Practice often fails to take carers'

own wider needs into account during

service user personalisation

Our unique study explores how carers are often inadequately considered during personalisation processes for service users, particularly, older people and those with learning disabilities.

Getting care right for vulnerable people demands an informed understanding of the needs and roles played by informal carers such as family and friends. Poor consideration of carers' own needs risks poor outcomes for users as well as carers.

That's why SSCR has funded a team from the University of York's Social Policy Research Unit (SPRU) to look at how carers' roles – and their own needs – are considered in the course of service user assessment, support planning and the management of personal budgets.

The SPRU study focused on older and learning disabled service users who have cognitive and/or communication impairments. These groups can face particular difficulties making their needs known, so it can be especially important that carers are involved in service users' assessments and personal budgets – so long as carers' own needs and their 'life beyond caring' are also taken into account. The needs and views of carers in relation to personal budgets have been little researched.

The team found diversity in the everyday practice of staff within the councils taking part in the study and confusion about what should actually be happening vis-àvis carers.

'Our study is shining a light on a more general problem of how carers should be involved,' says Dr Wendy Mitchell, Research Fellow who, is leading the SPRU team. 'The issues are particularly complex for the group we have been studying those caring for people with cognitive and/or communication impairments. These carers clearly need to be properly involved, but this is not always the case; there are considerable differences between authorities and between different teams within authorities. Staff are not always clear how best to involve carers. The issues arising for this group are relevant for all carers and service users as they highlight the lack of clarity within current processes.'

The team found that involving carers in service user assessments was common practice, especially if there was no conflict or tension between them. Carers were



'You can draw up the most wonderful support plan and then you suddenly find that the carer is shutting various things down, because it does not work for them, or does not work for the family. So you have to include the carer.'

asked about their own willingness and ability to continue providing support during service user assessments. Some staff viewed these questions as a 'mini carer assessment', whereas other staff felt the questions were important but weren't the same as a separate carer assessment. 'It might be hard for a carer to say things when their husband or partner is sitting there,' explains Dr Mitchell. 'A separate carer assessment gives carers the time and space to discuss their needs in-depth and in private.'

Another issue highlighted by the research was inconsistency surrounding how carer

assessments informed service users' personal budgets and support plans. 'It's not clear, for example, how resources allocated to the service user take account of carers' own needs,' explains Dr Mitchell.

The SPRU team's research also found that service user assessments and support planning often took place together rather than being separate processes. 'This can be problematic,' explains Dr Mitchell. 'The service user's support plan has often been discussed and may have been written up before a separate carer assessment has been conducted. It is therefore difficult to see how carers needs are actually being taken into consideration'.

The team makes a number of recommendations to improve carer involvement and for more consideration of carers' own needs within service user personalisation.

Project: Personalisation of carers: the roles of carers in assessment, support planning and

managing personal budgets

Lead: Dr Wendy Mitchell (wendy.mitchell@york.ac.uk)

Institution: University of York

Completion: Winter 2013