considering studies for this review

## Types of studies

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

## Types of participants

Adults (19-64) living in the community who require assistance to perform tasks of daily living (bathing, eating, getting around, etc.) due to permanent physical impairments.

With the exception of people living in student accommodation (e.g. residential schools or dormitories), adults living outside their own homes (e.g., in private or public institutions for people with impairments) will be excluded.

Adults with intellectual impairments will be excluded because these impairments affect activities and participation differently.

## Types of interventions

Personal assistance is paid individualised human support that is designed to promote participation of people with permanent impairments. In consultation with experts and the reference group, the reviewers sought to determine what minimal amount of assistance would could be offered and still follow the personal assistance model for this population. For inclusion in this review, personal assistance must have been delivered for at least 20 hours per week.

Comparisons might include, either singly or in combination, less intense interventions (e.g. homemaker services providing an hour a day of help), informal care (which might be delivered by partners or other family members), institutionalisation, service housing (cluster housing), on-demand services, night patrols, escort services, and other alternatives to personal assistance. 'No-treatment' and 'waiting list' groups will be included even if other services received are no described. These will be treated as separate comparisons.

Studies examining different forms of personal assistance (e.g., assistance organised by users compared to assistance organised by others) will be included in the review, though these comparisons will be discussed separately as the outcomes from such studies would not indicate the effectiveness of personal assistance relative to other interventions.

## Types of outcome measures

Primary outcomes will include:

1) Global quality of life, both (a) generic measures (e.g., the Short-Form Health Survey (SF-36; [Ware 1992](#)) and (b) impairment specific measures. Generic QOL measured are often appropriate for people with physical impairments ([Meyers 2000](#)).

- 2) User satisfaction. For example, measures might include the Client Satisfaction Inventory ([McMurtry 2000](#)).
- 3) Participation, including sense of control, employment, social life, sexual participation, ability to engage in spontaneous activities, time outside the home, and mobility. For example, measures might include the Craig Handicap Assessment and Reporting Technique (Whiteneck 1992).

Secondary outcomes will include:

- 1) Unmet needs, particularly the inability to perform activities of daily living.
- 2) Health outcomes, including direct measures of muscle strength, disease, injuries, abuse or pain and indirect measures such as hospitalisation, emergency room visits or need for institutionalisation.
- 3) Functional status measured using either generic or impairment-specific tools. Measures might include the FIM Instrument ([Heinemann 1993](#); [Linacre 1994](#)), Barthel Index ([Mahoney 1965](#)) or the Patient Evaluation and Conference System ([Harvey 1981](#)).
- 4) Psychological outcomes, including psychological disorders (e.g., anxiety and depression), self-harm, suicide and substance abuse. Generic measures are likely to be appropriate for adults with physical impairments ([Meyers 2000](#)) and might include the Beck Depression Inventory ([Beck 1961](#)) or the STAI ([Spielberger 1983](#)).
- 5) Impact on others, including family (spousal and parental) employment, satisfaction, and quality of family life.
- 6) Direct and indirect costs, both immediate and long-term.

### **Outcome intervals**

To account for the changing impacts of impairments, outcomes will be grouped by length of follow-up (e.g., 1-3 years, 4-6 years, 6+ years).

The organisation of services is often a complicated task and new users or their representatives must train personal assistants. Outcomes measured during the first year of receiving personal assistance will be considered apart from outcomes measured after one or more years to account for this adjustment period, which may not be representative of personal assistance as a whole.

## **Search strategy for identification of studies**

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

### **I. Electronic search**

Databases will be searched for published and unpublished studies. All electronic searches will be 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 believe it is extremely unlikely that any relevant trials were conducted before 1980.

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

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

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

The following databases will be 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 will be 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 will be used to search other databases.

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

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

## **II. Personal communications**

Appropriate government departments, non-governmental organisations, non-profit groups, advocacy groups, user groups, and experts in the field will be contacted and listed in an appendix to the review. These approaches and any replies will be documented by the authors. Additionally, impairment-oriented email lists (list-servs) will be sent a letter requesting assistance in locating studies.

The reviewers will contact 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 will be searched.

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

# **Methods of the review**

## **Trial selection strategy**

From the resultant list of articles, outcome evaluations about people with impairments will be identified through electronic and hand searches. Two authors (EMW and PM) will check titles for relevance. When a title appears potentially relevant, both authors will examine the abstract. If one author feels an abstract might be relevant, the full article will be obtained. Two authors will examine the remaining papers to determine eligibility. Study authors will be contacted if further information could resolve initial disagreements about inclusion. Remaining disagreements will be discussed with the third reviewer (JD). If a consensus cannot be reached, the Coordinating Editor of the CDPLPG will be consulted. A flowchart of the process of trial selection will be made in accordance with the QUORUM statement ([Moher 1999](#)).

## **Data management**

### *Data extraction*

Data extraction will be conducted independently by two authors (EMW and PM) using a specially developed data extraction form.

### *Data collection*

When more than two treatment arms are included in the same trial, all arms will be described.

The following data will be 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;
- 4) Outcome measures listed above.

The following data will be collected for all studies:

- 1) Programme differentiation ([Dane 1998](#); [MRC 2000](#)), including crossover between groups and the differences between the interventions received; and
- 2) Context.

### *Methodological quality*

Two reviewers (EMW and PM) will independently assign 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)
- (D) random allocation not used.

Studies in all quality categories will be 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 will be described in the description of studies to identify differences between intervention and control groups that may have existed at baseline.

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

The following components will be considered in the description of studies:

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

### *Multiple arms*

All eligible outcome measures for all trial arms will be reported in the review.

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.

#### *Multiple measures*

When a single study provides multiple measures of the same outcome, we will report all measures. For example, if a study includes two measures of quality of life (either measures completed by the same respondent or measures completed by different respondents), we will report both of them. If measures of an outcome are combined for meta-analysis, we will conduct multiple meta-analyses if multiple studies report multiple measures that can be combined in this way. If we conduct meta-analyses in which only one effect estimate can be used from each study, we will select one measure if it is more valid or reliable than the others. For example, if a single respondent completes both a validated scale assessing multiple domains of quality of life and an unvalidated visual analogue scale, we will select the validated scale. If a study includes several equally valid measures and only one effect estimate can be used for meta-analysis, we will calculate the average effect for this purpose (e.g. the average SMD or RR weighted by variance).

#### *Missing data*

When necessary, the corresponding author will be contacted to supply any unreported data (e.g., group means and standard deviations (SDs), details of dropouts, and details of interventions received by the control group). Other authors will be contacted if necessary. If a study reports outcomes only for participants completing the trial or only for participants who followed the protocol, authors will be contacted and asked to provide additional information to permit an intention-to-treat analyses.

### **Data synthesis**

#### *Outcome data*

RevMan 4.2 will be used to perform the following calculations.

Within studies, relative risks (RRs) and 95% confidence intervals (CIs) will be calculated for comparisons of dichotomous outcome measures. Mean differences, standardised mean differences (SMDs) and 95% CIs will be calculated for comparisons of continuous outcome measures.

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.

Dichotomous outcome measures may be combined by calculating an overall RR and 95% CI.

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  $I^2$  statistic ([Higgins 2002](#); [Higgins 2003](#)). If there is evidence of heterogeneity (Q-statistic  $p$  less than or equal to 0.1 coupled with an  $I^2$  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.

#### **Subgroup analyses**

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:

##### 1) *Organisation of services*

Personal assistance organised by users (e.g., through direct payment schemes) will be considered apart from personal assistance organised and managed by others (e.g., social workers or government agencies).

##### 2) *Place of residence*

The review will report separate effects for people living with their families and people living alone separately.

##### 3) *Acquisition of impairment*

Separate effects will be reported for people who had impairments from birth, who have long-standing impairments, and who recently acquired impairments.

##### 4) *Amount of assistance*

The number of hours of assistance received per week is related to user needs, which are determined by social context, the availability of other services, severity of impairments, etc. Separate effect estimates will be reported for users receiving different levels of assistance (e.g., 20-50 hours, 51-80 hours, more than 80 hours).

## **Assessment of bias**

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.

## **Graphs**

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.

## **Description of studies**

## **Methodological quality of included studies**

## **Results**

## **Discussion**

## **Reviewers' conclusions**

## **Implications for practice**

## **Implications for research**

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# Notes

## Unpublished CRG notes

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## Published notes

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