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Personal Budgets and the carer - service user relationship: developing the knowledge base about carers and personalisation

Carers Federation

and

De Montfort University

CARERS AND PERSONALISATION – THE RESEARCH TO DATE

- many 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 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 affect the lives of an increasing number of carers as it evolves AND the lives of the growing number of people in our society who will become carers
- policies are reflecting a recognition of the need to address carers' issues within the personalisation agenda

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
- triangulation of themes

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 RELATIONSHIPS

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, illness and/ disability of the service user

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% felt personal budgets were stressful to administer

- particularly at first
- paper work, recruitment and staff management were the most problematic
- 47 % 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

- produced findings about personal budgets and carer-service user relationships AND validated, refuted and extended existing knowledge about these relationships within personalisation more generally

Table 1: Summary of findings in relation to existing knowledge on the carer -service user relationship within personalisation

Existing knowledge confirmed	Knowledge refuted	New knowledge added
<p>improved relationship with the person for whom they care</p> <p>service users' needs can limit improvement in relationship</p>		<p>ways personal budgets can be used to facilitate an improved relationship</p>
	<p>contractual relationship with the service user was challenging</p> <p>the reduction in their control within the caring relationship is challenging for carers</p>	<p>a contractual relationship provides flexibility on the amount of caring provided</p> <p>these feelings ease with time and if carers have confidence in the staff employed</p>

RELATIONSHIP OF THIS STUDY TO EXISTING FINDINGS

- personal budgets and carer-service user relationships AND validated, refuted and extended existing knowledge about these relationships within personalisation more generally
- the impact of service users' personal budgets on carers AND validated and extended existing knowledge about the overall effects of personalisation on the carers

Table 2: Summary of findings in relation to existing knowledge of the effects of personalisation on carers

Existing knowledge confirmed	New knowledge added
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	<ul style="list-style-type: none"> • issues with LA processes and PBs • worry about effects of continuing budget cuts
managerial and administrative responsibilities are burdensome but previous employment experience helps	<p>For PBs.....</p> <ul style="list-style-type: none"> • particularly at first • paper work, recruitment and staff management were the most problematic • many need additional support

IMPLICATIONS OF THESE FINDINGS

This is the first study to focus exclusively on the carer - service user relationship

- increases the robustness of the emerging evidence base about the impact of personalisation on carers more generally
- provides a firmer foundation on which to develop effective practice and interventions
- indicates areas for further research e.g. ways of strengthening the carer-service user relationship, how the third sector can develop its support to carers within personalisation

PRACTICE AND INTERVENTIONS

Carers need :

- support planning that includes advice on the use of personal budgets to create the right environment to maintain and strengthen the carer - service user relationship
- more support with paperwork, and employment and managements of staff
- streamlined self-directed support processes

Thank you!
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