Title

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

Reviewers

Mayo-Wilson E, Montgomery P, Dennis J

Dates

Date edited: 23/08/2007
Date of last substantive update: 22/08/2007
Date of last minor update: / /
Date next stage expected 01/11/2007
Protocol first published: Issue 4, 2007
Review first published: Issue 2, 2008

Contact reviewer

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

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: / /

Text of review

Synopsis

Abstract

Background

Objectives

Search strategy

Selection criteria

Data collection & analysis

Main results

Reviewers' conclusions

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 both physical impairments (e.g., polio or paralysis) and intellectual impairments, which include learning impairments (e.g., Down's syndrome or autism), learning disability (also called 'intellectual disability' or 'mental retardation') and acquired brain injuries. Intellectual impairments and physical impairments affect activities and participation differently. Therefore, adults with physical impairments only will be considered in other Cochrane and Campbell reviews, as will children 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). 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 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 what is still recorded as 'mental retardation' (2%), 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 the ages of 18 and 65 (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). About 0.8% of Americans of the same age (1.4 million) report mental retardation in the U.S.

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 both physical impairments and intellectual 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.

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).

Most recipients of assistance are female (65%) and less than a quarter receive paid assistance (LaPlante 2002). More than 20 billion hours of assistance are provided each year in the U.S., estimated to be worth $200 billion at 1996 prices (LaPlante 2002).

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

Purpose

Personal assistance is support given to adults with impairments living in normal housing (e.g., family homes) 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 and carers. 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 with physical impairments as a 'right' may not be able or willing to provide comprehensive services for children or for adults with intellectual impairments. 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. In the U.S., authors note high turnover rates, low wages, and lack of training as potential problems (Keigher 2000). Families of people with physical and intellectual impairments might be relieved to have assistants, but assistants might interfere with users' need for privacy. 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 many working adults, groups that are underrepresented in the public discourse about the rights of people with impairments (e.g. people who experience communication difficulties and people living 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 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). 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 2005) 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.

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

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, 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) specific measures designed for people 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) or for people with both physical and intellectual impairments.
2) User satisfaction. Direct reports will be preferred, though proxies might be used if users are 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 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, 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 (HoNOS-LD, Roy 2002).
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) Outwardly directed challenging behaviour. Measures might include items from the externalising scale of the Behavior Problem Inventory (Sturmey 1993).
5) Psychological outcomes, including psychological disorders (e.g. anxiety and depression), self-harm, pica (eating non-food substances), suicide and substance abuse. For example, measures might include the PAS-ADD (Moss 1998; Prosser 1998).
6) Impact on others, including family (spousal and parental) employment, satisfaction, and quality of family life.
7) 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)
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 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 or their 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 people 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

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 Haluk Soydan and organised by the Swedish National Board of Health and Welfare (Socialstyrelsen) has been invaluable. Parts of this review dealing with personal assistance users, government policy, law, and service administration have been shaped by advice from Peter Brusen, Katarina Carlsson, Ulla Clevnert, Johan Glad, Carina Gustafsson, Kerstin Gynnerstedt, Elaine Johansson, Inger Ljung, Anders Printz, Lydia Springer and Karin Tengvald.

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

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

Potential conflict of interest

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

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. Prsonal 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.

Notes

Published notes

This protocol is co-registered within the Campbell and Cochrane Collaborations.

Amended sections

Cover sheet
Background
Objectives
Criteria for considering studies for this review
Search strategy for identification of studies
Methods of the review
Acknowledgements
Potential conflict of interest
References to studies
Other references

Contact details for co-reviewers

Dr Jane A Dennis
Co-ordinator, Cochrane Developmental, Psychosocial & Learning Problems Group
School for Policy Studies
University of Bristol
8 Priory Road
Bristol
UK
BS8 1TZ

Telephone 1: +44 117 954 6782
Telephone 2: +44 117 954 6755
Facsimile: +44 117 954 6756
E-mail: j.dennis@bristol.ac.uk
URL: http://www.bris.ac.uk/Depts/CochraneBehav/
Secondary address:
86 Cranbrook Road
Bristol
UK
BS6 7DB
Telephone: +44 117 9446336

Dr Paul Montgomery
University Lecturer
The Centre for Evidence-Based Intervention
University of Oxford
Barnett House
32 Wellington Square
Oxford
UK
OX1 2ER
Telephone 1: +44 1865 280 325
Facsimile: +44 1865 270 324
E-mail: paul.montgomery@socres.ox.ac.uk
URL: http://www.apsoc.ox.ac.uk/