Personalisation: The Beginning Of A New Dawn Or The End Of The Road For Third Sector Support For Carers?

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Personalisation has become a key aspiration of adult social care policy in England. Perspectives vary though as its meaning and the extent to which it signals a new paradigm in care. It is being seen as not only relevant to those directly accessing care but also for their carers. Carers’ support is an area in which third sector organisations (TSOs) have traditionally played a significant role, and changes to funding and the expected model of care will therefore potentially have an impact on the third sector. This study explores the issues that arise for TSOs who work with carers from the introduction of personalisation, through interviews with TSOs and public sector commissioners and policy makers.

**Key Findings**

- The key principles of personalisation, i.e. putting carers at the centre of their support plan with greater choice and control over what they receive is seen as a positive development.
- The potential benefits for carers may be lost through the need for local authorities to make significant savings, and for some respondents personalisation was being used as a means to reduce services.
- More personalised support was seen to reflect the mission of TSOs working with carers. The skills, experience and networks that they have built up were thought to enable TSOs to respond better than other sectors.
- A contrary view was that TSOs had become complacent and may not be attractive to carers who are purchasing support directly.
- Financial insecurity was raised by all, although for the TSOs interviewed there had generally been an increase in funding through individual packages and/or taking on new roles.
- Due to financial constraints and demographic changes the public sector will not be able to provide adequate discrete funding for carers support. TSOs will therefore need to develop new funding streams along with mainstream services being more responsive to the needs of carers.
**Background**

TSOs were instrumental in the development of personalisation as the current binding narrative of adult social care in England. There is broad agreement of key principles of personalisation such as clarity of what resources are available, co-production of support plans, and the right of the person to ultimately make decisions over their lives. Whilst there is evidence of the positive outcomes that personalisation related initiatives have made to service recipients and their carers there are also concerns regarding its broader impact. These include inequality of experience between individuals who are more or less able to take advantage of the new flexibilities, differences in expectations and therefore funding levels for user groups, and market pressures leading to poorer terms and conditions for care staff.

Researchers have indicated a need to move beyond generalised critiques to look in more detail at the processes and related experience within different user groups and localities.

Moving to a more personalised social care system has been largely welcomed by TSOs working in social care and their representative bodies. The need for major organisational and whole system changes have been identified if the aspirations are going to be achieved. Research indicates that TSOs vary in their knowledge of and responses to the new arrangements, and that these are dependent on internal and external factors such as local commissioning.

Evidence to date indicates that personalisation can lead to improved outcomes for carers. These include being more likely to be undertaking activities of their choice, having more time for themselves and for other family members, an improved social life and feeling in control of their daily lives. They are also more likely to enjoy caring and have a better relationship with the person for whom they care. However, such outcomes were found to vary with the nature of the needs of the person they are supporting, the amount and quality of the eligibility information available to carers and ways in which different local authorities implement self-directed support.

**The research**

TSRC has developed a programme of work exploring the impact of personalisation on the third sector. This includes an initial review of evidence regarding personalisation in general (Dickinson and Glasby 2010) which was followed by a more focused review regarding services for carers in particular (Larkin and Dickinson 2011). Stakeholders representing the third sector, local authorities, national policy makers and academia contributed to a workshop reflecting on the themes from the literature reviews. The workshop identified that an evidence base regarding personalisation and TSOs is yet to be developed, and the main research questions that should be explored.

This study sought to provide an initial response to the current knowledge gap by undertaking interviews with a sample of TSOs who work with carers, and related public sector commissioners and policy makers. In doing so it provides particular insights regarding carers’ services but also general TSO and public sector relationships.
Findings

What does personalisation mean?
Personalisation was seen as a positive development for carers. Whilst some saw it as having the potential for radical change, others queried how different it actually was to what had come before. Concerns centred on the risk that it may lead to the loss of current services valued by carers, the variation in approach between local authorities and that it was being used as a ‘trojan horse’ to introduce funding cuts.

Response to personalisation
TSOs were seen by most respondents as being able to implement the principles of personalisation in practice. This was due to the centrality of carers within their overall mission, their experience and skills, and their networks with carers and the community. Private and public sectors were both viewed as having conflicting interests that could distract them from focusing on carers. There were those that were more sceptical about TSOs ability and willingness to be personalised, and who saw competition for carers’ individual budgets as introducing a necessary pressures to existing TSOs. New local authority processes were seen as inhibiting more creative and flexible packages and as having greater transactional costs.

Impact on carers
Perceived improvements for carers were in line with existing findings. These included more flexibility, choice and control which could lead to carers having more freedom to pursue their own activities and other roles, as well as individualised and better quality care for those for whom they cared. However, the extent to which these could occur was shaped by a number of countervailing variables many of which provided new insights into the constraints on the extent to which personalisation can lead to improved outcomes for carers.

Examples of these variables were local variations in the availability of suitable services; inequalities within the social care system between service user groups; class and language barriers; and the paperwork and managerial responsibilities that inevitably accompany self-directed support. These could lead to a loss of identity as a carer, tensions in the carer-cared-for person relationship, and overall lack of support.

Impact on TSOs
Knowledge of personalisation centred reforms was high and all the TSOs had taken steps to respond internally to the new funding arrangements and potential user expectations. There was a sense though in some user groups, particularly mental health, that its importance was waning. The TSOs shared concerns regarding the loss of block funding arrangements and their ability to compete with the lower costs of private providers and carers employing their own staff. However, the overall financial impact was more complex. For example, whilst other TSOs were reported to have lost previous financial support, many of the TSOs interviewed had gained funding connected with the provision of direct services. There were also opportunities for growth in relation to ancillary work around the development, implementation and evaluation of personalisation.

The financial challenges connected with personalisation were seen to be directly impacting previously important aspects of the TSOs way of doing business (i.e.
positively rewarding staff through security of income) and to the loss of more congregate types of support that they had previously provided (such as day care). TSOs did not think that they had to radically change their practice as in their view they had always tried to provide ‘personalised’ support. Furthermore they retained a belief that the services they provided were still of value even if local authority commissioners did not want to grant fund them.

Conclusion

This study reveals that there is a general consensus across the public and third sectors regarding the basic principles that lie behind personalisation, their potential to be a force for improvement within carers’ services, and the need for a whole system change. Where consensus ends is in the parts of the system which are most in need of change and who should be trusted with the limited resources available to achieve personalisation. Put simply, is it local authorities that are out of step and therefore should trust the third sector to use its carer-centric values and governance arrangements to determine what support is required and how best to deliver this? Or are some parts of the third sector only responding to a small proportion of the current carer population through traditional services and therefore a consumer led approach is required to incentivise them to demonstrate innovation and efficiency?

These debates reflect those underway more broadly regarding the relationship between the public and third sectors (a partnership of equals or that of purchaser-supplier) and the emphasis of personalisation (a user-led grassroots movement or a market reform). They highlight that such differences in a strategic alliance can only be accommodated on a temporary basis before they surface and cause tension. Arguably though, neither of these paradigms of personalisation will enable the radical improvement in carers’ support that is required. The realities of the current financial environment and increasing numbers of carers means that any model that is reliant on significant discrete funding from the public sector is doomed to fail. The fundamental question therefore is not how to ensure that the third sector is able to access the available funding from the public sector or if the third sector is using this funding wisely. It is rather, how do we achieve the aspirations of personalisation for carers without additional public sector funding and who will shape and lead this change? And whilst it will not be easy, there is an argument that the third sector, with its long-term relationships, values and commitment to carers is uniquely placed to take on this role.