

Title

Personal assistance for children and adolescents (0-18) with intellectual 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 (Socialstyrelsen), SWEDEN

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: //

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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](#)). Though the ICIDH-2 refers to adults, 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 children and adolescents with intellectual impairments, which include learning impairments (e.g., Down's syndrome, global developmental delay, or pervasive developmental disorder), learning disability (also called 'intellectual disability' or 'mental retardation') and acquired brain injuries. Intellectual impairments and physical impairments affect activities and participation differently; interventions would aim to achieve different outcomes. Therefore, young people with physical impairments or both physical impairments and intellectual impairments will be considered in other Cochrane and Campbell reviews, as will working-age adults and older adults.

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](#)) and cross-national estimates of impairments and activity limitations in childhood and adolescence are even more variable than national estimates.

The prevalence of intellectual impairments is difficult to quantify due to problems in diagnosis and classification. Most children and adolescents with intellectual impairments have mild to moderate impairments. Relatively few have 'profound' impairments (DSM-IV R). Over five million (10.6%) American children and adolescents experience a limitation in learning ability; respectively, about 4.0% and 3.2% have moderate and severe limitations ([Hogan 1997](#)).

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). Recent increases in the prevalence of impairments among children and adolescents may be a result of changes in medical care. For example, very low birthweight babies are more likely than ever to survive ([Alberman 1991](#); [Allen 1993](#); [Doyle 1995](#)). These children are at high risk of both physical impairments and intellectual impairments ([Middle 1996](#); [Williamson 1983](#); [Wilson-Costello 2005](#)).

Over six million (12.3%) American children and adolescents experience some type of functional limitation (as defined by ([Hogan 1997](#))). Of the four million American children and adolescents who experience one serious functional limitation, about half experience one or more other functional limitations. About one million American children and adolescents experience serious limitations in two or more areas ([Hogan 1997](#)). Impairments are more prevalent in boys than in girls ([Newacheck 2004](#)) and more prevalent in low-income families than in high-income families ([Newacheck 2004](#); [UN 1990](#)).

Of non-institutionalised children and adolescents aged 5-17, 1.3% experience limitations in mobility and about .2% experience a moderate or severe limitation in mobility. Respectively, .9% and .5% experience limitations in self care; 5.5% and 1.2% experience limitations in communication ([Hogan 1997](#)). About 3.2% of American children attend special schools or classes ([Wenger 1995](#)).

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., allowing sufficient time between activities for children with impairments to toilet), the social model emphasises changes in public attitudes towards impairments to encourage increased participation and improved self-esteem.

Participation in age-appropriate activities may be limited for children and adolescents with impairments when social and attitudinal environments restrict their involvement ([Hammal 2004](#); [Mihaylov 2004](#)). Impairments in children are related to societal limitation, and different types of impairments contribute uniquely to societal limitations ([Hogan 1997](#)). Impairments may affect the quality of life, health, development, and family functioning of children and adolescents ([Neely-Barnes 2004](#); [Pit-Ten 2002](#); [Varni 2005](#)). Limited participation in activities may have negative impacts on the mental and physical functioning of children and adolescents and may lead to emotional and behavioural problems.

Children and adolescents with intellectual impairments are at increased risk for mental health problems; however, most children and adolescents who might benefit from psychological services do not receive them ([Witt 2001](#)). Comorbid problems can also impact carers. For example, challenging behaviour often occurs in the context of learning impairments and mental health problems ([Moss 2000](#)). Parents and siblings of children with impairments are at risk for psychological problems ([Rossiter 2001](#); [Sharpe 2002](#); [Thyen 1998](#)).

Total healthcare costs for children and adolescents with impairments may be four times greater than for those without impairments ([Newacheck 2004](#)). However, children and adolescents with impairments require varying degrees of support. For example, in one large study, 'those in the upper decile of the expenditure distribution accounted for 65% of all charges'. Costs born by families of children and adolescents with the most severe impairments were similarly high; out-of-pocket healthcare expenses (i.e. those not reimbursed by insurance or a health service) for the top 10% of the distribution accounted for 85% of all out of pocket expenses ([Newacheck 2004](#)).

All children and adolescents require some level of care. However, children and adolescents with severe impairments may require many hours of assistance every day in addition to the normal assistance required by their peers. Consequently, family members (notably mothers) may withdraw

from work and social life. Caring for a child with severe impairments can put great financial and emotional stress on parents and families ([Neely-Barnes 2004](#); [Witt 2001](#)).

In the U.S., parents of children with impairments are less likely to have attended college and more likely to be single and poor ([Hogan 1997](#)). The stress of caring for children with impairments may have negative impacts on parents, but some problems associated with impairments may increase the risk of impairment. For example, poor children are less likely than their peers to receive preventive healthcare (Newacheck 1988) and depressed mothers are less likely than other mothers to use injury prevention strategies like car seats and electrical plug covers ([McLennan 2000](#)). Furthermore, some evidence suggests that the development of intellectual impairments is affected by sociodemographic factors ([Resnick 1998](#)). Low birthweight black babies are more likely than white babies to survive ([Morse 2006](#)), which might affect the relative prevalence of impairments in different racial groups; however, 'controlling for socioeconomic differences and family structure, black children are no more at risk of functional limitation than whites' ([Hogan 1997](#)). Since the causes and consequences of impairments are often difficult to disentangle, retrospective studies are difficult to interpret.

Interventions

Increased participation (inclusion in activities of daily life) may have positive effects on the social functioning, development, and health of children and adolescents.

There are many ways to increase participation by children and adolescents with intellectual impairments. For example, social activities may be designed such that children and adolescents with intellectual impairments can engage in age-appropriate activities with their peers. Clinicians and policymakers can work together to influence policy, discourse, and planning and to apply the social model in support of children and their families ([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. Skills training, education, and human support help young people control their lives appropriately and engage in normal activities.

Personal assistance

Purpose

Personal assistance is support given to children and adolescents with impairments living in normal housing (e.g. family homes or school accommodation) to enable them to participate in mainstream activities in various settings. Personal assistance is directed by users and their representatives 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 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., parents) 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 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.

Previous studies

Compared to other interventions, personal assistance may have unique benefits and potential drawbacks. Assistants may increase social participation for many people, but having a personal assistant could be stigmatising. Parents of children with impairments might be relieved to have assistants help care for their children, but assistants might interfere with family life and with users' need for privacy, or with parents' own needs to see themselves as adequate carers for their children.

Even if personal assistance is clearly preferred over other services by working adults with physical impairments, groups that are underrepresented in the public discourse about the rights of people with impairments (e.g., children, older adults, people with intellectual impairments, and people in rural areas) 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 children and families who have difficulty finding an assistant, administering services, negotiating or giving instructions ([Pijl 2000](#)).

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](#)). 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](#)). 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 children and adolescents (0-18) with intellectual impairments, and the impacts of personal assistance on 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

Children and adolescents (0-18) living in the community who require assistance to perform tasks of daily living (bathing, eating, getting around, etc.) and participate in normal activities due to permanent intellectual impairments.

Young people living outside their own homes (e.g., in private or public institutions for people with impairments) will be excluded.

Children and adolescents with physical 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, family care, institutionalisation, on-demand services, 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 Pediatric Quality of Life Inventory; [[Varni 2005](#)]) and (b) specific measures designed for children with particular impairments. Though well-validated measures for the general population will be considered, a review of global health measures found that 'very few measures have been validated specifically for cognitively impaired respondents' ([Riemsma 2001](#)).
- 2) User satisfaction. Direct reports will be preferred, though proxies might be used if users are unable to communicate.
- 3) Participation, including social activities, ability to participate in spontaneous activities, time outside the home, and mobility.

Secondary outcomes will include:

- 1) Unmet needs, particularly the inability to perform activities of daily living.
- 2) Developmental outcomes, including cognitive milestones and acquisition of skills.
- 3) Health outcomes, including direct measures of muscle strength, disease, injuries, abuse or pain and indirect measures such as nutrition, emergency room visits or need for hospitalisation or institutionalisation.
- 4) Psychiatric outcomes, including self-harm, pica (eating non-food substances), and outwardly directed challenging behaviour. Measures might include items from the externalising scale of the Behavior Problem Inventory ([Sturmeijer 1993](#)).
- 5) Impact on others, including parental (maternal) employment, satisfaction, and quality of family life. For example, measures might include the Short-Form Health Survey (SF-36; ([Ware 1992](#))) or General Health Questionnaire (GHQ; ([Counsell 1994](#))).
- 6) Direct and indirect costs, both immediate and long-term.

Outcome intervals

To account for normal development and 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)

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 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, 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 user representatives (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) Acquisition of impairment

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

3) 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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Potential conflict of interest

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Notes

Published notes

This protocol is co-registered within the Campbell Collaboration.

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