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# **Personal Assistance for Children and Adolescents (0- 18) with Both Physical and Intellectual Impairments**

Evan Mayo-Wilson, Paul Montgomery, Jane Dennis



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# Colophon

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# **Personal assistance for children and adolescents (0-18) with both physical and intellectual impairments**

Evan Mayo-Wilson  
Paul Montgomery  
Jane A Dennis

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 both physical and intellectual impairments

## Review information

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02 April 2008 New citation: conclusions changed	Substantive amendment

# **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 both physical and 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 both physical and 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. 130 full papers were examined. None met the inclusion criteria.

## **Results**

No eligible studies were found.

## **Authors' conclusions**

Research in this field is limited, though one related review provides some evidence of the effectiveness of personal assistance for children and adolescents with intellectual impairments. 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 both physical and intellectual 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 both physical and intellectual 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 *both* physical impairments (e.g., paralysis) and 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 alone and physical impairments alone 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 only or physical impairments only are considered separately, as are working-age adults and older adults ([Montgomery 2008a](#), [Montgomery 2008b](#), [Mayo-Wilson 2008b](#), [Mayo-Wilson 2008a](#), [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.

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).

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., 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 impairments when physical, 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 et al., 1997). Impairments may affect the quality of life, health, development, and family functioning of children and adolescents (Lavigne 1993; Neely-Barnes 2004; Pit-Ten 2002; Varni 2005).

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). 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, mental and physical health of children and adolescents.

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

## ***Personal assistance***

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.

## **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 both physical and 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 physical and intellectual 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 physical impairments only and intellectual impairments only 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 people 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) or for people with both physical and intellectual impairments. Other measures were included.
- 2) User satisfaction. Direct reports were preferred, though proxies might have been 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, acquisition of skills, and school attendance.
- 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.

### **Outcome intervals**

Outcomes are planned to be 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 used to search CENTRAL, MEDLINE, EMBASE, ASSIA, Sociological Abstracts, EconLit, PsycINFO, SIGLE and C2-SPECTR 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

Assistenter: handikappade

Dagliga livets aktiviteter

Funktionshindrade (Svenska MeSH)

Handikaplagstiftning

Handikappolitik

Handikappreformen

Lagen om assistansersättning

Lagen om stöd och service till vissa funktionshindrade

Lagstiftning Handikappade

LASS LSS LSS-insatser  
Personer med funktionshinder - hem och bostäder (Svenska ämnesord)  
Personer med funktionshinder - vård och omsorg (Svenska ämnesord)  
Personlig assistant  
Personlig assistans (Svenska ämnesord)  
Personliga assistenter: handikappade  
Psyiskt funktionshindrade (Svenska MeSH)  
Psyiskt 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***

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.

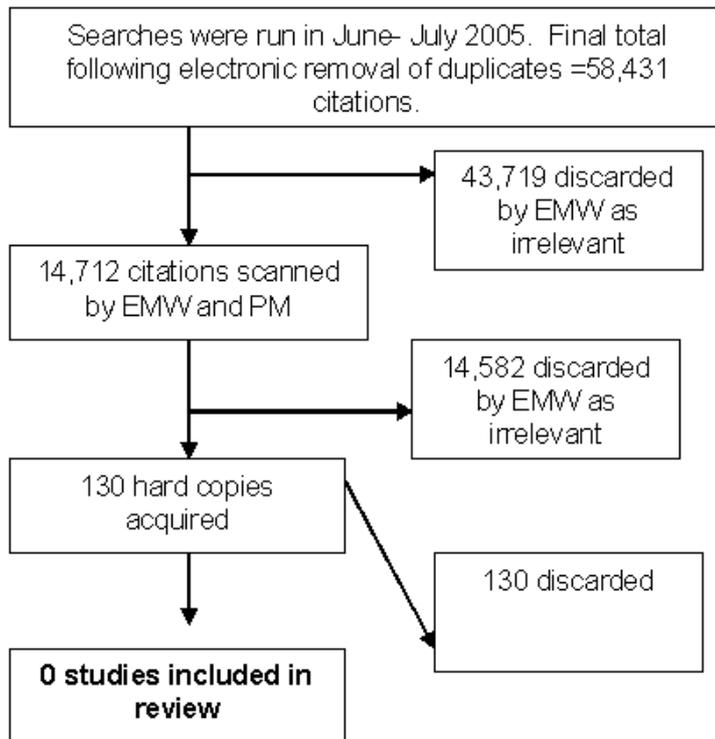
After removing duplicates electronically, 58,431 citations were retrieved for this and related reviews. Based on their titles or abstracts, one reviewer (EMW) eliminated most citations. Two reviewers (EMW and PM) reviewed 14,712 citations independently. Full-texts were reviewed for 130 citations identified 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. While some may have had physical impairments, most participants' needs for

assistance appeared to be related to intellectual impairments. 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 as 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 both physical and intellectual impairments, though the results from a

review of children and adolescents with intellectual impairments might be relevant to users and policymakers.

## **Authors' conclusions**

### **Implications for practice**

There have been few controlled studies of personal assistance for children who require a great deal of assistance for any reason and none for children who require assistance due to both physical and intellectual impairments.

Decisions to provide or not to provide and to take-up or not to take-up personal assistance will be informed by personal values and preferences in addition to evidence of its effectiveness. Some users may wish to consider evidence from other populations and discuss their options with family and friends.

### **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 one study was included in a related review, 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 for children and adolescents with both physical and intellectual impairments. 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**

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## **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

## **Summary of findings tables**

### **Additional tables**

### **References to studies**

#### **Included studies**

#### **Excluded studies**

#### **Studies awaiting classification**

#### **Ongoing studies**

## **Other references**

### **Additional references**

#### ***Abberley 1987***

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Allen MC., Donohue PK, Dusman AE. The limit of viability--neonatal outcome of infants born at 22 to 25 weeks' gestation [see comment]. *New England Journal of Medicine* 1993;329(22):1597-1601.

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## **Other published versions of this review**

## **Classification pending references**

## **Data and analyses**

## **Figures**

## **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

CENTRAL searched via the Cochrane Library Issue 2, 2005

- #1 HOME CARE SERVICES
- #2 ACTIVITIES OF DAILY LIVING
- #3 PERSONAL HEALTH SERVICES
- #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 via CSA 1987 to June 2005 and Sociological Abstracts searched 1980 to June 2005

((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 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)

## 6 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)

#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 (("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\*)

#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

## 7 SIGLE seach 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

## 8 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\*

## 9 Methods from the protocol for use in future updates

Issue	Method
Data extraction and management	<p>Data extraction will be conducted independently by two authors (EMW and PM).</p> <p>The following data will be collected for all trial arms:</p> <ol style="list-style-type: none"><li>1) Descriptive data, including participant demographics (age, gender, types and extent of impairments, living arrangements, social and economic status);</li><li>2) Intervention characteristics (including delivery, duration, and within-intervention variability);</li><li>3) Other interventions received; and</li><li>4) Outcome measures listed above (including multiple measures of outcomes where available).</li></ol> <p>The following data will be collected for all studies:</p> <ol style="list-style-type: none"><li>1) Programme differentiation, i.e. differences in the services received by participants in different arms (<u>Dane 1998</u>; <u>MRC 2000</u>), including crossover between groups; and</li></ol>

	2) Context.
Assessment of risk of bias	<p>Two reviewers (EMW and PM) will independently assign each included study to a quality category described in the Cochrane Handbook (<a href="#">Higgins 2005</a>) where:</p> <p>(A) indicates adequate concealment of the allocation (for example, by telephone randomisation, or use of consecutively numbered, sealed, opaque envelopes);</p> <p>(B) indicates uncertainty about whether the allocation was adequately concealed (for example, where the method of concealment is not known);</p> <p>(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</p> <p>(D) indicates that random allocation was not used.</p> <p>Studies in all quality categories were considered for inclusion in the review and meta-analyses.</p> <p>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 (<a href="#">Deeks 2003</a>). 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.</p> <p>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' (<a href="#">Juni 2001</a>; see also <a href="#">Moher 1995</a>).</p> <p>The following components are considered in the Description of Studies and in Additional Tables:</p> <ol style="list-style-type: none"> <li>1) Allocation bias (Was group assignment determined randomly or might it have been related to outcomes or the interventions received?);</li> <li>2) Performance bias (Could the services provided have been influenced by something other than the interventions being compared?);</li> <li>3) Detection bias (Were outcomes influenced by anything other than the constructs of interest, including biased assessment or the influence of exposure on detection?);</li> <li>4) Report bias (Were the outcomes, measures and analyses selected a priori and reported completely? Were participants biased in their recall or response?);</li> <li>5) Attrition bias (Could deviations from protocol, including missing</li> </ol>

	<p>data and dropout, have influenced the results?) (<a href="#">Delgado 2004</a>; <a href="#">Juni 2001</a>); and</p> <p>6) Outcome validity (Were the outcome measures objective, validated for the population, reported directly by the user or obtained through official records, etc.?).</p>
Multiple measures	<p>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).</p>
Multiple arms	<p>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.</p>
Data synthesis (Outcome data)	<p>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.</p>
Continuous data	<p>Mean differences, standardised mean differences (SMDs) and 95% CIs will be calculated for comparisons of continuous outcome measures.</p>
Dichotomous data	<p>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.</p>
Continuous outcomes	<p>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</p>

	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 ( <a href="#">Higgins 2005</a> ). SMDs will be calculated using Hedges g.
Types of analyses	Studies in which participants are analysed as members of the groups to which they were originally assigned (intention-to-treat analysis), studies that include only those participants who were willing or able to provide data (available-case analysis), and studies that analyse participants who adhered to the study's design (per-protocol analysis; <a href="#">Higgins 2005</a> ) will be analysed separately. Studies in which the reasons for excluding participants from analyses can not be determined from relevant reports or through contact with the authors will be considered with per-protocol analyses.
Homogeneity	The consistency of results will be assessed using the I-squared statistic ( <a href="#">Higgins 2002</a> ; <a href="#">Higgins 2003</a> ). 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.
Subgroup analyses	Large numbers of subgroups may lead to misleading conclusions and are best kept to a minimum ( <a href="#">Counsell 1994</a> ; <a href="#">Oxman 1992</a> ; <a href="#">Yusuf 1991</a> ). 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
Sensitivity analysis	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 ( <a href="#">Deeks 2005</a> ; <a href="#">Egger 1997</a> ; <a href="#">Sterne 2001</a> ). In the event of asymmetry, the reviewers will seek input from methodologists, including the Cochrane and Campbell Collaboration Methods Groups, on appropriate analyses.
Graphs	When meta-analyses are performed, data will be entered into RevMan in such a way that the area to the left of the line of no effect indicates a favourable outcome for personal assistance.