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**Developing the evidence base for adult social care practice:
The NIHR School for Social Care Research**

**Martin Knapp, Jill Manthorpe, Angela Mehta, David Challis, Caroline
Glendinning, Gill Hastings, Jim Mansell, Ann Netten**

Paper for the *Journal of Care Services Management*

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- Caroline Glendinning** is Research Director (Adults, Older People and Carers) in the Social Policy Research Unit, University of York. Over the years her research has focused on user experiences of social care, informal (family) care, partnerships between social care and health services, the governance of social care and comparative studies of social and long-term care in other countries.
- Gill Hastings** is Senior Scientific Administrator for the NIHR School for Social Care Research. She is an experienced senior manager, with a background in healthcare and medical

research science. She has previously developed and managed national patient safety, healthcare improvement and personal fellowship programmes.

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is Associate Director of the NIHR School for Social Care Research. He is Professor of Learning Disability and Director of the Tizard Centre at the University of Kent. His research includes studies of deinstitutionalisation and community living in the UK and internationally; the relationship between characteristics of residential services, quality of care and the quality of life of residents; and services for people with challenging behaviour.

Ann Netten

is Associate Director of the NIHR School for Social Care Research. She is Professor of Social Welfare at the University of Kent and Director of the Kent branch of the PSSRU. Her research interests include developing theoretically based but pragmatic approaches to the measurement of costs, quality, outputs and outcome in social care, housing and care of older people and economic evaluation of social welfare interventions, including criminal justice.

ABSTRACT

In a foreword to *Shaping the Future of Care Together*, Prime Minister Gordon Brown says that a care and support system reflecting the needs of our times and meeting our rising aspirations is achievable, but 'only if we are prepared to rise to the challenge of radical reform'. A number of initiatives will be needed to meet the challenge of improving social care for the growing older population. Before the unveiling of the green paper, The National Institute for Health Research (NIHR) announced that it has provided £15m over a five-year period to establish the NIHR School for Social Care Research. The School's primary aim is to conduct or commission research that will help to improve adult social care practice in England. The School is seeking ideas for research topics, outline proposals for new studies and expert advice in developing research methods.

Keywords:

social care, research, England, National Institute for Health Research

INTRODUCTION

Consider these statistics for England from the Commission for Social Care Inspection's (CSCI) final State of Social Care in England report published in 2009 with data from 2007–08¹:

- 1.75 million adults used social care services;
- £16.5bn was spent by councils on social care for adults;
- another £3.5bn was spent by older people not eligible for public support on their own care;

- overall, about 1.5 million people work in adult social care;
- 5.2 million people provide unpaid care (with a third of them doing so for 20 or more hours per week).

Clearly, social care touches the lives of a great many people, not always by choice, of course. It contributes a huge amount to the nation's wellbeing and health. To improve the experiences of those who use services and support the efforts of people working in social care (with or without pay), a new research initiative has been launched. The National Institute for Health Research (NIHR) School for Social Care Research (SSCR) has been funded by the Department of Health through the NIHR, bringing together researchers and research groups working in social care in England. Its mission is to develop the evidence base for adult social care practice by commissioning and conducting high-quality research.

BASIC PARAMETERS

The NIHR SSCR formally began work in May 2009 with a budget of £15m over five years. It is a partnership between six leading centres of social care research in England: the three branches of the Personal Social Services Research Unit (at the London School of Economics and Political Science, University of Kent and University of Manchester), the Social Policy Research Unit (University of York), the Social Care Workforce Research Unit (King's College London) and the Tizard Centre (University of Kent).

Activities

The SSCR will pursue its mission through a number of interlinked activities:

- conducting high-quality research to produce new knowledge including, where appropriate, reviewing and synthesising existing knowledge, in order to inform the future development of adult social care practice;
- commissioning high-quality research through competitive tendering;
- providing a focus for adult social care research within the NIHR, as well as strategic leadership for the development of social care research more generally;
- developing methodological rigour and broadening the methodological repertoire, including bringing into social care research a number of disciplinary perspectives currently not well represented;
- consulting widely on research priorities;
- contributing to ongoing efforts by others to build social care research capacity and improve research awareness;
- disseminating findings and supporting other knowledge transfer activities.

Through these various activities, the School's work is intended to help to improve the quality of care and support services for all those people who use them.

Structure

The work of the School is coordinated by an Executive Group comprising the Director (Martin Knapp) and five Associate Directors (David Challis at Manchester, Caroline Glendinning at York, Jill Manthorpe at King's College London, Jim Mansell and Ann Netten at Kent). The School's Associate Directors were selected following an open

call for statements of eligibility in February 2009. The Executive Group is supported by the School's Senior Scientific Administrator (Gill Hastings) and Finances and Communications Administrator (Anji Mehta). The Executive Group is responsible for the research questions that are to be examined, the commissioning processes and decisions, monitoring of ongoing studies and assessment of final reports. It also has an important role to play in dissemination and knowledge transfer.

The Executive Group is advised by an enthusiastic Advisory Board (chaired by David Behan, Director General for Social Care, Local Government and Care Partnerships in the Department of Health) and supported by a recently established Reference Group of people who use services, carers and practitioners.

As well as the Associate Directors, the other researchers associated with the School are of two kinds:

- principal investigators (PIs) of research projects commissioned by the School; and
- advisers and external experts (funded or otherwise by the School) who support the School through their experience and expertise.

Over the five-year period, approximately half the research budget will be spent on studies carried out by teams in the Executive Group's research units, and half on studies carried out by others.

COMMUNICATIONS

Research in an area such as social care is not simply the production of findings, of course, but the formulation of approaches that address real-world issues and the communication of the findings of completed studies to stakeholders so that there is the potential to influence practice. Social care research has particularly strong traditions of user and practitioner engagement in both areas of activity. The NIHR SSCR therefore has an important communications function, both in respect of its research programme (see Appendix) and also in relation to its various other roles. An effective communications strategy — providing for ongoing two-way dialogue — is crucial. For example, every team receiving project funding from the School will be required to produce a brief, accessible, lay summary for wider dissemination on the School website and through other channels, one or more peer-reviewed paper(s) for publication in high-quality academic journals and a short report reflecting on the methods used and any issues/lessons that arise in their use. All such outputs will be subject to the School's peer-review process. More generally, there will be an electronic newsletter, an annual conference (the first in spring 2010), descriptive and summary articles in social care, social work and other professional outlets and the trade press, an annual report and regular updates on the School's website. In other words, considerable efforts will be made to disseminate findings and announcements widely to policy, practice, carer, service user, education and lay audiences. At the same time, there is commitment to ensuring that there are plenty of opportunities for each of these groups and individuals to feed their views into the School's identification of research questions to be addressed, methods to be used and other activities. To ensure the widest dissemination of its research findings, the School will also work with other knowledge transfer organisations, such as Making Research Count, Research into Practice for Adults and the Social Care Institute for Excellence. It is probably fair to say that — compared, for example, with the health field — robust research evidence is less plentiful and less well communicated to social care

users, carers, practitioners, managers, provider organisations, commissioners and policy makers (local and national). These groups have also not been as well engaged as would be helpful in the processes of generating research ideas, designing and undertaking studies. This is one reason why the NIHR set up the School, and why the School wants to engage the interest and support of all relevant stakeholders.

COMMISSIONING RESEARCH

The core aim of the NIHR SSCR is to conduct and commission high-quality ('world class') research to inform the development of adult social care practice.

Consultation for research ideas

As part of the commissioning process, the School is consulting with a wide range of stakeholders in social care about research topics and questions, the methods needed to answer them, the processes through which these methods are to be implemented, and how findings can be translated so as to aid the development of practice. The purpose of this ongoing consultation is to identify priorities for topics, methods and processes, not just as the School gets underway but throughout its five-year funding period.

A range of processes are underway to help the School identify evidence gaps or 'grey areas'. These include discussions with the Advisory Board and the User, Carer and Practitioner Reference Group (UCPRG); open consultation with researchers, commissioners, providers, people who use services, carers, front-line professionals and other key individuals; an online facility for making suggestions; and discussions with social care organizations and groups, such as the Social Care Institute for Excellence, Making Research Count, Research in Practice for Adults and the Joint University Council Social Work Education Committee. Research reviews to synthesise existing knowledge and identify gaps where further research is needed will also be incorporated into the design of some of the School's research projects.

In July 2009, a call was made for outline research proposals, with the emphasis on originality, relevance and potential improvements for adult social care practice in England. There will be further such calls on a regular basis. The authors would be delighted to hear from readers of the Journal of Care Services Management about areas where experience has shown that there is a need for better evidence so that practice can be developed and people's lives improved.

Within the School, the desire is to build as clear an understanding as possible of what people working in care services want to know so as to inform what they do. While there is likely to be no shortage of ideas of what research might be done, it is important to ensure that questions are addressed that relate to the reality of social care as delivered and experienced. There will be many opportunities to contribute to this consultation but readers are welcome to contact the NIHR School at any time to start conversations.

Commissioning

The School aims to commission research of the highest quality. It must be ethical and it will be independently peer-reviewed and widely disseminated. Each of the studies will need to engage as fully as possible with people who use services and

other stakeholders. All projects commissioned by the NIHR SSCR will have their details lodged on the central Research Register for Social Care.

The Executive Group takes decisions on what projects to commission and whether research should be commissioned from the group itself or externally, after taking advice. Among the factors to be taken into consideration will be the current state of evidence in the field, the type of research to be undertaken, the most appropriate design for that type of research, the expected value for money of the work and, most importantly, its relevance to the improvement of social care practice in England. To reiterate an earlier point, half of the overall budget will be allocated 'externally' (ie to groups other than those headed by Executive Group members). This will be through open competitive tendering. Every research project — whether external or internal — will be peer-reviewed by at least one researcher who is independent of the School and at least one service user or carer.

Opportunities to apply for research funding are being advertised widely. Proposals will be required to specify the research questions, the design or approach to be followed (where relevant), the expected length of the study and an indicative cost. Decisions on the proposals to be funded will be informed by criteria such as:

- feasibility, excellence and originality;
- relevance to social care practice in England;
- potential to have an impact on practice and on the lives of people using services and their carers;
- value for money;
- strength of the research team;
- ethical considerations; and
- contribution to the coherence of the programme and to the work of NIHR SSCR more broadly.

The quality of the research commissioned will be monitored.

Disciplines and principles

If the work of the new School is to be of the highest standard and relevant it will need to draw on a wide range of academic disciplines and employ a range of research methods. It will be important to strike a balance between what is sometimes called 'world-class science' (ie of a standard that warrants publication in the best academic journals in the field) and research that will have an impact on social care as experienced and delivered everyday. Of course, there is not necessarily always a tension between the two. The findings from research will need to be translated into outputs that are accessible and usable by all relevant stakeholders within social care and related systems.

Certain core principles will consistently guide the School's research activities, and a number of themes are likely to be common to most research studies:

- user, carer and practitioner engagement will be emphasized throughout the School's activities;
- the highest ethical and research governance standards will be essential;
- the pursuit of scientific excellence is imperative, but must be proportionate to the real-world relevance of the question and the likely impact of the findings;

- research commissioned and conducted by the School should have real-world impact;
- peer-review processes are being employed to ensure that funded proposals are of a high standard and are relevant;
- completed reports will be similarly assessed;
- the details of commissioned projects and the findings of completed studies will be highly visible within the public domain, and accessible to all relevant stakeholders.

Among the themes that will run through much of the work of the School will be:

- the use of robust outcome measures, not just for the people who use services but also for their carers and relevant others;
- attention also to 'process outcomes', reflecting how individuals access and experience care and support;
- examination of cost-effectiveness, ensuring that resource impacts are addressed alongside outcome impacts and that any trade-offs are transparent;
- recognition of cultural, ethnic and socioeconomic diversity;
- exploration of the interfaces between social care, healthcare and relevant other systems (such as housing, pensions and benefits);
- identification of the consequences of practice changes for the paid workforce in the statutory, third and private sectors, and for unpaid carers.

PROJECTS IN THE FIRST WAVE

The first 'wave' of work funded by the School is a small set of projects led by members of the Executive Group. (As noted earlier, the 'second wave' of projects will be carried out by other research groups.) Formal proposals were drawn up for each of those early projects, sent out for external peer review, and amended in the light of comments received. Four such projects have been started in 2009. The brief descriptions that follow can be supplemented with fuller details from the NIHR SSCR website.

Individualisation of services — A scoping study

In Putting People First, the Department of Health² set out a vision of a transformed approach to adult social care. A key approach in this process is personalisation, particularly through the use of personal budgets. For the ambitious policy outcomes to be achieved, it is important that there is a wide range of options available in order to meet individuals' needs and to help them achieve their personal outcomes in ways that suit them best. Ann Netten, Director of the PSSRU at the University of Kent, is leading a preliminary scoping study that will identify approaches and interventions that merit evaluation. It will provide a platform for formulating research questions and designing studies that will help to build the evidence base for what works in 'personalised' care, thereby helping councils and providers in commissioning, developing and refining effective and cost-effective care and support arrangements. The scoping study will also identify those services likely to face reductions in demand, with consequent challenges, not only for providers, but for both commissioners and services users. The overall aim of what is expected to become a stream of work is that there will be a steady stream of relevant, robust evidence about the challenges that need to be addressed by individuals and their

carers, the variety of personalised means available or developed to address those problems, and the likely effectiveness and cost-effectiveness of each of them.

Social care practice with carers: An investigation of practice models

The need to support people providing unpaid care for adults with an illness or disability has become increasingly important in government policy. As a result, numerous social care jobs have been established, some aimed at strategic development, others at coordination of support and some at provision of direct assistance for carers. Other than internal unpublished evaluations of these roles and descriptive accounts written in the professional press, little work has been done to analyse the ways in which these staff undertake their work and consider their effectiveness. This study will employ a concurrent mixed-methods design to consider practice activities and models, and their effectiveness as measured by the staff, commissioners and carers themselves. A target has been set of 84 interviews with professional staff and carers, a national postal/online survey of councils (hoping for data from 75 on the basis of a 50 per cent response rate) and analysis of a sample of 40 care/ support plans set up after a carer's assessment. The last of these will be carried out in conjunction with the practitioner and carer to establish the model of practice being employed and its effectiveness. Taken together, these methods will provide new information on an under-researched practice area that is likely to be increasingly important in light of the personalisation agenda. This project is led by Jill Manthorpe, Director of the Social Care Workforce Research Unit, King's College London, and the principal investigator is Jo Moriarty, who has worked on influential studies involving carers for many years.

Care and support for people with complex and severe needs: Innovations and practice — A scoping study

People with complex and severe needs constitute a relatively small proportion of the population of all adult social care users; however, this group is growing in number, and individuals with these complex and severe needs are actually quite problematic for service commissioners and providers. One reason for this is the high costs of their support; another is that they often need personalised, coordinated and specialised services from a wide range of providers. Caroline Glendinning, Research Director (Adults, Older People and Carers) at the Social Policy Research Unit, University of York, is leading a scoping study that will identify:

- key features of the service and support arrangements desired by different groups of adults and older people with severe and complex needs; and
- evidence of initiatives to deliver support to people with complex and severe needs that have the desired features and the potential to constitute examples of 'good practice'. Examples may focus on some or all of the different levels of commissioning, operational organisation and front-line delivery.

The study involves:

- consultation with key stakeholders, including organisations of and for service users and carers, on the desired features of good support and service arrangements for people with severe and complex needs;
- a review of recent published and grey research on relevant service developments and initiatives; and

- a survey of English adult social care departments on patterns of services, new developments and potential examples of good practice.

Examples of good practice will be identified that could subsequently be subject to rigorous evaluation.

Costs and outcomes of skilled support for adults with complex needs in supported accommodation

The opportunities presented by more personalised service models need skilled staff support if they are to be realised by people with complex needs. The aims of this project, led by Jim Mansell, Director of the Tizard Centre at the University of Kent, are:

- to evaluate the impact of skilled staff support on the lives of people with complex needs; and
- to describe the nature of the support required and its implications.

In this particular study, the focus is on people with severe and profound learning disabilities who have (a) serious challenging behaviour, and/or (b) additional multiple disabilities, and/or (c) autism. The aim is to recruit approximately 65 people in each of three sub-groups, including people using residential services, people living in supported accommodation and people with self-directed services.

The study will identify supported accommodation settings for people with severe and profound learning disabilities with one or more of the characteristics ((a) to (c) above), where the settings provide active support, augmentative and alternative communication, positive behaviour support or the National Autistic Society 'SPELL' framework (the 'experimental' group); and broadly comparable services not providing these kinds of support (the 'comparison' group). In each of these settings, participant characteristics will be measured, as well as quality of life, quality of the support received, service use patterns and costs. Both observational methods and questionnaires will be used. The support provided in the experimental group will be described, along with its implications. The next step will be to select matched samples of residents from the experimental and comparison groups, and then to compare quality of life, quality of support and costs. Multivariate statistical analyses will be carried out to identify and illustrate the relationships between support, quality of life and participant characteristics.

CONCLUSIONS

In announcing the establishment of the new research School, the then Care Services Minister said: 'We want to improve the evidence for social care practice so we can be sure that people in this country are provided with better and more effective services in the future. This new National School for Social Care Research will make a major contribution to improving the volume and quality of the research in the English social care sector.'³

Professor Dame Sally Davies, Director General of Research and Development at the Department of Health, noted:

'The new NIHR SSCR . . . will give researchers the time and 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.⁴

The new School is committed to helping to improve the quality of care and support services. This means that it must make sure that the research undertaken really is relevant to people who use services, to unpaid carers, to practitioners, and to other operational and strategic decision makers. How researchers intend to communicate their findings to these and any other relevant stakeholders will be one of the factors taken into account when proposals for research are being assessed. However, social care research in England today is conducted by quite a small group of people, certainly in comparison with the number of health service researchers. In support of the principal aims of the School to conduct and commission world-class research, the authors are also hoping to contribute to the efforts made by others to develop greater capacity — both in the supply of research and in its utilisation by decision makers throughout the statutory, third and private social care sectors.

In concluding, the launch of the NIHR School marks an important new opportunity. Its focus is on adult social care practice — an area where, for example, occupational therapists, care assistants and social workers operate with relatively little evidence or best practice to guide them. Traditionally, research efforts with families and children or offenders have commanded greater funding and have been more widely promulgated. Messages from research about adult social care are often not ‘translated’ into practitioner material or professional guidelines. One of the underlying reasons for this is that research on adult social care has sometimes stemmed from clinical and medical models with their focus on dysfunction, illnesses or long-term conditions. There are enormous bodies of literature on specific diseases and disorders but little work that broadens this out to address the social care needs of people with multiple, complex, fluctuating social problems and their wider lives. For instance, in such an approach, people with dementia are often grouped together as if they all have the same characteristics, needs and expectations. Some medical or health services research fails to distinguish between people it terms ‘carers’ and ‘paid carers’ or what it terms ‘institutional care’ (which can range, of course, from nursing homes with over 100 residents to small group homes). Residential care is not just at risk of being seen as homogeneous, but it can be portrayed as a ‘failure’ of community-based support, rather than the positive move or choice that it might be for some people. While these may appear to be stereotypes, they do sometimes seem to characterise research that is produced within health service settings and designed to inform health services policy and practice development. The new NIHR School, although located within the National Institute of Health Research, will not be constrained in this way. The focus is on adult social care practice, and an important platform for the research to be conducted is the set of theories and methodologies that have been developed in social care contexts.

The establishment of the School and its location within the NIHR acknowledge the substantial contribution that social care practitioners also make to the nation’s health. The Department of Health’s National Health Research Strategy, *Best Research for Best Health*⁵ established a more centralised system for research and development to promote more open and competitive processes for allocation of funding, underpinned by strong governance.

Not surprisingly, the NIHR has great expectations of the School. There is a need for greater understanding of the issues, for analysis of the realities of practice, and the need to look at processes and outcomes. The School is aspiring to conduct and

commission research that social care professionals and decision makers will be able to use with confidence in different practice settings, agencies and team relationships. All funded studies must demonstrate that service users, carers and practitioners view the research questions as relevant. On completion, the findings of these studies will also need to be widely disseminated. The authors hope that readers of the Journal of Care Services Management will work with the School to make the most of these opportunities.

Note

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APPENDIX

Research programmes

Five (overlapping) programme areas have been identified to provide an initial framework for identifying research questions. This structure is certainly not set in stone and will be re-examined and adjusted over time. (In order to secure the contract with the NIHR, the authors needed to set out a broad programme of research, but of course this was ahead of the Department of Health's selection of the Executive Group and ahead of any concerted programme of consultation about research topics and questions.) Each programme can be described in terms of a summary question:

- How can we best prevent or reduce the development or exacerbation of circumstances that lead to the need for social care? For short, we are presently referring to this as the Prevention and Reduction programme.
- How can we best empower and safeguard people who use social care services? This is the Empowerment and Safeguarding programme.
- How can we best equip and support people — practitioners, volunteers and informal carers — to provide optimum social care? How can we ensure that people who use social care and their carers are enabled and supported in paid work and other types of meaningful activity? This is the Care and Work programme.
- What interventions, commissioning and delivery arrangements best achieve social care outcomes? This is the Service Interventions, Commissioning and Change programme.

- How can social care and other public resources best be deployed and combined to achieve social care outcomes? This is the Resources and Interfaces programme.

The term 'social care' here refers to the full range of care and support arrangements made available or possible for adults with a wide range of needs, characteristics and circumstances. It includes care and support provided by families and communities, and whether publicly funded or privately purchased. The term 'best' in each bullet point above will include such criteria as effective, cost-effective and equitable (in terms of opportunity/access and/or in terms of resources used or outcomes achieved).

Various types of research will be undertaken: reviews, initial 'scoping' of the issues, exploratory studies and full evaluations.