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

Evan Mayo-Wilson, Paul Montgomery, Jane Dennis
Personal assistance for children and adolescents (0-18) with physical impairments

The Campbell Collaboration

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10.4073/csr.2008.6
27
20 February, 2008


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

Evan Mayo-Wilson (EMW) wrote the background and methods with Paul Montgomery (PM) and Jane Dennis (JD). JD developed the search strategy with EMW and PM. EMW and PM conducted data extraction. EMW wrote the results and discussion with PM and JD.

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

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.

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Personal assistance for children and adolescents
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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 physical impairments

Review information

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Dates

| Assessed as Up-to-date: | 29 June 2005 |
| Date of Search: | 29 June 2005 |
| Next Stage Expected: | 31 May 2009 |
| Protocol First Published: | Issue 4, 2006 |
| Review First Published: | Issue 3, 2008 |
| Last Citation Issue: | Issue 3, 2008 |

What's new

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Abstract

Background
There is a high and increasing prevalence of 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 physical 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 physical 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. 130 full papers were examined. None met the inclusion criteria.

Results
No eligible studies were found.

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
Studies urgently needed to assess effects of Personal Assistance for children and teens with physical impairments

Personal assistance is here defined as paid support of at least 20 hours per week for people with impairments. This review investigated the effectiveness of personal assistance versus any other form of care for children and adolescents with physical impairments. A literature search identified no studies that met the inclusion criteria. This review is part of a series of reviews; evidence from related reviews about different populations might be informative to researchers and practitioners.

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 physical impairments. 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 intellectual impairments or both physical impairments and intellectual impairments are considered separately, as are adults and the elderly (Montgomery 2008a, Montgomery 2008b, Mayo-Wilson 2008a, Mayo-Wilson 2008b, Mayo-Wilson 2008c).

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.

A recent American survey (N=13,792) found that 7.3% of people under 18 years old have impairments that restrict their participation in age-appropriate activities (Newacheck 2004). 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).

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. making buildings accessible), 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 physical impairments when physical, social and attitudinal environments restrict their involvement (Hammal 2004, Mihaylov 2004). Impairments may affect the quality of life, health, development, and family functioning of children and adolescents (Lavigne 1993, Neely-Barnes 2004, Pit-Ten Cate 2002, Varni 2005).

Children with 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. 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, mental and physical health of children and adolescents.

There are many ways to increase participation by children and adolescents with physical impairments. For example, building regulations and school schedules may be designed such that some children and adolescents with 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, such broad interventions may not be sufficient to meet all needs. People with severe impairments require interventions tailored to their unique impairments, lifestyles, living arrangements, etc. Assistive devices, physical therapy, education, and human support help young people control their lives appropriately and engage in normal activities.

Personal assistance is paid support given to 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.

**How the intervention might work**

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.

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, other recipients may be more susceptible to abuse and less able to manage employees. Groups that are underrepresented in the public discourse about the rights of people with impairments may prefer other services. Direct payments for personal assistance may not be ideal for 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 physical 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 family 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 physical impairments.

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

Children and adolescents with intellectual 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 and (b) specific measures designed for people with particular impairments. For example, measures might have included the Child Health Questionnaire (Landgraf 1997) or the Pediatric Quality of Life Inventory (Varni 2005).

2) User satisfaction. For example, measures might have included the Client Satisfaction Inventory (McMurtry 2000).

3) Participation, including sense of control, school attendance, social life, ability to
participate in spontaneous activities, time outside the home, and mobility. For example, measures might have included the Lifestyle Assessment Questionnaire (Mackie 1998).

Secondary outcomes

1) Health outcomes, including direct measures of muscle strength, disease, injuries, abuse or pain and indirect measures such as hospitalisation, emergency room visits or need for institutionalisation.
2) Developmental outcomes, including educational achievement and attainment, university attendance, and cognitive milestones.
3) Psychiatric outcomes, including psychological disorders (e.g., anxiety and depression), self-harm, suicide and substance abuse. For example, measures might have included the Strengths and Difficulties Questionnaire (Goodman 1999, Goodman 1998).
4) 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 the Euroqol (EuroQol-Group 1990).
5) Direct and indirect costs, both immediate and long-term.

Outcome intervals

Outcomes were planned to be grouped by length of follow-up.

Search methods for identification of studies

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 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 and 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
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
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 articles were reviewed if one author felt a paper might be relevant.

Data extraction and management
No studies were identified for this review. Methods described in the protocol which have been archived for use in future updates can be seen in Appendix 9.

Assessment of risk of bias in included studies
See Appendix 9.

Measures of treatment effect
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

No eligible studies were found.

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 involving children with intellectual impairments was included in a related review. No studies were included in this review.

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

No studies were found that met the inclusion criteria of the review.

Effects of interventions

An exhaustive search for controlled prospective studies identified some qualitative and uncontrolled studies in this population, but no studies that met basic inclusion criteria.

Discussion

No randomised, quasi-randomised, or controlled prospective studies were found. Consequently, no studies could be included in this review. Several related reviews found evidence about the effectiveness of personal assistance for other groups. There is no reliable evidence about the effectiveness of personal assistance for children and adolescents with physical impairments.

Authors' conclusions

Implications for practice

No randomised, quasi-randomised, or controlled prospective studies were found. Consequently, no studies could be included in this review. Several related reviews found evidence about the effectiveness of personal assistance for other groups. There
is no reliable evidence about the effectiveness of personal assistance for children and adolescents with physical impairments.

**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). This is as true for children and adolescents as it was twenty years ago. It would be possible to compare personal assistance to other services or to different forms of personal assistance in locations implementing new programmes. Similarly, new users might be assigned to new models of personal assistance in places with long-standing personal assistance services.

Services for 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 Couldrey for assistance retrieving articles. We thank Celia Almeida and Katinka Hodin for translating documents.

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

Additional references

**Abberley 1987**

**Agree 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**

**Dupré 2003**

**Egger 1997**

**EuroQol-Group 1990**
Goodman 1998

Goodman 1999

Hagglund 2004

Hammal 2004

Higgins 2002

Higgins 2003

Higgins 2005

Hogan 1997

Jackson 2005

Juni 2001

Keigher 2000

Landgraf 1997

Larroque 2008

Lavigne 1993

Mackie 1998

Mayo-Wilson 2008a

Mayo-Wilson 2008b

Mayo-Wilson 2008c

McLennan 2000

McMurtry 2000

Mihaylov 2004

Moher 1995

Moher 1999

Montgomery 2008a

Montgomery 2008b

Morse 2006

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

Neely-Barnes 2004

Newacheck 1988

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
Pit-Ten Cate 2002

Ratzka 1986

Resnick 1998

Rossiter 2001

Sharpe 2002

Socialstyrelsen 2005

Sterne 2001

Thyen 1998

UN 1990

Varni 2005

Ware 1992
Wenger 1995

WHO 2003

Witt 2001

Yusuf 1991

Zarb 1994

Other published versions of this review
Classification pending references

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

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

## 2 MEDLINE search strategy

MEDLINE 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 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.
14 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
15 10 and (11 or 12 or 13 or 14)
16 14 or 15

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 financ* 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 search 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 financ* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*)) or (state support*)) and ((("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*)) or ("Independent-Living-Programs" in MJ,MN) or ("Assisted-Living" in MJ,MN) or ("Home-Care-Personnel" in MJ,MN) or (explode "Home-Care" in MJ,MN) or (home care) or (independent living) or (direct assistance) or (direct pay*) or (personal care) or (allowanc* or fee or fees or financ* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*)) or (state support*)) and (explode "Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*))

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

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

#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
#16 "Home-Care-Personnel" in MJ,MN
#15 explode "Home-Care" in MJ,MN
#14 (personal assistance) or ((allowanc* or fee or fees or financ* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*) or (state support*)) and ("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*)) or ("Independent-Living-Programs" in MJ,MN) or ("Assisted-Living" in MJ,MN) or ("Home-Care-Personnel" in MJ,MN) or (explode "Home-Care" in MJ,MN) or (home care) or (independent living) or (direct assistance) or (direct pay*) or (personal care)
#13 (allowanc* or fee or fees or financ* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*) or (state support*)) and ("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*)
#12 allowanc* or fee or fees or financ* or fund* or money* or monies or pay* or paid* or remunerat* or salar* or wage* or (state-support*) or (state support*) and ("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*)
#11 ("Caregivers-" in MJ,MN) or (caregiver*) or (care-giver*)
#10 home care
#9 independent living
#8 direct assistance
#7 direct pay*
#6 personal care
#5 personal assistance
#4 "Independent-Living-Programs" in MJ,MN
#3 "Assisted-Living" in MJ,MN
#2 "Home-Care-Personnel" in MJ,MN
#1 explode "Home-Care" in MJ,MN

8 SIGLE search strategy

#12 ((independent living) or (direct assist*) or (direct pay*) or (personal care) or (caregiver* or care-giver*) or (home-care) or (personal-care) or (home care) or (independent living) or (personal assistance)) and (PY:SI = 1980-2005)
#11 (independent living) or (direct assist*) or (direct pay*) or (personal care) or (caregiver* or care-giver*) or (home-care) or (personal-care) or (home care) or (independent living) or (personal assistance)
#10 independent living
#9 direct assist*
#8 direct pay*
#7 personal care
#6 caregiver* or care-giver*
#5 home-care
#4 personal-care
#3 home care
#2 independent living
#1 personal assistance
9 Methods from protocol for use in future updates

<table>
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<tr>
<th>Issue</th>
<th>Method</th>
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<tbody>
<tr>
<td>Data extraction and management</td>
<td>Data extraction will be conducted independently by two authors (EMW and PM). 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; and 4) Outcome measures listed above (including multiple measures of outcomes where available). The following data will be 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.</td>
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<tr>
<td>Assessment of risk of bias</td>
<td>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); 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</td>
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give differing (even opposing) ratings of trial quality in systematic reviews. At present, evidence indicates that 'scales should generally not be used to identify trials of apparent low quality or high quality in a given systematic review. Rather, the relevant methodological aspects should be identified a priori and assessed individually’ (Juni 2001; see also Moher 1995).

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

**Multiple measures**

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

**Multiple arms**

If two or more eligible intervention groups are compared to an eligible control, thus requiring that the reviewers choose a single intervention group for comparison or inclusion in a meta-analysis, the most intense service or the service that best follows the goals of personal assistance (e.g., services that give users more control) will be included in the meta-analysis. If a single eligible intervention group is compared to multiple eligible control groups, 'no-treatment' controls will be chosen over other groups for comparison and inclusion in meta-analyses. For studies that do not have no-treatment condition, the most common intervention in clinical practice will be chosen to maximise the external validity of the results.

**Data synthesis**

Meta-analyses may be conducted to combine comparable outcome
(Outcome data) 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.

<table>
<thead>
<tr>
<th>Continuous data</th>
<th>Mean differences, standardised mean differences (SMDs) and 95% CIs will be calculated for comparisons of continuous outcome measures.</th>
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<tbody>
<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>
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<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>
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<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 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.</td>
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<td>Homogeneity</td>
<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>
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<td>Subgroup analyses</td>
<td>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</td>
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| 2) Place of residence  
3) Acquisition of impairment  
4) Amount of assistance |
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<tr>
<td><strong>Sensitivity analysis</strong></td>
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<td><strong>Graphs</strong></td>
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