Personal assistance offers people with impairments choice of service and greater quality of life

Six new Campbell systematic reviews examine research on the effect of personal assistance for people with impairments and elderly people. Several studies, including a large US randomised controlled trial, suggest that personal assistance increases the quality of life for elderly people as well as younger people with impairments. The state of evidence may change as new studies emerge.

A widely used intervention
People who have muscular dystrophy, suffer from a brain injury or who have become frail with old age often have difficulties taking part in society on equal terms with others. An increasing number of people are born with physical or intellectual impairments or acquire them later in life. Furthermore, the elderly population is increasing. A great number of local-government authorities therefore offer personal assistance for people with impairments to help people take part in all parts of society. Personal assistance is customised support that may include help in all areas of life, including transportation, social activities, work, education, shopping, eating and hygiene. Personal assistance is offered in different forms in most western countries. This type of intervention is especially widespread in the Nordic countries, where personal assistance is often a statutory right.

Six new Campbell systematic reviews have examined the effect of personal assistance on quality of life for people of all ages with physical and intellectual impairments.

Can increase quality of life
A very large US randomised controlled trial examined the effect of personal assistance on quality of life and user satisfaction in four out of the six target groups, namely children with intellectual impairments, adults with physical impairments, adults with both physical and intellectual impairments and older adults (65+). The study suggests that personal assistance has a positive effect on quality of life and user satisfaction for all four target groups. The positive outcomes for older adults (65+) in this trial are consistent with outcomes in three smaller studies using less rigorous designs. Furthermore, the positive outcomes for adults with physical and intellectual impairments are consistent with the outcomes in another small study.

The US study randomised the participants to personal assistance or to other publicly-paid support (the control group). Participation in the trial was on a voluntary basis, that is, participants were themselves interested in having a personal assistant. Participants with a personal assistant became more satisfied with life. About half were very satisfied with the way they were spending their lives,
whereas this was true for only just under one-third in the control group. Children with intellectual impairments experienced the greatest progress, as reported by their parents.

These studies all aim to assess ‘soft values’ (such as quality of life and user satisfaction) as well as hard outcomes, such as nursing home admission. They show that rigorous research designs, including randomised controlled trials, can measure impacts on all sorts of outcomes. Randomised controlled trials actually provide a very accurate picture of the effect on users’ quality of life and satisfaction.

**One among many interventions**
In the systematic reviews, personal assistance is defined as: support for at least 20 per week, in the user’s home, by a paid assistant other than a healthcare professional. The paid assistant is therefore typically trained and employed directly by the user. In many places, users form cooperatives to help train and pay assistants. These user groups may charge a fee to handle administrative duties like performing background checks and collecting taxes.

All six systematic reviews emphasise that there might also be disadvantages from personal assistance. Frequent replacements, low salaries and lack of training and education of paid assistants may limit positive impacts. Furthermore, there is the risk that a personal assistant might reduce rather than enhance a user's self-sufficiency relative to alternative forms of support. To allow people to make best use of resources, policymakers might allow people to spend money on assistants, home modification, assistive devices, transportation, or whatever mix of services they feel would be most useful.

**More studies are needed**
Four of the systematic reviews, the outcomes of which are outlined above, examine the effects for four different groups: older adults (65+), adults with physical impairments, adults with physical and intellectual impairments, and children and adolescents with physical impairments. For these groups, the authors found studies with relevant, reliable and mutually consistent outcomes.

However, for the two remaining systematic reviews, the authors did not find any relevant studies of a quality high enough to warrant inclusion in the reviews. These reviews hoped to examine the effect of personal assistance for children with physical impairments and children with both physical and intellectual impairments.

All six systematic reviews observe that personal assistance schemes are increasingly popular. However, personal assistance can be organised in different ways, and other combinations of services might be ideal for certain groups of people. Further studies would help users and policymakers determine the best mix of service options.