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# **PERSONAL BUDGETS AND THE CARER - SERVICE USER RELATIONSHIP**

The Carers Federation  
and  
De Montfort University

# Carers and personalisation – the research to date

- carried out within a particular local authority only
- very few studies have focused exclusively on carers and hence the findings about them tend to be incidental to or only part of the main study

# Carers and personalisation – the findings to date

- Positive outcomes: more in control of their time and their daily lives, higher quality of life, improved health and wellbeing, enjoying caring, better relationship with the person for whom they care
- Less positive outcomes: stress associated with self directed support processes, additional managerial and administrative responsibilities, have to cope with several changes in their caring role, no increase in opportunities to undertake paid employment

# **The need for more research about carers and personalisation**

Personalisation will impact on the lives of an increasing number of carers as it evolves and on the lives of a growing number of people in our society who will become carers because of the following:

- policy drive to extend personal budgets and personal health budgets
- increase in number of carers

# This study.....

Aimed to develop better understandings of changes in the carer-service user relationship because :

- can make a productive contribution to the emerging knowledge base about carers and personalisation by exploring a hitherto under researched key issue
- this relationship is central to the experience and quality of care within personalisation
- changes in this relationship that occur within personalisation require further exploration in order to ensure the successful implementation of personalisation

# Methods

- 23 semi structured interviews with carers who were in a dyadic relationship with an adult in receipt of social care who had changed to a personal budget
- interview schedule piloted
- 18 (78%) in partner relationships and 5 (22%) in parent adult child relationships
- 11 English local authorities
- held either in the participants' homes or at a public venue, such as a local carers centre and lasted between 60 to 90 minutes
- transcribed and thematically analysed using inductive coding primarily at a semantic level d

# Relationship findings – less control

35% said hard to cope with having less control within the caring relationship

- feelings of being ‘pushed’ out and ‘redundant’
- worried that someone else does not know “what to look out for” and cannot cope with complex needs

BUT these feelings did ease with time and if they had confidence in the staff employed

# Relationship findings – enhanced personal relationship

56% felt that personal budgets had enhanced their personal relationship:

- more relaxed with each other
- more independence as individuals
- more control over their lives

Those in spousal type relationships felt they “can be a couple” because:

- more time to do activities together
- pursue interests together
- socialize together

BUT limited by the age of the service user as well as or in addition to their illness or disability

# Carer findings – positive outcomes

78% happier because:

- more freedom and time to themselves
- could pursue their own interests

“before I had to do it all, everything, I felt much more trapped and almost resented it and I don’t anymore”

- the person they cared for was also happier

“Well, if he’s happy, I’m happy, it rubs off, doesn’t it?”

- felt healthier and less stressed

# Carer findings –negative outcomes

56 per cent felt personal budgets were stressful to administer

- particularly at first
- paper work, recruitment and staff management were the most problematic
- 47 per cent reported inadequacies in the level and nature of support provided by their Local authority

BUT

- some of the difficulties had eased over time
- previous employment expertise helped
- 40% used other services to support them with managing the personal budget

# Relationship of this study to existing findings

Insert Table 2

Existing knowledge confirmed	New knowledge added
improved relationship with the person for whom they care	what helps to make the relationship better
Service users needs can limit improvement in relationship	
Carers' find the reduction in their control within the caring relationship challenging	these feelings ease with time and if they have confidence in the staff employed
more in control of their time and their daily lives	
higher quality of life	
improved health and wellbeing	
stress associated with self directed support processes	Issues with LA processes specifically worry about effects of continuing budget cuts
managerial and administrative responsibilities are burdensome but previous employment experience helps	<ul style="list-style-type: none"> <li>• particularly at first</li> <li>• paper work, recruitment and staff management were the most problematic</li> <li>• many need additional support</li> </ul>

# Implications of these findings

increases the robustness of the emerging evidence base about the impact of personalisation on carers more generally