

Social Care: a new initiative in England to fill evidence gaps

Martin Knapp and Angela Mehta

Many millions of adults in Europe are receiving social care, which can be defined as support for individuals with the activities of their daily lives, which can range across personal needs, domestic tasks, social activities and friendship. Most of this support is unpaid care from family and friends, but there are also large numbers of community organisations, charities, for-profit (private) companies and state bodies delivering 'organised' care services.

With the ageing of populations in European countries, and indeed with the longer survival into old age of increasing numbers of people with disabilities and enduring illnesses (people who, in previous generations, would generally not have lived for as long), the future social care challenge facing Europe is clearly enormous.

The largest groups of users are older people, children and adolescents, people with long-term disabilities or conditions, and those with sensory impairments. Depending on the country, other groups might be using social care services. Indeed, the term 'social care' is not universally applied: other common terms are 'welfare services', 'personal social services', and 'social services'. Unlike health care, there is less international consensus not only about terminology, but about what is included in the sector, and certainly there is less awareness among the general population of the social care needs of

individuals or what services can do to meet them.

Again, in contrast to health and health care, the evidence base upon which practice and policy decisions are taken in social care is rather less well developed. Although hard to substantiate with figures, it would generally be recognised that there has not been the same level of investment in robust research. Consequently, governments, state agencies, community organisations and others do not have much of a platform of evidence about how to meet needs, improve quality of life, or pursue cost-effectiveness.

Challenges

It is an enormous task to ensure that support and care are available for people who need them, and that the arrangements are what those individuals want. So too is the task of generating and organising resources so as to achieve the best outcomes in an efficient, equitable manner. Another challenge is to dovetail responses and activities across different sectors – making sure that central, regional and local government agencies work effectively with the voluntary and community sector, as well as with for-profit entities.

Most importantly, responses must be planned sensitively and appropriately with families and other unpaid carers. There is also an obvious need to make sure that action across different service systems – particularly social care, health, housing, education, social security and transport –

is coordinated with the best interests and the preferences of the individual in mind, while cognisant of resource constraints.

Research needs

Clearly social care touches the lives of many people. It contributes a huge amount to the nation's well being and health. To support the development of social care practice in Europe, there is a need for research evidence on what people want, how it can be provided, what works and what it costs. All of this is needed to provide policy makers with the tools to develop innovative, cost-effective services.

Evidence generated by research has the potential to contribute substantially to meeting these challenges. But that research needs to be carefully planned, competently executed and skilfully communicated to target audiences.

New investment in adult social care research in England

The National Institute of Health Research (NIHR)*, located within the Department of Health, spends considerable amounts on health and social care research in England. Established in April 2006 to carry forward the vision, mission and goals outlined in the Government's health research strategy for England, *Best Research for Best Health*, the NIHR had a £790 million revenue budget with £31 million capital funding in 2008/09.^{1,2} Its vision is to improve the health and wealth of the nation through research.

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* The National Institute for Health Research (www.nihr.ac.uk) provides the framework through which the research staff and research infrastructure of the National Health Service (NHS) in England is positioned, maintained and managed as a national research facility. The NIHR provides the NHS with the support and infrastructure it needs to conduct first-class research funded by the Government and its partners alongside high-quality patient care, education and training. Its aim is to support outstanding individuals (both leaders and collaborators), working in world class facilities (both NHS and university), conducting leading edge research focused on the needs of patients.

The impacts of social care services both to the public purse and to individuals in England are substantial (Box 1). In 2008, the Department of Health in England announced plans to set up a national School for Social Care Research (SSCR), to be established within the NIHR. The new School formally began work in May 2009 with a budget of £15 million over five years, almost all of which was to be spent on new research.

The School is a partnership between six leading centres of social care research in England. It is directed by Martin Knapp (London School of Economics and Political Science) and there are five Associate Directors: David Challis (University of Manchester), Caroline Glendinning (University of York), Jill Manthorpe (King's College London), Jim Mansell (University of Kent) and Ann Netten (University of Kent). Its primary aim is to develop the evidence base for adult social care practice in England and so help to improve the quality of care and support experienced by individuals and families. It will conduct and commission high-quality ('world class') research to produce new knowledge (including, where appropriate, reviews and syntheses of existing evidence) to inform the development of adult social care practice in England.

Consultation and commissioning

The School is consulting with a wide range of people interested in social care – whether as users, unpaid carers, paid practitioners, providers, managers, strategic decision-makers, and researchers. More than a hundred research suggestions have been received thus far. One reason is to identify areas where new research evidence could help to improve practice and so improve people's lives. The School is also working with an Advisory Board of highly experienced, motivated individuals; and with a User, Carer, Practitioner Reference Group to develop research ideas and to ensure wider involvement in the projects that are funded.

The SSCR is now commissioning research projects with a clear element of originality, and which have relevance and potential to improve adult social care practice in England. Research can be commissioned from anywhere – not just from researchers in England – but the findings must be relevant to English adult social care. Further calls for proposals are expected in 2010 and details will be provided on the School's website (www.sscr.nihr.ac.uk), which also

has summaries of commissioned studies.

The School is also currently commissioning expert reviews on research methods in the field, with a number recently agreed (for completion by summer 2010). They focus on:

- Randomised controlled trials
- User-led research
- Modelling
- Research methods and visual impairment
- Observational methods with a focus on learning disabilities
- Sexualities in social care research
- Outcome measurement overview
- Cost-effectiveness
- Large-scale datasets
- End-of-life care research methods
- Social care research and black and minority ethnic groups
- Research in care homes
- Qualitative methods
- Systematic reviewing

It takes longer to commission research projects, but again some progress has been made. Among those projects commissioned are: a scoping study focusing on individualisation of services; an investigation of practice models for social care practice with carers; a scoping study on care and support for people with complex and severe needs, looking at innovations and practice; and a study of the costs and outcomes of skilled support for adults with complex needs in supported accommodation. Another five projects are soon to be commissioned.

Path-breaking initiative

The NIHR School for Social Care Research is the first of its kind. It was the initiative of Professor Dame Sally Davies, Director General of Research and Development at the Department of Health, who announced the establishment of the School with the aspiration that "the new NIHR SSCR ... will give researchers the time and

Social care practice in England

In England, social care services are utilised by many people and much of the population will use such services in their lifetime – the lifetime risk of entering residential or nursing home care is around one in six for a man and one in three for a woman in England. In 2007–08, 1.75 million adults in England used social care services, with a spend of £16.5 billion by local municipalities on social care for adults, while another £3.5 billion was spent by older people on their own care because they were ineligible for public financial support.

Social care provision in England is provided through services and support offered by local authority adult services departments, the independent sector, third sector organisations, unpaid family and other carers. In 2007–08 there were approximately 18,000 care homes with 450,000 places for adults and 42,000 home care agencies in England, with an additional one million people supported in their own homes.³ About 1.5 million people worked in adult social care, and 5.2 million people provided unpaid care (and a third of them did so for twenty or more hours per week).

funding to ask the important questions and improve our understanding of what works, what doesn't work and why. This new School will provide considerable benefit to the health and well-being of the population through the new knowledge gained."

Social care aims to reduce, lessen the consequences of, or compensate for disability or disadvantage by supporting families and communities as well as empowering individuals by lessening their dependence, and to improve quality of life. A key objective is often to support people so that they can enjoy the ordinary, everyday aspects of life experienced by the rest of the population. In this context of a multitude of unanswered questions about social care, £15 million is modest, but it represents a very important step in the development of this research area.

For further information visit the School's website at www.sscr.nihr.ac.uk or contact the SSCR (sscr@lse.ac.uk).

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Child and adolescent mental health in Europe

Research on best practice

Dainius Puras and Egle Sumskiene

This snapshot looks at the Child and Adolescent Mental Health in an Enlarged European Union: Development of Effective Policies and Practices (CAMHEE) project. This European Commission (EC) funded project aimed to provide a set of guidelines for effective mental health policies and practices. One element of the work was to map research on best practice with the specific objective of analysing community based child and adolescent mental health (CAMH) activities, specifically focusing on successful examples of deinstitutionalisation. The research uncovered predominant service areas, the most frequently targeted client groups, philosophies and ways in which services are structured, budgets, financing and other aspects of service provision. The most problematic issues identified by the research were political passiveness and a lack of transparency in some settings.

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Further information on the CAMHEE project is available at <http://www.camhee.eu/>

Moving up the European policy agenda

It is stated that European citizens have a right to a good mental health. This especially should be true for our youngest generation, upon whom rest our future hopes for strong social cohesion, productivity and better health. Through the enlargement of the European Union (EU) in 2004, as well as in preparations for a World Health Organization (WHO) European Region Ministerial conference on Mental Health in 2005, the importance of CAMH began to be addressed through the concerted efforts of the EC, WHO and national authorities of EU member states. Recommendations of a pre-conference on Child and Adolescent Mental Health in Luxembourg in September 2004, as well as the final Declaration and Action Plan approved in the Ministerial Conference on Mental Health in Helsinki in January 2005, put a clear emphasis on the urgent need for the development of effective CAMH policies and practices in an enlarged Europe. Most countries that joined EU in 2004 and 2007 have had to contend with major problems in the field of CAMH, revealed by strikingly high rates of poor mental health among children and young people.

There remains a concern that in many countries in central and eastern Europe financial and human resources are still

largely invested in services that contribute to traditional patterns of social exclusion, institutionalisation and stigmatisation of children, youth and parents at risk. This creates and reinforces the vicious circles of a culture of dependence, learned helplessness, exclusion and a lack of tolerance. Many new EU member states acknowledge that they need to undergo a complicated transition to a system based on principles of participation, the involvement of families and communities and strong primary care involvement. Moreover, there needs to be an emphasis placed on mental health promotion and the concept of citizenship as basic prerequisites for the good mental health of children and their parents.

The CAMHEE initiative: mapping best practice

In January 2007 a new EU-wide initiative in CAMH emerged in Lithuania, through the creation of the CAMHEE project supported by the EC's Public Health programme. As noted above, CAMHEE had the objective of providing a set of recommendations and guidelines for effective CAMH policy and practice in EU, with a special emphasis on new EU member states. It was conducted in light of the Declaration and Action Plan endorsed by WHO European Ministerial Conference on Mental Health in 2005.