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

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

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REVIEW



The Campbell Collaboration Social Welfare Group

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

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

Review information

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History

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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 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

Personlig assistans (Svenska ämnesord)
Personliga assistenter: handikappade
Psykiskt funktionshindrade (Svenska MeSH)
Psykiskt utvecklingsstörda (Svenska MeSH)
Psykiatireformen
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 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

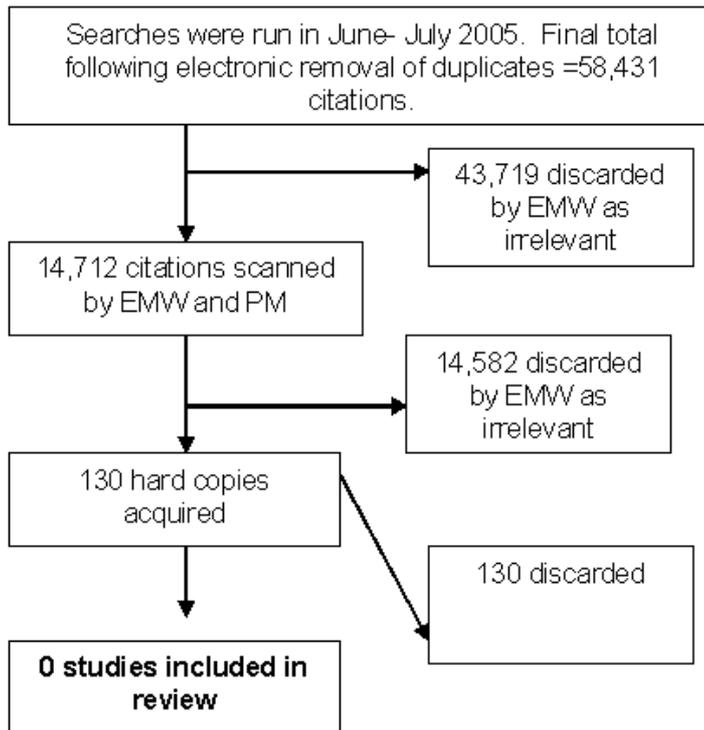
No eligible studies were found.

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.

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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

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Other references

Additional references

Abberley 1987

Abberley P. The concept of oppression and the development of a social theory of disability. *Disability and Handicap in Society* 1987;2:5-19.

Agree 2003

Agree E, Freedman V. A comparison of assistive technology and personal care in alleviating disability and unmet need. *Gerontologist* 2003;43(3):335-44.

Colver 2005

Colver A. A shared framework and language for childhood disability. *Developmental Medicine and Child Neurology* 2005;47:780-4.

Counsell 1994

Counsell C, Clarke M, Slattery J, Sandercock P. The miracle of DICE therapy for acute stroke: fact or fictional product of subgroup analysis? *BMJ Clinical Research* 1994;309(6970):1677-81.

Dane 1998

Dane A, Schneider B. Program integrity in primary and early secondary prevention: Are implementation effects out of control? *Clinical Psychology Review* 1998;18:23-45.

Deeks 2003

Deeks J, Dinnes J, D'Amico R, Sowden A, Sakarovitch C, Song F, et al. Evaluating non-randomised intervention studies. *Health Technology Assessment* 2003;7(27):1-173.

Deeks 2005

Deeks J, Macaskill P, Irwig L. The performance of tests of publication bias and other sample size effects in systematic reviews of diagnostic test accuracy was assessed. *Journal of Clinical Epidemiology* 2005;58(9):882-93.

Delgado 2004

Delgado Rodriguez M, Llorca J. Bias. *Journal of Epidemiology and Community Health* 2004;58(8):635-41.

Dupré 2003

Dupré, Karjalainen A. Employment of disabled people in Europe in 2002. EuroStat, European Union; 25 November 2003.

Egger 1997

Egger M, Davey Smith G, Schneider M, Minder C. Bias in meta-analysis detected by a simple, graphical test. *BMJ Clinical Research* 1997;315(7109):629-34.

EuroQol-Group 1990

EuroQol-Group. EuroQol-a new facility for the measurement of health-related quality of life. The EuroQol Group. *Health Policy* 1990;16(3):199-208.

Goodman 1998

Goodman R, Meltzer H, Bailey V. The strengths and difficulties questionnaire: A pilot study on the validity of the self-report version. *European Child and Adolescent Psychiatry* 1998;7(3):125-30.

Goodman 1999

Goodman R. The extended version of the Strengths and Difficulties Questionnaire as a guide to child psychiatric caseness and consequent burden. *Journal of Child Psychology and Psychiatry* 1999;40(5):791-9.

Hagglund 2004

Hagglund KJ, Clark MJ, Mokelke EK, Stout BJ. The current state of personal assistance services: implications for policy and future research. *Neurorehabilitation* 2004;19(2):115-20. 2004;19(2):115-20.

Hammal 2004

Hammal D, Jarvis S, Colver A. Participation of children with cerebral palsy is influenced by where they live. *Developmental Medicine and Child Neurology* 2004;46(5):292-298.

Higgins 2002

Higgins J, Thompson S. Quantifying heterogeneity in a meta-analysis. *Statistics in Medicine* 2002;21(11):1539-58.

Higgins 2003

Higgins J, Thompson S, Deeks J, Altman D. Measuring inconsistency in meta-analyses. *BMJ Clinical Research* 2003;327(7414):557-60.

Higgins 2005

Higgins JPT, Green S, editors. *Cochrane Handbook for Systematic Reviews of Interventions* 4.2.5 [updated May 2005]. In: *The Cochrane Library, Issue 3*. Chichester, UK: John Wiley & Sons, Ltd, 2005.

Hogan 1997

Hogan DP, Msall ME, Rogers ML, Avery RC. Improved disability population estimates of functional limitation among American children aged 5-17. *Maternal & Child Health Journal* 1997;1(4):203-16.

Jackson 2005

Jackson N, Waters E. Criteria for the systematic review of health promotion and public health interventions. *Health Promotion International* 2005;20(4):367-74.

Juni 2001

Juni P, Altman DG, Egger M. Systematic reviews in health care: Assessing the quality of controlled clinical trials. *BMJ Clinical Research* 2001;323(7303):42-6.

Keigher 2000

Keigher S. The interests of three stakeholders in independent personal care for disabled elders. *Journal of Health and Human Services Administration* 2000;23(2):136-60.

Landgraf 1997

Landgraf J. Functional status and well-being of children representing three cultural groups: Initial self-reports using the CHQ-CF87. *Psychology and Health* 1997;12(6):839-854.

Larroque 2008

Larroque B, Ancel P-Y, Marret S, Marchand L, André M, Arnaud C, Pierrat V, Rozé J-C, Messer J, Thiriez G, Burguet A, Picaud J-C, Bréart G, Kaminski M, for the EPIPAGE Study group. Neurodevelopmental disabilities and special care of 5-year-old children born before 33 weeks of gestation (the EPIPAGE study): a longitudinal cohort study. *The Lancet* 2008;371:813-820.

Lavigne 1993

Lavigne J, Faier Routman J. Correlates of psychological adjustment to pediatric physical disorders: a meta-analytic review and comparison with existing models. *Journal of Developmental and Behavioral Pediatrics* 1993;14(2):117-23.

Mackie 1998

Mackie P, Jessen E, Jarvis S. The lifestyle questionnaire: An instrument to measure the impact of disability on the lives of children with cerebral palsy and their families. *Child: Care, Health and Development* 1998;24(6):473-486.

Mayo-Wilson 2008a

Mayo-Wilson E, Montgomery P, Dennis J. Personal assistance for adults (19-64) with both physical and intellectual impairments. *Cochrane Database of Systematic Reviews* 2008, Issue 2. Art. No.: CD006860. DOI: 10.1002/14651858.CD006860.pub2.

Mayo-Wilson 2008b

Mayo-Wilson E, Montgomery P, Dennis J. Personal assistance for children (0 - 18) with both physical and intellectual impairments. *Cochrane Database of Systematic Reviews* 2008, Issue 3.

Mayo-Wilson 2008c

Mayo-Wilson E, Montgomery P, Dennis J. Personal assistance for adults (19 - 64) with physical impairments. *Cochrane Database of Systematic Reviews* 2008, Issue 3.

McLennan 2000

McLennan JD, Kotelchuck M. Parental prevention practices for young children in the context of maternal depression. *Pediatrics* 2000;105(5):1090-5.

McMurtry 2000

McMurtry S, Hudson W. The Client Satisfaction Inventory: Results of an initial validation study. *Research on Social Work Practice* 2000;10(5):644-63.

Mihaylov 2004

Mihaylov S, Jarvis S, Colver A, Beresford B. Identification and description of environmental factors that influence participation of children with cerebral palsy. *Developmental Medicine and Child Neurology* 2004;46(5):299-304.

Moher 1995

Moher D, Jadad AR, Nichol G, Penman M, Tugwell P, Walsh S. Assessing the quality of randomized controlled trials: An annotated bibliography of scales and checklists. *Controlled Clinical Trials* 1995;16(1):62-73.

Moher 1999

Moher D, Cook D, Eastwood S, Olkin I, Rennie D, Stroup D. Improving the quality of reports of meta-analyses of randomised controlled trials: the QUOROM statement. *Lancet* 1999;354:1896-900.

Montgomery 2008a

Montgomery P, Mayo-Wilson E, Dennis J. Personal assistance for adults (65+) without dementia. *Cochrane Database of Systematic Reviews* 2008, Issue 2. Art. No.: CD006855. DOI: 10.1002/14651858.CD006855.pub2. [Other: DOI]

Montgomery 2008b

Montgomery P, Mayo-Wilson E, Dennis J. Personal assistance for children and adolescents (0-18) with intellectual impairments. *Cochrane Database of Systematic Reviews* 2008, Issue 3.

Morse 2006

Morse SB, Wu SS, Ma C, Ariet M, Resnick M, Roth J. Racial and gender differences in the viability of extremely low birth weight infants: a population-based study. *Pediatrics* 2006;117(1):106-112.

MRC 2000

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

Neely-Barnes 2004

Neely-Barnes S, Marcenko M. Predicting impact of childhood disability on families: Results from the 1995 National Health Interview Survey Disability Supplement. *Mental Retardation* 2004;42(4):284-293.

Newacheck 1988

Newacheck PW, Halfon N. Preventive care use by school-aged children: differences by socioeconomic status. *Pediatrics* 1988;82(3):462-8.

Newacheck 2004

Newacheck P, Inkelas M, Kim SE. Health services use and health care expenditures for children with disabilities. *Pediatrics* 2004;114(1):79-85.

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

Oliver M. The politics of disablement. London: Macmillan, 1990.

Oxman 1992

Oxman A, Guyatt G. A consumer's guide to subgroup analyses. *Annals of Internal Medicine* 1992;116(1):78-84.

Pit-Ten Cate 2002

Pit-Ten Cate I, Kennedy C, Stevenson J. Disability and quality of life in spina bifida and hydrocephalus. *Developmental Medicine and Child Neurology* 2002;44(5):317-22.

Ratzka 1986

Ratzka A. Independent living and attendant care in Sweden: A consumer perspective: Monograph no. 34. New York: World Rehabilitation Fund, 1986.

Resnick 1998

Resnick MB, Gomatam SV, Carter RL, Ariet M, Roth J, Kilgore KL. et al. Educational disabilities of neonatal intensive care graduates. *Pediatrics* 1998;102(2):308-14.

Rossiter 2001

Rossiter L, Sharpe D. The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies* 2001;10:65-84.

Sharpe 2002

Sharpe D, Rossiter L. Siblings of children with a chronic illness: A meta-analysis. *Journal of Pediatric Psychology* 2002;27(8):699-710.

Socialstyrelsen 2005

Socialstyrelsen. Personlig assistans. En inventering av forskningslaget. [personal assistance. An overview of research].. Stockholm, The Swedish National Board of Health and Welfare (Socialstyrelsen).

Sterne 2001

Sterne J, Egger M. Funnel plots for detecting bias in meta-analysis: guidelines on choice of axis. *Journal of Clinical Epidemiology* 2001;54(10):1046-55.

Thyen 1998

Thyen U, Terres N, Yazdgerdi S, Perrin J. Impact of long-term care of children assisted by technology on maternal health. *Journal of Developmental & Behavioral Pediatrics* 1998;19(4):273-282.

UN 1990

UN. Disability Statistics Compendium (Statistics on Special Population Groups). Department of International Economic and Social Affairs Statistical Office, United Nations.

Varni 2005

Varni J, Burwinkle T, Sherman S, Hanna K, Berrin S, Malcarne V, et al. Health-related quality of life of children and adolescents with cerebral palsy: Hearing the voices of the children. *Developmental Medicine and Child Neurology* 2005;47(9):592-597.

Ware 1992

Ware J, Sherbourne C. The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical Care* 1992;30(6):473-483.

Wenger 1995

Wenger B, Kaye S, LaPlante M. Disabilities Among Children. Disability Statistics Abstract No 15:. U.S. Department of Education 1995.

WHO 2003

WHO. International classification of functioning, disability and health. Geneva: World Health Organization, 2003.

Witt 2001

Witt W-P. Family stressors, psychosocial functioning, and mental health care utilization among disabled children: Results from the 1994 -1995 national health interview survey, disability supplement [PhD]. The Johns Hopkins University; 2001.

Yusuf 1991

Yusuf S, Wittes J, Probstfield J, Tyroler HA. Analysis and interpretation of treatment effects in subgroups of patients in randomized clinical trials. JAMA 1991;266(1):93-8.

Zarb 1994

Zarb G, Nadash P. Direct payments for personal assistance. Findings: Social Policy Research 1994;64.

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

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 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)
#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

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

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"> 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). <p>The following data will be collected for all studies:</p> <ol style="list-style-type: none"> 1) Programme differentiation, i.e. differences in the services received by participants in different arms (Dane 1998; MRC 2000), including crossover between groups; and 2) Context.
Assessment of risk of bias	<p>Two reviewers (EMW and PM) will independently assign each included study to a quality category described in the Cochrane Handbook (Higgins 2005) 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 (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.</p> <p>Existing scales for measuring the quality of controlled trials have not been properly developed, are not well-validated and are known to</p>

	<p>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).</p> <p>The following components are considered in the Description of Studies and in Additional Tables:</p> <ol style="list-style-type: none"> 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	<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	<p>Meta-analyses may be conducted to combine comparable outcome</p>

(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.
Continuous data	Mean differences, standardised mean differences (SMDs) and 95% CIs will be calculated for comparisons of continuous outcome measures.
Dichotomous data	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.
Continuous outcomes	Continuous outcome measures may be combined when means and standard deviations or complete significance testing statistics are available, unless statistical tests assuming normality would be inappropriate. For example, for scales beginning with a finite number (such as 0), effect estimates will not be combined unless a mean is greater than its standard deviation (otherwise the mean would be very unlikely to be an appropriate measure of the centre of the distribution). If continuous outcomes are measured identically across studies, an overall weighted mean difference (WMD) and 95% CI may be calculated. If the same continuous outcome is measured differently across studies, an overall standardised mean difference (SMD) and 95% CI may be calculated (Higgins 2005). SMDs will be calculated using Hedges g.
Types of analyses	Studies in which participants are analysed as members of the groups to which they were originally assigned (intention-to-treat analysis), studies that include only those participants who were willing or able to provide data (available-case analysis), and studies that analyse participants who adhered to the study's design (per-protocol analysis; Higgins 2005) will be analysed separately. Studies in which the reasons for excluding participants from analyses can not be determined from relevant reports or through contact with the authors will be considered with per-protocol analyses.
Homogeneity	The consistency of results will be assessed using the I-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.
Subgroup analyses	Large numbers of subgroups may lead to misleading conclusions and are best kept to a minimum (Counsell 1994; Oxman 1992; Yusuf 1991). If possible, this review will include separate effect estimates for the following subgroups: 1) Organisation of services

	<p>2) Place of residence</p> <p>3) Acquisition of impairment</p> <p>4) Amount of assistance</p>
Sensitivity analysis	<p>Sensitivity analyses will investigate the influence of lower quality studies (i.e., those rated C and D on allocation concealment) on the results of the review. To investigate the possibility of bias, including publication bias, funnel plots will be drawn (Deeks 2005; Egger 1997; Sterne 2001). In the event of asymmetry, the reviewers will seek input from methodologists, including the Cochrane and Campbell Collaboration Methods Groups, on appropriate analyses.</p>
Graphs	<p>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.</p>