Carers and personalisation

Outline of a research project funded by the NIHR School for Social Care Research

Improving the evidence base for adult social care practice

What role should informal carers play in the delivery of personalised adult social care?

Personalised adult social care seeks to fulfil the aspirations and preferences of service users. At the same time informal carers also have rights of their own, for example to an assessment of their needs. So far these policy themes have developed largely separately and have failed to take into account the substantial interdependencies between the needs of disabled and older people and their carers. In particular, there is little clarity on what roles carers should play in the processes of personalisation, including (self) assessment, user-led support planning, reviews and the on-going management of personal budgets.

The roles of carers within the context of personalisation are likely to be particularly complex when service users have communication or cognitive impairments (CCIs) and are wholly or partially dependent on carers to communicate their needs/wishes. Clarification of carers' roles in the processes of delivering personalisation would assist practitioners, service users and their carers.

This project

- will provide guidance on how the processes of personalisation could be developed to reflect more accurately both service users' and carers' needs and wishes.

It aims to

- describe current local policies and practices in English adult social care regarding the role of carers in the processes of personalisation

- examine how far these policies and practices recognise and balance the respective needs and aspirations of service users and informal carers, especially when service users have CCIs

- investigate the views of service users with CCIs and their carers on the roles they wish carers to play

- identify potential issues and/or areas of tension between practitioners, service users and carers

- recommend changes to the processes of personalisation so that they more accurately reflect the aspirations of service users and carers respectively.

WHAT IS THE CONTEXT?

English adult social care departments are introducing personalised assessment and support arrangements for service users. At the same time, they are required to assess and support informal carers. Many carers, particularly those assisting people with CCIs, are likely to be heavily involved in planning and managing personalised support arrangements for service users. This may make it difficult for both service users and carers to express their own views and wishes to practitioners involved in personalised assessment and support planning. In some cases, practitioners may try to discourage carers' involvement, regardless of the wishes of carers and/or users.

Clarification is needed of carers' roles in the processes of delivering personalisation. For example, Personal Budgets (PBs) play an important role in personalisation and carers are often involved in managing the service user's PB. Yet research on PBs' impact on informal carers found that implementation focused initially on (self-)assessment, resource allocation and support planning for potential PB holders. Only subsequently did local authorities begin considering how to align or integrate PB implementation with arrangements for assessing and supporting carers.

Across the Individual Budgets (IB) pilot sites there was no consistency in how help provided by carers was treated in the disabled/older person's assessment and resource allocation processes. There were discrepancies in the relationships between the assessment and allocation processes for IBs and those for assessing needs and providing support to carers; and inconsistencies in the roles carers were expected to play in helping older and disabled people to plan, use and manage their IBs. Importantly, the research found that carers provided greater inputs of time to IB holders than for those using conventional services.

Within the context of personalisation, there is thus a need for social care practice to recognise and balance the needs and interests of both service users and informal carers in what may be very individual and specific ways. Particular tensions may arise when service users have CCIs, as carers may be acting as a user's advocate and

Key questions for research

- what roles should informal carers play in assessments and support planning when the disabled/older person cannot communicate independently?

- how far are carers' roles in such situations recognised and supported?

- what roles do disabled/older people with cognitive or communication impairments (CCIs) want (where they are able to express a view) their carers to play?

- what roles do carers themselves want to play?

- how can these desired roles be accommodated within social care practice?

IB manager, while also needing to voice their own needs. Practitioners similarly must balance the rights of service users (to direct their own assessment and make service choices) with carers' rights to have their own needs met.

This study will focus on two sub-samples of service users with CCIs: older people with dementia and young adults with learning disabilities and additional communication impairments. However, the findings will inform wider policy and practice relating to the role of carers in personalised support.

HOW WILL THE PROJECT WORK?

The study will examine and compare English local authority policies with practitioners' actual practices; and then compare these with service users' and carers' own experiences of current practice, and with their respective wishes.

STAGE 1: Selection of study sites

Reseachers will survey all the local authorities (between 30 and 40) in two English regions to obtain an overview of current local authority policies and practices relating to personalis-ation and carers. The regions will be selected to include a range of rural and metropolitan areas and unitary and two-tier councils.

The electronic survey will cover:

- the authority's formal policy and practice guidance on the role of carers in service users' personalised care

- the links (or not) between personalisation processes and local authority practice for carers' assessments and support

- Personalisation and Carers' lead officers' own knowledge and understanding of how this policy and guidance is implemented, including any differences between different groups of service users and their carers.

The qualitative survey data will also be used to identify three authorities for Stages 2 and 3 of the study.

STAGE 2: Interviews and focus groups

This stage will examine professional and practitioner perspectives in the three selected local authorities.

In each of the selected local authorities the Personalisation and Carers' leads will be interviewed about development and application of policies and practice. This will supplement information from Stage One. Interviewees will be asked how they think local guidance is actually used by front-line staff.

To access practitioners' perspectives, four focus groups will be conducted in each of the three local authorities: two with front-line staff working with older people, and two with staff working with people with learning disabilities. These staff will have experience of conducting personalised assessments, support planning and reviews with service users with CCIs and their carers. Topics for discussion will include:

- knowledge of their local authority's relevant policies and/or guidance

- everyday practice with carers and users with CCIs in assessments, planning and use of personal budgets/self-directed support; differences between user groups and between different parts of the personalisation processes will be explored

- the usefulness of local authority policies and/or guidance, including any training,

and reflections on their own practice where this diverges from guidance

- suggestions for future policy and practice development.

STAGE 3: Service users' and carers' views

A total of 24 older and learning disabled service users with CCIs, plus their carers, will be recruited to examine user and carers' experiences of personalised care, and the actual and desired roles played by carers in these processes. Users and their carers will be selected who have recently undergone and/or are currently involved in personalised/supported (self-) assessments, support planning or review processes. Appropriate verbal and/or symbol-based research interview methods will be used for each service user. Only service users who can give informed consent will be included.

Issues to be explored in interviews include:

- users' feelings about their own and their carer's involvement at different stages of the process, and their future involvement

- how carers have experienced their own involvement in personalised support arrangements; how far they want to be involved; and how they feel about their level of involvement

- how help provided by carers has been treated in the assessment and support planning process

- how carers' own assessment and support has been linked to those of the service user they help.

'Framework Analysis' will be used to analyse the data from all three stages of research.

Project publications

The study will inform guidance on how assessment and support planning processes and management of personalised support arrangements could be developed to reflect more accurately both service users' and carers' wishes. This guidance will be disseminated with the help of voluntary and professional groups, such as Carers UK and the British Association of Social Workers (BASW).

Research project outline

HOW DOES THE PROJECT FIT THE AIMS OF THE SCHOOL FOR SOCIAL CARE RESEARCH?

The research will identify the range of practices currently operated by front-line staff involved in promoting personalised assessment and support arrangements, across a sample of social care departments. It will compare current practice with the actual experiences and desired preferences of carers and, as far as it is possible to ascertain, those of service users with CCIs. These insights will enable the appropriateness of current practices to be assessed, and potential developments in guidance and front-line practice to be identified. In particular, it will allow the views of an often-overlooked group of service users – those with CCIs – to be heard, separately from those of their carers.

This work has relevance across a number of SSCR research themes. In particular, it will help equip and support practitioners and informal carers to provide optimum social care. By improving the implementation of personalisation, the guidance will also assist in empowering and safe-guarding people who use social care services. In turn, this should help reduce the circumstances which lead to the need for higher level social care, e.g. when carers' own rights and needs are not properly addressed.

The NIHR School for Social Care Research

The School for Social Care Research was set up by the National Institute for Health Research to develop and improve the evidence base for adult social care practice in England. It officially launched on 1 May 2009 with funding of £15 million over five years.

The School conducts and commissions high-quality research across five overlapping programme areas:

Prevention and reduction – How can we best prevent or reduce the development or exacerbation of the circumstances that lead to the need for social care?

Empowerment and safeguarding – How can we best empower and safeguard people who use social care services?

Care and work – How can we best equip and support people – practitioners, volunteers, 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?

Service interventions, commissioning and change – What interventions, commissioning and delivery arrangements best achieve social care outcomes?

Resources and interfaces – How can social care and other public resources best be deployed and combined to achieve social care outcomes?

Further information about the NIHR School for Social Care Research is available at www.sscr.nihr.ac.uk

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Personalisation and carers; the roles of carers in assessment, support planning and managing personal budgets

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