

Campbell Collaboration Social Welfare Coordinating Group
Title Registration Form

Please complete this form to begin the process of registering a review with the Campbell Collaboration Social Welfare group. When approved by the editorial board, the title and registration form will be posted in the Campbell Library (<http://www.campbellcollaboration.org/Fralibrary2.html>). Please be explicit about what you will and will not do. Use as much space in the form as you wish. Please return the completed form to awi@nokc.no.

1. Title of review (Suggested format: [intervention/s] for [outcome/s] in [problem/population] in [location/situation]. Example: behavioural therapy for reducing violence among adolescents in institutions)

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

2. Background and objective of this review (Briefly describe the problem and the intervention.)

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.

Over six million (12.3%) American children and adolescents experience some type of functional limitation. 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. Impairments are more prevalent in boys than in girls and more prevalent in low-income families than in high-income families.

Proponents of the social model of disability regard activity restrictions as caused by societal and structural barriers and stress the need for their removal. Independence is defined not as doing things alone but as making decisions for oneself and exerting control over how help is provided.

Personal assistance is paid support given to people 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 is designed for people with permanent impairments and differs from rehabilitative services and from services provided for fixed periods of time in that it is indefinite and ongoing.

Some form of personal assistance is now available (often by statutory right) in all Nordic countries, most Western European countries, Australia, parts of Asia, the U.S. and Canada. The naming and management of personal assistance (including degree of user control) may vary from country to country, which is often related to legislative categories rather than types of interventions.

This review will assess the effectiveness of personal assistance and the impacts of personal assistance on families and carers compared to other interventions.

3. Define the population (Who is included and who is excluded?)

Children and adolescents (0-18) living in the community who require assistance to perform tasks of daily living (bathing, eating, getting around, etc.) and 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 outside their own homes (e.g., in private or public institutions for people with impairments) will be excluded.

Children and adolescents with physical impairments only and intellectual impairments only will be excluded because these impairments affect activities and participation differently.

4. Intervention/s (What is given, by whom, and for how long? What are the comparison conditions?)

In consultation with experts and the reference group, the reviewers sought to determine what minimal amount of assistance could be offered and still follow the personal assistance model for this population.

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 partners 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.

5. Outcome/s (What are the intended effects of the intervention? Primary and secondary outcomes should all be mentioned.)

Primary outcomes will include:

- 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 will be considered, a review of global health measures found that 'very few measures have been validated specifically for cognitively impaired respondents' (Riemsma 2001) or for people with both physical and intellectual impairments.
- 2) User satisfaction. Direct reports will be preferred, though proxies might be used if users are unable to communicate.
- 3) Participation, including social activities, ability to participate in spontaneous activities, time outside the home, and mobility.

Secondary outcomes will include:

- 1) Unmet needs, particularly the inability to perform activities of daily living.
- 2) 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 include 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 include the Short-Form Health Survey (Ware 1992) or General Health Questionnaire (Counsell 1994).
- 6) Direct and indirect costs, both immediate and long-term.

6. Methodology (What types of studies are included and excluded? Please describe eligible study designs, control/comparison groups, measures, and duration of follow-ups.)

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.
All relevant measures will be assessed and longterm followup will be sought.

Reviewer/s

Lead reviewer (Name, address, telephone, fax, e-mail):

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Other reviewer/s:

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Do you need support in any of these areas: methodology and causal inference, systematic searches, coding, statistics (meta-analysis)?

Once the editorial board approves the registration of your title, you have six months to complete the protocol. If the protocol is not finished after six months, the review area is opened up for others. Queries should be addressed to awi@nokc.no

Revised 22 July 2005