Personal Assistance for Children and Adolescents (0-18) with Intellectual Impairments

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Personal assistance for children and adolescents (0-18) with intellectual impairments

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REVIEW

The Campbell Collaboration Social Welfare Group

This review is co-registered within both the Cochrane and Campbell Collaborations. A version of this review can also be found on Cochrane Library
Personal assistance for children and adolescents (0-18) with intellectual impairments

Review information

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Abstract

Background
There is a high and increasing prevalence of intellectual impairments among children and adolescents in the West. Many countries offer personal assistance in the form of individualised support for people living in the community by a paid assistant other than a healthcare professional for at least 20 hours per week.

Objectives
To assess the effectiveness of personal assistance for children and adolescents with intellectual impairments, and the impacts of personal assistance on others, compared to other interventions.

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

Selection criteria
Children and adolescents with intellectual impairments (0-18 years) living in the community who require assistance to perform tasks of daily living (e.g., bathing and eating) and participate in normal activities due to permanent impairments. Controlled studies of personal assistance in which participants were prospectively assigned to study groups and in which control group outcomes were measured concurrently with intervention group outcomes were included.

Data collection and analysis
Titles and abstracts were examined by two reviewers. Outcome data were extracted. Studies were assessed for the possibility of bias. Results and potential sources of bias are presented for included studies.

Results
One included study randomised 1002 participants to personal assistance or usual care. Whilst personal assistance was generally preferred over other services, some people prefer other models of care. This review indicates that personal assistance may have some benefits for some recipients and may benefit caregivers. However, near complete dependence on proxy respondents raises concerns about the validity of these results. Paid assistance probably substitutes for informal care and may cost government more than alternatives; however, the total costs to recipients and society are currently unknown.

Authors' conclusions
Research in this field is limited. When implementing new programmes, recipients could be randomly assigned to different forms of assistance. While advocates may support personal assistance for myriad reasons, this review demonstrates that further
studies are required to determine which models of personal assistance are most effective and efficient for particular people.

**Plain language summary**

One study supports use of Personal Assistance for children and teens with intellectual impairments: more research is needed

Personal assistance is here defined as paid support of at least 20 hours per week for people with impairments. This review investigated the effectiveness of personal assistance versus any other form of care for children and adolescents with intellectual impairments. A literature search identified one study that met the inclusion criteria, which included 1002 participants. It suggested that personal assistance may be preferred over other services; however, some people prefer other models of care. This review indicates that personal assistance may have some benefits for some recipients and their informal caregivers. Paid assistance might substitute for informal care and cost government more than alternative arrangements; however, the relative total costs to recipients and society are unknown.

**Background**

**Description of the condition**

**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, 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 includes children and adolescents with intellectual impairments (which include 'learning impairments', 'learning disabilities', 'intellectual disabilities', 'mental retardation', and impairments resulting from acquired brain injuries or 'traumatic brain injury'). Intellectual impairments and physical impairments affect activities and participation differently, and interventions to improve participation differ according to user needs. Furthermore, impairments affect people differently over the course of their lives. This is part of a series of reviews conducted with the Cochrane and Campbell collaborations; young people with physical impairments or both physical impairments and intellectual impairments are considered separately, as are working-age adults and older adults (Mayo-Wilson 2008a, Mayo-Wilson 2008b, Mayo-Wilson 2008c, Montgomery 2008, Mayo-Wilson 2008d).

**Prevalence of impairments**

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 (Larroque 2008; Middle 1996; Williamson 1983; Wilson-Costello 2005).

Many children who experience limitations in learning ability also experience functional limitations. 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.

Impacts

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).

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 and costs are positively related to severity of impairment (Newacheck 2004). Caring for a child with impairments may cause family members (notably mothers) to withdraw from work and social life and put great financial and emotional stress on parents and families (Neely-Barnes 2004; Witt 2001).

Description of the intervention

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

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

**How the intervention might work**

Compared to other interventions, personal assistance may have unique benefits and potential drawbacks. High staff turnover rates, low wages, and lack of training are potential problems (Keigher 2000). 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, children and people with intellectual impairments may be more susceptible to abuse and less able to manage their care. Groups that are underrepresented in the public discourse about the rights of people with impairments may prefer other services. Direct payments for personal assistance may not be ideal for children and families who have difficulty finding an assistant, administering services, negotiating or giving instructions (Pijl 2000).

**Why it is important to do this review**

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

**Objectives**

To assess the effectiveness of personal assistance for children and adolescents (0-18) with intellectual impairments, and the impacts of personal assistance on families and carers, compared to other interventions.

**Methods**

**Criteria for considering studies for this review**

**Types of studies**

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

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

Young people living in institutions for people with impairments were excluded.

Children and adolescents with physical impairments were excluded because these impairments affect activities and participation differently.

**Types of interventions**

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

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

Comparisons could have included, either singly or in combination, informal care (which might be delivered by parents or other family members), institutionalisation, service housing (cluster housing), on-demand services, night patrols, transportation services, and other alternatives to personal assistance. 'No-treatment' and 'waiting list' groups were eligible even if other services received were not described. Studies examining different forms of personal assistance (e.g., assistance organised by users compared to assistance organised by others) were included. These were treated as separate comparisons.

**Types of outcome measures**

**Primary outcomes**

1) Global quality of life, both (a) generic measures (e.g., the 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 were considered, a review of global health measures found that 'very few measures have been validated specifically for cognitively impaired respondents' (Riemsma 2001). Other measures were included.

2) User satisfaction. Direct reports were preferred, though proxies were used if users were unable to communicate.

3) Participation, including social activities, ability to participate in spontaneous activities, time outside the home, and mobility.

**Secondary outcomes**

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 have included items from
the externalising scale of the Behavior Problem Inventory (Sturmey 1993).
5) Impact on others, including parental (maternal) employment, satisfaction, and
quality of family life. For example, measures might have included the Short-Form
Health Survey (Ware 1992) or General Health Questionnaire (Counsell 1994).
6) Direct and indirect costs, both immediate and long-term.

Outcomes were grouped by length of follow-up.

**Search methods for identification of studies**

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

**Electronic searches**

Databases were searched for published and unpublished studies. All electronic
searches were limited to research reported since 1980 because scoping for this project,
including a review of relevant laws and policy documents and contacts with
international experts, found that widespread personal assistance programmes began in
the mid 1990s. Experts have noted that personal assistance was available in some
form before the introduction of programmes in the 1990s, but they and the reviewers
believed it was unlikely that any relevant trials were conducted before 1980.

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

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

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

The following databases were searched electronically from 1980 to June 2005:

**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  

The search strategies that were used to search CENTRAL, MEDLINE, EMBASE, ASSIA, Sociological Abstracts, C2-SPECTR, EconLit, PsycINFO and SIGLE can be found in Appendix 1, Appendix 2, Appendix 3, Appendix 4, Appendix 5, Appendix 6, Appendix 7, Appendix 8.

Similar terms were used to search other databases.

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

ADL (Svenska MeSH)  
Assistansreformen  
Assistent: 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)  

**Searching other resources**
**Personal communications**
Appropriate government departments, non-governmental organisations, non-profit groups, advocacy groups, user groups, and experts in the field were contacted. These approaches and any replies were documented by the authors. Additionally, impairment-oriented email lists (list-servs) were sent a letter requesting assistance in locating studies.

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

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

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

**Data collection and analysis**

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

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

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

The following data were collected for all studies:
1) Programme differentiation, i.e. differences in the services received by participants in different arms (Dane 1998; MRC 2000), including crossover between groups; and
2) Context.

**Assessment of risk of bias in included studies**
Two reviewers (EMW and PM) independently assigned the one included study to a quality category described in the Cochrane Handbook (Higgins 2005) where:
(A) indicates adequate concealment of the allocation (for example, by telephone randomisation, or use of consecutively numbered, sealed, opaque envelopes);
(B) indicates uncertainty about whether the allocation was adequately concealed (for example, where the method of concealment is not known);
(C) indicates that the allocation was definitely not adequately concealed (for example,
open random number lists or quasi-randomisation such as alternate days, odd/even date of birth, or hospital number); and (D) indicates that random allocation was not used.

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

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

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

The following components are considered in the Description of Studies and the 'Characteristics of Included Studies' and accompanying 'Risk of bias' table:
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.)

**Measures of treatment effect**
No meta-analysis was possible in this review. For details of all methods planned in the protocol and archived for use in future updates of this review, see Appendix 9.

**Dealing with missing data**
See Appendix 9.

**Assessment of heterogeneity**
See Appendix 9.

**Assessment of reporting biases**
See Appendix 9.
Data synthesis
See Appendix 9.

Subgroup analysis and investigation of heterogeneity
See Appendix 9.

Sensitivity analysis
See Appendix 9.

Results

Description of studies

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

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

One study met the inclusion criteria.

A flowchart of the process of trial selection was made in accordance with the QUOROM statement (Moher 1999) and is included as Figure 1.
**Included studies**

One included study randomised 1002 participants to personal assistance or usual care (Carlson 2007).

Carlsson 2007 conducted a study involving children, adults and the elderly in three states. Inclusion criteria, contextual factors and implementation differed across sites. In this and related reviews, results for each group at each site are treated as individual trials to allow inclusion of data in the appropriate reviews, to facilitate subgroup analyses and to permit tests for homogeneity across sites. The review includes data for children in Florida (FL).

Eligible Medicaid beneficiaries were randomly assigned to receive a monthly payment (personal assistance) in lieu of other Medicaid services or to receive usual care from 1999 to 2003. Children and adolescents qualified if they had sufficient need, low intelligence quotient, and a diagnosis of mental retardation, autism, spina bifida, cerebral palsy or Prader Willi syndrome. At baseline, most participants were under 13 years old (see table 'Characteristics of Included Studies').

All participants or their representatives - 501 in each the intervention and control group - completed a baseline survey (99% by proxy, mostly parents). Participants in the intervention group were contacted by a counsellor who helped them develop spending plans, provided advice and monitored services. They received more paid care than control participants, who often paid for care out of pocket (20 versus 15 hours per week).

After assignment, the authors describe the intervention enrolment process as complex and discouraging; only 22% of participants received cash assistance within 3 months,
29% never received assistance, and 20% disenrolled during the following year (of whom, 88% withdrew before the assistance started). The average monthly payment at enrollment was $1108 Of those still living in the community, 69% of the personal assistance group was receiving cash at 9 month follow-up. At 9 months, 79% and 65% of participants in the personal assistance and control groups reported receiving paid care in the previous two weeks (p<0.01). They received 237 hours and 247 hours in total (p=0.23), 40 and 30 of which was paid (p<0.01). Of those who hired a worker in the first 9 months, 41% hired a worker who lived with them.

**Excluded studies**

Other data from the Cash and Counseling study are not included in this review, though data from several groups of participants are included in related reviews.

**Risk of bias in included studies**

In Carlson 2007, the risk of bias overall was low, as described in the Description of Studies and in the 'Risk of Bias' table, below.

**Performance bias**

The study was somewhat vulnerable to performance bias. Participants were probably unsatisfied with existing services and control participants may have been motivated to report negative outcomes. Satisfaction with the intervention was a primary outcome of this review and insofar as satisfaction with services influences one's perception of other outcomes, it may be impossible to disentangle these variables.

**Detection bias**

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

**Report bias**

There was some evidence of report bias in publications, as detailed in Table 9, though further data are available online. Details presented here are based on published reports and available manuscripts (see: www.mathematica-mpr.com). As more information from this trial emerges, we plan to include it in updates of this review.

**Attrition bias**

The risk of attrition bias appeared low, though the number of participants in different analyses at the same interval varies considerably; means are predicted using ordinary least squares regression or logit models.

**Outcome validity**

The study used a mix of objective outcomes and other outcome measures, some of which were not validated.

The proportion of data collected by proxy is noteworthy because services for people with intellectual impairments can provide the 'illusion of client involvement, rather than the reality', particularly for people who have difficulty communicating verbally (Williams 2000).
Effects of interventions

**Primary outcomes**

**Quality of life**

Carlson 2007 used a single question to measure satisfaction with the way participants were spending their lives. In the intervention and control groups, 52% and 29% (p<0.01) of parents indicated that participants were 'very satisfied'.

**User satisfaction**

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

There were 'large' and significant relationships favouring the treatment group for satisfaction with: the relationship with the paid caregiver, daily living assistance (e.g. eating, dressing, toileting, transferring and bathing), help around the house/community (excluding transportation), routine health care assistance, transportation assistance, overall care arrangements. For several measures of satisfaction, there were not significant effects in favour of the treatment group: rude and disrespectful behaviour by a paid caregiver, paid caregivers taking something without asking, and paid caregiver giving unwanted help. In the treatment and control groups, 56% and 27% (p<0.01) of participants were very satisfied with overall care arrangements.

**Participation**

The study measured participation, but these data are not yet reported.

**Secondary outcomes**

**Unmet needs**

Some evidence suggests personal assistance may reduce unmet needs.

For several measures of unmet needs, there were 'large' and significant relationships favouring the treatment group: unmet needs for help with ADLs (e.g. eating, dressing, toileting, transferring and bathing), unmet needs for help with IADLs (e.g. preparing meals, doing laundry, doing housework and doing yard work), unmet needs for help with routine health care (e.g. medication, checking blood pressure and doing exercises), and neglect by a paid caregiver. For unmet needs for help with transportation (e.g. to and from a physician's office, shopping, school, work, and social and recreational activities), there was a 'modest' (less than 10% and less than half the size of the control group proportion or its complement) and significant relationship favouring the treatment group. In the treatment and control groups, 33% and 45% (p<0.01) of participants reported an unmet need with an activity of daily living.

**Physical health**

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

**Mortality**

About 1% of intervention participants died. Data for controls were not reported.

**Morbidity and Medical Care**

Several adverse health outcomes were measured. The control group was not superior to the intervention group on any measure. There were some differences favouring the intervention group, for example between the number of intervention and control participants who had a fall (27% and 36%, p<0.01) or a urinary tract infection (3% and 6%, p<0.05), whose contractures developed or worsened (9% and 13%, p<0.05) or whose bedsores developed or worsened (3% and 6%, p<0.05).

**Challenging behaviour**

Measures of challenging behaviour were not reported.

**Mental health**

Measures of mental health were not reported.

**Impact on others**

Impacts on caregivers were measured through a caregiver survey administered 10 months after the baseline interview. In the previous two weeks, primary caregivers provided similar amounts of assistance to both groups (150 versus 155 hours, p=0.35). Nonetheless, personal assistance increased satisfaction with overall care arrangements (42% and 22% were very satisfied, p<0.01). However, it had little effect on emotional strain (39% and 42% experienced a great deal of strain, p=0.50), the feeling that caregiving limited privacy (61% and 66%, p=0.13) or free time (81% and 82%, p=0.78). Personal assistance reduced financial strain (44% and 56% said caregiving caused a great deal of strain, p<0.01), but not the chance that a person who wanted outside work would not seek employment due to caregiving (53% and 57%, p=0.19). The intervention did not reduce absenteeism (84% and 83%, p=0.66). It reduced the chance of experiencing a great deal of physical strain (35% and 42%, p<0.05) and experiencing negative health outcomes due to caregiving (42% and 55%, p<0.01).

**Abuse and Neglect**

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

**Costs**

The program increased participants' ability to receive care to which they were entitled, which increased government costs. Estimated costs to Medicaid were $29974 and $29095 per client in the first year, $33458 and $30877 in the second year. Notably, these estimates do not account for costs to other government agencies, private charities, family and friends or consumers.
Discussion

Summary of main results

This review identifies some evidence that personal assistance recipients may benefit children with intellectual impairments. Impacts on carers appear somewhat mixed. Further data would be required to draw conclusions about cost.

This review did not identify any studies that investigated the impact of personal assistance on mental health outcomes for children with intellectual impairments or their families. Children and adolescents with intellectual and physical 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). Parents and siblings of children with impairments are also at risk for psychological problems (Rossiter 2001, Sharpe 2002, Thyen 1998). Further studies would be required to determine if personal assistance has broad impacts on mental health outcomes and how those outcomes might change as children mature.

The substantial amount of paid assistance received by participants in the control group underscores the fact that people receive both unpaid and paid assistance without external intervention. These data suggest that providing personal assistance is likely to raise government or insurance costs by paying for work that users would otherwise hire themselves and by paying for time that people would otherwise spend providing assistance for free.

Overall completeness and applicability of evidence

This review included 1002 participants in one U.S. state. More trials would be required to demonstrate if these results generalise to other countries and populations. Furthermore, the follow-up period was short and this review does not provide information about the long term impacts of personal assistance.

No study compared a very large amount of personal assistance (e.g., 90 hours per week) to another form of service. Large amounts of assistance are increasingly common in Europe, particularly in Scandinavia. As a result, the conclusions of this review may not extend to users with very severe impairments or to more intense models of personal assistance.

Cost data have limited generalisability. Data from Carlson 2007 are not comprehensive and implications for different stakeholders may be quite different; the relative costs of personal assistance and other services may be contextually dependent, varying from country to country.

Research and service provision for people with intellectual impairments may both be limited. It has been noted that 'despite the concentration in the literature on programs delivering personal assistance services, the reality is that the vast majority of persons with severe disabilities have no contact with formal programs' (Nosek 1991). For example, Askheim 2003 identified 24 users with intellectual impairments in Norway. Of those, 16 answered a survey. Askheim notes 'there are no exact official figures of how many intellectually disabled personal assistance users there are in Norway. Investigations after we did our survey show that the number is a little higher than 24.' As services like Cash and Counselling expand, which is similar to 'Direct Payments'
in Britain and similar services that are expanding throughout Europe, there will be
more users with intellectual impairments. The impacts of personal assistance for
children and for people with intellectual impairments should be investigated further.

Quality of the evidence

Carlson 2007 has high internal validity, but low uptake and non-response raise
questions about the external validity of these results. Dropout may suggest that some
users eventually determine they prefer other services or it may indicate that they
become unable to manage personal assistance. For this reason, Nosek suggests that
personal assistance be offered to some individuals on a trial basis for a limited time so
that 'both consumers and providers of services could assess the feasibility of
management arrangements and mutually define the parameters of management
responsibilities' (Nosek 1991). When intervention participants can choose to return to
other models of support rather than receive personal assistance, it may not be
surprising that consumers select the option that leads to the best outcomes for them.
Consequently, it is difficult to separate the benefits of personal assistance per se and
the benefits of consumer choice.

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

Authors' conclusions

Implications for practice

There have been relatively few controlled studies of personal assistance for children
who require a great deal of assistance. Existing evidence suggests that personal
assistance is generally preferred over other services by people who agree to
participate in research; however, some people prefer other models of care. This
review indicates that personal assistance may have some benefits for some recipients;
however, the relative total costs to recipients and society are unknown. This review
does not indicate that personal assistance would be superior to other services for
people who are already satisfied with the assistance they receive.

Implications for research

In 1986, Ratzka noted that 'there has been surprisingly little in the way of policy
evaluation. The work that has been done in this area is restricted to gathering
descriptive statistics on number of hours provided by one type of service, number of
consumers, staff, and expenditures' (Ratzka 1986). While several studies have been
conducted since the 1980s, few studies have compared directly personal assistance
and other services and further evaluations are required to determine the relative merits
of different ways of organising assistance. It would be possible to compare personal
assistance to other services or to different forms of personal assistance in locations
implementing new programmes. Similarly, new users might be assigned to different
models of personal assistance in locations with long-standing personal assistance
services.
Services for children and adolescents with impairments are organised differently around the world. While advocates may support personal assistance for myriad reasons, this review demonstrates that further studies are required to determine (i) what marginal benefits are gained from personal assistance (i.e. the added value compared to other services that exist today), (ii) at what total relative cost and (iii) which models of personal assistance are most effective and efficient for particular people.

Acknowledgements

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

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

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

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

Contributions of authors

EMW wrote the background and methods with PM and JD. JD developed the search strategy with EMW and PM. EMW and PM conducted data extraction. EMW wrote the results and discussion with PM and JD.

Declarations of interest

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

Published notes

This review is co-registered within the Campbell Collaboration.

Characteristics of studies

Characteristics of included studies

Carlson 2007

<table>
<thead>
<tr>
<th>Methods</th>
<th>Allocation was random. Participants were assessed by telephone at baseline and 9 months. Carers were assessed at 10 months.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants</td>
<td>Participants had to be current users of the state's personal care benefit. They ranged in age from 3 to 17 years; 21% were 3 to 6, 28% were 7 to 9, 22% were 10 to 12, 17% were 13 to 15, and 12% were 16 or 17. Overall, 37% were female, 80% white and 19% Hispanic (regardless of race). Few (18%) lived in a rural area. Most participants were dependent in several ADLs; 61%, 84% and 91% were not independent in transferring, toileting and bathing; 66% expressed a need for more help with personal care.</td>
</tr>
<tr>
<td>Interventions</td>
<td>Participants received a monthly allowance that could be used to hire caregivers. Intervention participants received approximately 20 hours of paid care per week compared to 15 hours of paid care per week in the control group.</td>
</tr>
</tbody>
</table>
| Outcomes | Quality of life  
User satisfaction  
Unmet needs  
Physical health  
Impact on others  
Costs |

Notes

Risk of bias table

<table>
<thead>
<tr>
<th>Item</th>
<th>Judgement</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate sequence generation?</td>
<td>Yes</td>
<td>Description: The report implies that randomisation was conducted by a person not connected to the administration of the measures or intervention. Randomisation created balanced groups. Comment: Sequence generation was adequate.</td>
</tr>
<tr>
<td>Allocation concealment?</td>
<td>Yes</td>
<td>Description: The report indicates that the generation of the allocation sequence was unconnected to its...</td>
</tr>
<tr>
<td>Question</td>
<td>Answer</td>
<td>Description</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td>--------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Blinding?</td>
<td>Unclear</td>
<td>Description: It would have been impossible to blind participants or personnel. Many outcomes included questions that required assessors to know a participant's allocation and it would have been practically difficult to blind them. Comment: The nature of the intervention prevented blinding most individuals involved. Given the nature of the assessments, this probably introduced little bias.</td>
</tr>
</tbody>
</table>
| Incomplete outcome data addressed?                           | Yes    | Description: Data are available online (www.cashandcounseling.org); however, in current published reports, many scales with four options were collapsed to create dichotomous outcome measures of the most extreme options and data for most outcomes are not reported numerically. Minimum detectable differences are reported. Participants were excluded from certain analyses if relevant conditions were met (e.g. paid caregivers acting as proxy respondents were not asked about consumer satisfaction with care). This was designed to prevent detection biases that would overestimate programme effects and might result in biases that underestimate program impacts (e.g. impacts on informal caregivers might be biased as a result of excluding those caregivers who became paid caregivers). The authors sent a 26 page survey to all participating consultants (who were also involved in trials of cash and counselling for older adults) 18 months after enrolment began, which included many open-ended questions; 37 of 50 consultants responded. This may have increased the probability of detecting problems in the intervention group and strengthens the claim that consumer-directed personal assistance is safe. None of the main outcomes included all participants randomised. Some outcomes were measured through program records while others were measured thorough client interviews or interviews with proxies. Consequently, the number of participants in different analyses at the same interval varies considerably; outcome measures included 441 and 418 participants for service use, 289 and 273 for satisfaction with paid caregivers, 378 and 418 for unmet needs, 439 and 418 for adverse events, and 378 and 418 for overall satisfaction with care. At nine months, survey response rates in the intervention and control groups were 87% and 82%, all of which were completed by parents (14% and 0% by paid...
The authors report that they attempted to contact participants in the intervention group who disenrolled from the intervention, most of whom returned to agency-directed services. Means are predicted using ordinary least squares regression or logit models.

Comment: Reasons for exclusion are well-documented and logically justified. Appropriate models appear to have been used to account for missing data. Criteria for including participants in particular analyses may have impacted the results, though the resultant biases were not consistent in direction. Incomplete outcome data were adequately addressed.

<table>
<thead>
<tr>
<th>Free of selective reporting?</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description: Most results are not reported in detail (though simplified presentation of outcomes is understandable given the number of outcomes measured). Complete study data are available online, but we have not been able to reanalyse them. The authors indicate that reported outcomes are representative of other outcomes. We have not located reports of participation outcomes, which were measured and could have been included in this review. Comment: The data may be vulnerable to reporting bias, particularly with regard to participation outcomes.</td>
<td></td>
</tr>
</tbody>
</table>

**Footnotes**

**Characteristics of excluded studies**

**Characteristics of studies awaiting classification**

**Characteristics of ongoing studies**

**Summary of findings tables**

**Additional tables**

**References to studies**

**Included studies**

*Carlson 2007*

*Published and unpublished data*


**Excluded studies**

**Studies awaiting classification**

**Ongoing studies**

**Other references**

**Additional references**

*Abberley 1987*


*Alberman 1991*


*Allen 1993*


*Askheim 2003*


*Colver 2005*


*Counsell 1994*


*Dane 1998*

Deeks 2003

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

Doyle 1995

Egger 1997

Hagglund 2004

Hammal 2004

Higgins 2002

Higgins 2003

Higgins 2005

Hogan 1997

Jackson 2005


Juni 2001


Keigher 2000


Larroque 2008


Mayo-Wilson 2008a


Mayo-Wilson 2008b


Mayo-Wilson 2008c


Mayo-Wilson 2008d


McLennan 2000


Middle 1996

Mihaylov 2004

Moher 1995

Moher 1999

Montgomery 2008

Morris 2001

Morse 2006

Moss 2000

MRC 2000

Neely-Barnes 2004

Newacheck 2004

Nosek 1991
Nosek M. Personal Assistance Services: A Review of Literature and Analysis of Policy Implications, Department of Physical Medicine and Rehabilitation. Houston, TX: Baylor College of Medicine, 1991.
**Oliver 1990**

**Oxman 1992**

**Pijl 2000**

**Pit-Ten 2002**

**Ratzka 1986**

**Resnick 1998**

**Riemsma 2001**

**Rossiter 2001**

**Sharpe 2002**

**Socialstyrelsen 2005**

**Sterne 2001**

**Sturmey 1993**

Thyen 1998

UN 1990

Varni 2005

Ware 1992

Wenger 1995

WHO 2003

Williams 2000

Williamson 1983

Wilson-Costello 2005

Witt 2001
Witt WP. Family stressors, psychosocial functioning, and mental health care utilization among disabled children: Results from the 1994-1995 national health

**Yusuf 1991**


**Zarb 1994**


**Other published versions of this review**

**Classification pending references**

**Data and analyses**

**Sources of support**

**Internal sources**

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

**External sources**

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

**Feedback**

**Appendices**

**1 CENTRAL search strategy**

<table>
<thead>
<tr>
<th>Search Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1 HOME CARE SERVICES</td>
<td></td>
</tr>
<tr>
<td>#2 ACTIVITIES OF DAILY LIVING</td>
<td></td>
</tr>
<tr>
<td>#3 PERSONAL HEALTH SERVICES</td>
<td></td>
</tr>
<tr>
<td>#4 (personal near/2 assist*)</td>
<td></td>
</tr>
<tr>
<td>#5 (personal near/2 care*)</td>
<td></td>
</tr>
<tr>
<td>#6 exp HOMEMAKER SERVICES</td>
<td></td>
</tr>
<tr>
<td>#7 independent living</td>
<td></td>
</tr>
<tr>
<td>#8 direct assistance</td>
<td></td>
</tr>
<tr>
<td>#9 direct payment</td>
<td></td>
</tr>
<tr>
<td>#10 attendant care</td>
<td></td>
</tr>
</tbody>
</table>
#11 in home
#12 CAREGIVERS
#13 (allowance* or fee or fees or finance* or fund* or money* or monies* or pay* or paid or remunerate* or salar* or wage*)
#14 state-support*.
#15 state support*.
#16 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11
#17 #12 and (#13 or #14 or #15 or #16)
#18 #16 or #17

### 2 MEDLINE search strategy

MEDLINE searched via OVID 1980 to June 2006

1 Home Care Services/
2 Activities of Daily Living/
3 Personal Health Services/
4 (personal adj2 assist$).mp.
5 (personal adj2 care$).mp.
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$).mp.
14 state-support$.mp.
15 state support$.mp.
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

### 3 EMBASE search strategy

EMBASE searched via OVID 1980 to June 2005

1 *Home Care Services/
2 **"Activities of Daily Living"/**
3 *Personal Health Services/
4 (personal adj2 assist$).mp.
5 (personal adj2 care$).mp.
6 exp Homemaker Services/
7 independent living.mp.
8 direct assistance.mp.
9 direct payment.mp.
10 *CAREGIVERS/
11 (allowanc$ or fee or fees or financ$ or fund$ or money$ or monies$ or pay$ or paid or remunerat$ salar$ or wage$).mp.
12 state-support$.mp.
13 state support$.mp.
4 ASSIA and Sociological Abstracts search strategy

ASSIA searched 1987 to June 2005 and Sociological Abstracts searched 1980 to June 2005 via CSA

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

5 C2-SPECTR search strategy

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

6 EconLit search strategy

EconLit searched via SilverPlatter 1980 to June 2005

((home-care) or (personal-care) or (home care) or (independent living) or (personal assistance) or (independent living) or (direct assist*) or (direct pay*) or (personal care) or (caregiver* or care-giver*)) and (PY:ECON = 1980-2005)

7 PsycINFO search strategy

PsycINFO searched via SilverPlatter 1980 to June 2005

#28 (personal assistance) or ((allowanc* or fee or fees or finance* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*)) or (state support*)) and ("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*)

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

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

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

#24 home care

#23 independent living

#22 direct assistance

#21 direct pay*

#20 personal care

#19 personal assistance

#18 "Independent-Living-Programs" in MJ,MN

#17 "Assisted-Living" in MJ,MN
Multiple 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
<table>
<thead>
<tr>
<th>measures</th>
<th>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).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple arms</td>
<td>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.</td>
</tr>
<tr>
<td>Data synthesis (Outcome data)</td>
<td>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.</td>
</tr>
<tr>
<td>Continuous data</td>
<td>Mean differences, standardised mean differences (SMDs) and 95% CIs will be calculated for comparisons of continuous outcome measures.</td>
</tr>
<tr>
<td>Dichotomous data</td>
<td>Within studies, relative risks (RRs) and 95% confidence intervals (CIs) will be calculated for comparisons of dichotomous outcome measures. Dichotomous outcome measures may be combined by calculating an overall RR and 95% CI.</td>
</tr>
<tr>
<td>Continuous outcomes</td>
<td>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.</td>
</tr>
<tr>
<td>Types of analyses</td>
<td>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</td>
</tr>
</tbody>
</table>
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.

<table>
<thead>
<tr>
<th>Homogeneity</th>
</tr>
</thead>
<tbody>
<tr>
<td>The consistency of results will be assessed using the I-squared statistic (Higgins 2002; Higgins 2003). If there is evidence of heterogeneity (Q-statistic p less than or equal to 0.1 coupled with an I-squared value of 25% or greater), the authors will consider sources according to pre-specified subgroup analyses and sensitivity analyses (below) but will not report an overall estimate of effect size. If heterogeneity remains within these subgroups, the review will report the results on a trial-by-trial basis, in a narrative summary.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subgroup analyses</th>
</tr>
</thead>
</table>
| 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  
2) Place of residence  
3) Acquisition of impairment  
4) Amount of assistance |

<table>
<thead>
<tr>
<th>Assessment of bias</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Graphs</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
</tr>
</tbody>
</table>