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Working Paper 64 July 2011

Personalisation: what will the impacts be for carers?

Dr Mary Larkin and Dr Helen Dickinson

INTRODUCTION

- Personalisation potentially has profound implications for carers
- lack of knowledge about the outcomes of personalisation for carers, and a limited evidence base on which the third sector can draw when addressing carers' needs
- a body of research is required to help the third sector understand the implications of the changes
- this paper therefore aimed to:
 - review the existing evidence base available to the third sector about the impact of personalisation on carers
 - identify those areas of further research required to inform practice across the third sector
 - identify issues that local and national policy makers will need to consider in relation to service delivery as personalisation evolves

WORKING PAPER 64 OUTLINE

- overview of the main features of the personalisation agenda
 - review of the evidence base on the impact of personalisation on carers
 - evidence required by the third sector in order to support carers as the personalisation agenda progresses
 - reflection on gathering the evidence identified and the implications for the next stage in the TSRC's research programme into personalisation
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MAIN FEATURES OF THE PERSONALISATION AGENDA

- Personalisation ‘become a unifying theme and a dominant narrative across public services in England’ (Needham, 2011: pg. 54)
 - Broad aims and a potentially malleable concept. Significant history but potential ambiguity allows it to serve multiple different agendas
 - Search for a clear and consistent policy programme – and be implication an evidence-base underpinning this agenda – may not be entirely fruitful
 - Important that third sector organisations understand the agenda and possible implications
 - Not yet clear if personalisation will deliver a step change in services and outcomes. This will depend on implementation of this agenda and carers play an important part in this process, yet we know little about the impact of personalisation on carers
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REVIEW OF THE EVIDENCE BASE ON THE IMPACT OF PERSONALISATION ON CARERS 1

- the personalisation agenda impacts at organisational and personal levels
- the importance of carers to the successful implementation of the personalisation agenda is consistently acknowledged
-but carers have received relatively little attention compared to some other groups
- the majority of the findings about carers and personalisation have emerged from studies into the different forms of self-directed support which show there are both positive and less positive outcomes
- to optimise the outcomes of personalisation for carers a more comprehensive evidence base about the impact of personalisation on carers is required

EVIDENCE REQUIRED BY THIRD SECTOR ORGANISATIONS TO SUPPORT CARERS AS PERSONALISATION PROGRESSES

- self-directed support initiatives are likely to have the most significant implications for carers within personalisation
- examples of evidence required by the third sector to provide carers with the support they need in order to maximise the benefits of self-directed support
 - *Skills* e.g. those associated with being an employer
 - *Service design* e.g. up-to-date information about the full range of specialist support services within their locality
 - *Emotional impacts* e.g. role changes
 - *Ways of supporting carers* e.g. approaches that work best
 - *Policy development* e.g. to feed back into policy about the impacts of personalisation in practice

TAKING THE AGENDA FORWARD

- obtaining evidence in the areas identified is complex and raises methodological and ethical dilemmas
 - need to establish how to conduct efficacious research into the issues about carers and personalisation
 - hence this event bring together leading academics, practitioners and policy makers to set the future research agenda in relation to the role of the Third Sector in supporting carers in an age of personalisation
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....for discussion

- are the issues raised in the paper correct?
 - are there important issues that are not considered?
 - other evidence/sources not included?
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FUTURE RESEARCH PRIORITIES

- what research is currently underway?
 - future research priorities to develop a body of knowledge that can be used to inform third sector practice and support a commissioning environment which can provide carers with support in an era of personalisation?
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