The role of ICT support services to promote ageing in place

The ACTION service

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Summary: ACTION (Assisting Carers using Telematics Interventions to meet Older people’s Needs) is an innovative example of an Information and Communication Technology (ICT) based support service that is currently running in Sweden to help empower older people with chronic conditions and their family carers in their daily lives. The service is outlined and the main evaluation findings are presented. Sirpa explains how ACTION has been of direct benefit in her caring situation. The main lessons learned over a fourteen year period of implementing ACTION in Sweden are highlighted, concluding with the main challenges facing researchers, policy makers and decision makers in the immediate future.

Key words: family caregivers, frail older adults, empowerment, videoconferencing, multimedia, Sweden

ACTION, ‘Assisting Carers using Telematics Interventions to meet Older people’s Needs’, stemmed from an EU-funded project (1997–2000) and is an Information and Communication Technology (ICT) based support service designed together with older people with long-standing chronic conditions living at home and their family carers to help empower them in their daily lives. It is currently running as a mainstream service in the Borås municipality in western Sweden, with implementation projects in an additional twenty municipalities across Sweden.

ACTION is a self-care and family care support service which promotes ‘ageing in place’ as older people with chronic illnesses and their family carers are able to access relevant and accessible information, education and support when needed from the comfort of their own home. Furthermore, the ICT based service helps to promote social inclusion within the current digital information society for those older citizens who are at risk of being excluded from the benefits afforded by modern technology.1

The ACTION service in brief

The ACTION service consists of the following integrated components:
1. Multimedia educational caring programmes
2. The ACTION application
3. The ACTION call centre
4. Education and support

Multimedia educational programmes

The multimedia educational programmes are based on carers’ and older people’s needs identified from the empirical literature and extensive user consultation in the EU and Swedish ACTION projects. These programmes are: caring skills in daily life; planning ahead; respite care; economic support; a service guide; coping strategies; living with dementia; and life after a stroke. Additionally, there are programmes for physical and cognitive training and online games for leisure2,3.

ACTION application

The ACTION application consists of a personal computer with broadband connection which is installed in each family’s home. Families also have access to the Internet itself and email facilities. The multimedia programmes are accessed over the Internet. Internet videophone facilities are provided via a small web camera placed on top of the computer screen and an integrated user-friendly videophone programme installed in the computer. This enables families to have visual and oral contact with other participant families, as well as with care practitioners at a dedicated call centre.

ACTION call centre

The ACTION call centre is run by practitioners with experience in caring for older people and their families. They maintain regular contact with families to ensure that they are managing their situation as well as providing advice and support on an as need basis. They are also responsible for computer education and facilitate and maintain informal networks between users.
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Education and supervision

Fourth, families are invited to take part in an initial education programme to learn how to use the ACTION service, as the majority of users are predominantly computer novices. This programme consists of a series of small group ‘hands on’ computer education sessions during which participants get to know each other and subsequently initiate videophone contact. Additionally, the comprehensive education, follow-up and certification programme, including regular supervision, is targeted at care practitioners working in the ACTION call centres in the municipality.4

Evaluation results

Evaluation results from successive projects with a total of approximately 400 users reveal that the majority, similar to Sirpa, are highly satisfied with the service and consider it to have helped improve everyday quality of life. The over-riding result is that both family carers and the older person they care for feel less isolated as they developed informal support networks with other participant families in similar situations. Also, service users feel that new technology is good to use providing that it is easy to understand and use and is of direct benefit in their caring situations. Nearly all users were previously computer novices and included older people with chronic long-standing conditions and older family carers who are to a large extent housebound due to illness

and/or caring responsibilities2,5,6. In this way, ACTION helped to enhance their social inclusion.

Questionnaire and interview data revealed that after using the ACTION system in their own homes for a minimum period of three months, participant family carers, such as Sirpa, felt more competent and secure in their caregiving role; they had gained more control over their individual caring situation and had increased their self confidence in their ability to care. Focus group interview data with ACTION call centre practitioners highlighted that they experienced improved job satisfaction as a result of working in partnership with families to help empower them in their situation. They saw significant scope for future development in the area of telecare as a means of providing a more effective way of providing ‘non-hands on’ elements of care such as advice, information giving and support for older people with long term care needs and their family carers.3,6

At the municipality level, a small cost descriptive study involving five ACTION families revealed reduced care costs with an average saving of €10,300 per family per year as a result of reduced use of home help services and delayed entry to nursing home. A Needs Assessor who knew the families well was asked to calculate what they should have needed in terms of care services if they had not received ACTION. The researcher (LM) then carried out a cost calculation which was sent to the families prior to a home visit in which the researcher and Needs Assessor reviewed the data together with the respective participant families. All the families except one agreed with their cost calculation. The carer who did not agree explained that she could never accept under any circumstances to ‘send’ her husband to a nursing home. In this case, the costs were modified accordingly.7

Main lessons learned

There are relatively few examples of ICT based support interventions for older people and their carers within Europe that have successfully undergone the transformation from a project to a mainstream service. This leads to the question of what are the critical success factors behind ACTION? The main reasons behind ACTION’s success can be summarised as follows.

First, the service was designed together with older people with chronic illnesses and their carers to meet their needs, preferences and situation, as opposed to being based solely on what professionals consider older people want and need (see6 for methods of user involvement within the design of ACTION).

A second success factor is the overall acceptability of the mode of delivery of the service which means that ACTION continues to have an innovative appeal and is a socially desirable phenomenon amongst end users many of whom are computer novices.

Third, the service is research-based and has undergone iterative cycles of development and evaluation based on extensive feedback from all key stakeholder groups. Interestingly, the cost evaluation data together with the quality of life data proved to be
critical in the formal decision making process taken by Börås’s older people social services committee in 2004 to integrate the ACTION service within their existing support services for older people. Furthermore, in the case of Börås municipality, the ACTION service has received ongoing support from all key stakeholder groups from end users, care practitioners, decision makers, politicians and representatives of voluntary and pension organisations through to business partners and university representatives. Without solid partnerships and co-operation with all these diverse players the continued adoption of the service would not have been possible.

Nevertheless, there remain significant hurdles as the ACTION service has not penetrated all 290 municipalities in Sweden. The key challenges largely reflect those previously identified within the empirical literature in the field and which can be summarised as follows: implementing ACTION within everyday practice is not simply about installing and learning to use the technology, rather it involves changing the way in which care practitioners and managers view and carry out their work. Namely, to work proactively in partnership with older people to help empower families to manage their caring situations, rather than being crisis oriented. A second and related barrier is the negative attitudes held by many health and social care professionals regarding the use of modern technology within care for older people. To this end we have developed a comprehensive education, supervision and certification programme directed at staff involved in implementing ACTION in municipalities, so as to provide credible role models (see www.actioncaring.se).

A third challenge is the continuous work required to maintain ongoing support from all stakeholder groups. Frequent staff turnover rates at management and grassroots level in the municipalities calls for regular awareness raising and education sessions with front-line staff, management and other health and social care professionals working with older people, as well as user and carer representatives.

A fourth challenge, which is commonly highlighted within the empirical literature, is the lack of rigorous empirical evidence. Similarly to the ACTION service, there is some evidence with regards to its impact at the level of the individual/family. However, it is much more difficult to reveal the long-term cost effectiveness of the service at a meso or organisational level and further at a macro or societal level. Frequently quoted challenges in the literature are the lack of a suitable comparator, the need for sufficient data collected on a systematic basis over time, and the need for sensitive outcome measures.

A fifth challenge is the lack of a sufficient critical mass of end users that have used ACTION over a prolonged period of time. Municipalities are often wary of investing in more than twenty users and for a longer period than a year. This leads to a “Catch 22” situation as the lack of rigorous evidence is often cited as the main reason for decision makers in Sweden to decline making a major investment in ACTION.

A sixth challenge concerns the need for a sound and responsive business plan and model. In order to make ACTION more widely available following the EU project, a university spin-off research and development company was established and a business agreement struck with Telia Sonera, Sweden’s largest telecommunication company. Nevertheless, a business plan needs to continually respond to the demands of a fluid market so that other potential options are considered, such as a consumer oriented model in which the service is offered directly to private users and/or entering into collaboration with a civil society organisation to jointly offer the service.

A seventh challenge concerns the need for suitable policy to be in place at all levels: local, regional, national and EU level as this helps to ‘push-start’ the use of new technology based solutions within health and social care for older people. Finally, funding from governmental and research and development agencies in Sweden has been crucial for the continued research and development of the ACTION service. In the future, there needs to be strategic larger-scale and long term implementation work, otherwise there will continue to be the risk of financing small-scale pilot projects which may duplicate results without creating a sufficient critical mass to have the significant impacts outlined in this article.

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