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“I live with other people and not alone”: a survey of the views and experiences of older people using Shared Lives (adult placement)

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Abstract

Purpose – *The purpose of this paper is to report on the views and experiences of older people using Shared Lives (adult placement) in 2012/2013.*

Design/methodology/approach – *As part of a survey collecting information about outcomes for older users of Shared Lives issues of whether it had made a difference to quality of life, and positive and negative experiences of support were explored.*

Findings – *Questionnaires were returned by 150 older people using Shared Lives services. Findings suggest that this model of community-based support has a number of advantages for some older people, such as reducing social isolation and loneliness, promoting independence, choice and control, providing emotional support and increased well-being.*

Research limitations/implications – *The questionnaire was self-completed and so responses were not followed up to provide deeper insights.*

Practical implications – *Shared Lives is not appropriate for everyone but it is suggested that this option should form part of local commissioning strategies, be part of a range of options for social care practitioners to consider in their work with older people and helps to meet various current policy imperatives.*

Originality/value – *The potential of Shared Lives for older people is under-researched and this paper contributes to the literature in exploring the views of older people about family-based support in the community.*

Keywords *Loneliness, Older people, Social isolation, Personalization, Adult placement, Community-based support*

Paper type *Research paper*

Introduction

Key to current social care policy both in the UK and across Western Europe is the personalisation of services, with an emphasis on jointly provided, high quality, flexible services that give people active choice and control over their care and support (HM Government, 2007; Department of Health, 2010). Another key factor is the change in demographics, that is, how best to meet the needs of a rapidly ageing population. There has also been a shift away from institutionalised care towards “prevention”, with services being delivered in community-based settings, and with local authorities being encouraged to reduce inappropriate admissions to residential care through improving options for community-based provision (Department of Health, 2010).

The appropriate response to the housing and care needs of a rising elderly population is much debated in the policy and practice literature in England. Sheltered housing still provides the majority of specialised housing for older people (Darton and Muncer, 2005), and from the early 1980s there has been a trend towards greater support for people living in their own homes. Shared Lives, formerly known as adult placement, is a model of community-based support where an adult who needs support and/or accommodation moves into or regularly visits the home of an approved Shared Lives carer, after they have been matched for compatibility. Many of the 12,000 people using Shared Lives in the UK become a settled part of a supportive family, but it is also used as day support, as breaks for unpaid family carers, as home from hospital care and as a stepping stone for someone to get their own place to live. Shared Lives is used primarily by people with learning disabilities, but also people with mental health issues, older people, care leavers, disabled children becoming young adults, parents with learning disabilities and their children, people who misuse substances and (ex-) offenders. There are nearly 8,000 Shared Lives carers in the UK, recruited, trained and approved by local schemes, the majority of which are local authority run. Shared Lives is regulated by the Care Quality Commission (CQC) and in 2013/2014 Shared Lives was rated as out-performing other community care services and as achieving 100 per cent compliance with quality standards in connection with respect and dignity (Care Quality Commission, 2014).

Although at present it represents a small proportion of social care provision, Shared Lives would seem to embody the core principles of current social care policy: prevention, personalisation, partnership, plurality and protection. To date, there has not been a great deal of research undertaken about the potential benefits of Shared Lives, and in particular there is little published evidence about the views and experiences of users of the service. A synthesis of the literature about adult placement (Fiedler, 2004) highlighted that very few studies had been carried out of service users' experiences of and satisfaction with the service. This situation has not changed a great deal in the last ten years, there are some examples of research where this element is included but generally these have involved a small number of participants. For example, NAAPS and IESE (2009) conducted focus groups including 23 service users, and Bell and Litherland (2013) also included a small number of service users and carers (5 and 14, respectively) in a project exploring the use of Shared Lives for people living with dementia and their family carers.

The research described here was part of a wider study conducted between January 2012 and April 2014 exploring the potential of Shared Lives in relation to older adults. This paper reports on the views and experiences of a sample of older people supported by the Shared Lives service. There follows a discussion of the implications of the findings in the context of service users and their families making decisions about meeting care needs, and also for practitioners and commissioners in making decisions about offering Shared Lives as an option for this particular client group.

Methods

A research method combining both quantitative and qualitative approaches was used to collect data, that is, a questionnaire with both closed and open questions. Older users of Shared Lives were invited to provide their views and experiences of the support they had received through open questions, the focus here.

Participants

The questionnaire was distributed by Shared Lives schemes who were recruited through the development phase of the wider project and also through an e-mail request for participation from Shared Lives Plus (the UK network for family-based and small-scale ways of supporting adults). Documentation was sent to the schemes for distribution, including invitation letters, the questionnaire and pre-paid envelopes for their return to the research team. Schemes were asked to post questionnaires to all eligible users of their service. Inclusion criteria was set as: older people (65 years old or over); older people with a learning disability; and the use of any form of Shared Lives support. Only individuals with capacity to consent and to understand the questions were to be included (a decision made by the Shared Lives schemes distributing the questionnaire). One follow-up mail out was conducted by the participating schemes.

Data collection

An anonymous self-completed questionnaire was developed using items from existing surveys (for outcomes), demographic information and open-ended questions asking about individual experiences of Shared Lives (the focus here). The open-ended questions were:

- What support do you get from Shared Lives?
- Has Shared Lives changed your life in any way? If yes, please could you tell us in what ways?
- What are the good things about Shared Lives?
- What are the not so good things about Shared Lives?

An “easy-read” version of the questionnaire was developed following consultation with an expert from the learning disability field and a service user with a learning disability who was involved in training for easy-read tools.

Ethical approval for the project as a whole was obtained from the national Social Care Research Ethics Committee and research governance approval was obtained from participating local authorities.

Analysis

Responses from the open-ended questions were entered manually into NVivo 9 to assist with managing and coding the data. Content analysis was conducted and themes and sub-themes identified. Analysis was not conducted based around question asked due to the amount of overlap between responses to questions. The procedure for assessing trustworthiness of the data analysis was through credibility or stakeholder checks with research participants and other people with a specific interest in the research. Interpretations and conclusions were also verified by on-going discussion within the research team.

Findings

In total, 150 questionnaires were returned, of the number requested (430) the response rate was 29 per cent (it was not possible to identify how many were actually sent out). Of this 150, 136 respondents completed the open questions. Varying levels of support were required to complete the questionnaire, the most frequently reported was the service user being assisted by someone reading out the questions or writing down the answers for them. In total, 17 (12.5 per cent) were completed by proxy, that is someone answering on behalf of the service user.

Questionnaires were returned from ten schemes covering the following regions: South-East (three); South-West (two); Yorkshire and Humberside (two); East (one); Greater London (one); and East Midlands (one). Demographic details of the participants were gathered as part of the questionnaire and are presented in Table I. The majority of responses came from service users supported in long-term placements and those accessing an outreach service (this differs from other Shared Lives provision in that the Shared Lives carer goes to the individual’s home). Similar numbers of men and women completed a questionnaire and most were under the age of 85. In relation to activities of daily living (Morris *et al.*, 1999) the median for the respondent group was a score of 6 with the majority having a score of 8 or under (scores range from 0 to 16, the higher the score the greater difficulty in performing activities).

Categories from the questionnaires were classified as four main themes for older users of Shared Lives: social contact; support; occupation; and satisfaction with the Shared Lives service.

Social contact

I live with other people and not alone. We are a family. (male, 71 years old, long term placement).

One of the most common themes identified related to social contact (61 per cent), service users highlighted one of the good things about Shared Lives was that it had increased their opportunities for this. It included three sub-themes of feeling part of a family, companionship and an increase in social experiences. Many participants mentioned the benefits of feeling part of a family and this was associated with increased confidence, being involved with the local

Table 1 Characteristics of the respondents

	<i>n</i>	% ^a
<i>Gender</i>		
Male	64	48
Female	69	52
Total	133	
<i>Age group (years)</i>		
65-69	30	23
70-74	28	21
75-79	24	18
80-84	24	18
85-89	11	8
90+	14	11
Total	131	
<i>Ethnicity</i>		
White	130	98
Other	3	2
Total	133	
<i>Type of Shared Lives support</i>		
Long-term arrangement	49	36
Day support	30	22
Respite/short break	8	6
Outreach	49	36
Total	136	
<i>Activities of daily living^b</i>		
0	19	15
1-4	54	43
5-8	26	21
9-12	17	14
13-16	8	6
Total	124	

Notes: ^avalid per cent; ^b0 score indicates least difficulty performing activities, 16 the most

community and feeling “wanted” by others. This was reported across all types of Shared Lives provision from long-term placements to those receiving day support, which could account for only a few hours a week. One participant reported:

Being made to feel part of a family gives me confidence and a feeling of being wanted and not alone. Gives me something to look forward to and a purpose in life, someone to speak to and have fun with. (male, 68 years old, day support).

Other respondents stated:

I have been diagnosed with dementia but I am still with the people I call my family and over the twelve years I have been with them I have seen the family grow and always feel a part of it. (male, 72 years old, long-term placement).

I'm part of a family now, where I am also able to be part of the local community. (male, 73 years old, long-term placement).

Many participants commented that they enjoyed the company of the Shared Lives carer and even considered them to be a friend. Friendship, company and companionship were mentioned frequently by the older users of Shared Lives as particular benefits of the service and “never feeling lonely”. As one respondent stated:

I am well cared for by friends. (male, 68 years old, short breaks).

Another commented:

(Shared Lives means) to have company around me, friends are my life. (female, 70 years old, long-term placement).

In addition, increasing social experiences such as meeting new people, making new friends and contact with the Shared Lives carer's friends and relatives was also important to many respondents. This is illustrated by the following comments:

Events and meetings and activities if we want to go with our carers we can which is good and meet people like ourselves. (male, 70 years old, long-term placement).

I can have someone to chat to, and she takes me out in my wheelchair where I meet neighbours. (male, 83 years old, outreach service).

Support

I was in residential care with limited choices. I now get to go to places I want and I have choices. (male, 75 years old, long-term placement).

This theme referred to the support provided by Shared Lives, participants' responses indicated that Shared Lives was a fundamental source of support for them (65 per cent). It included three sub-themes of independence, emotional support and practical support. Respondents commented frequently about how Shared Lives had enabled them to regain and maintain their independence. One participant described how getting the balance of care right meant they felt like they had got their life back and stated:

Even though I'm cared for I'm able to feel independent and have my own life. This makes my life very good and carefree. (male, 68 years old, long-term placement).

Being able to choose what they did and when they did it, was seen as a key factor in Shared Lives enabling the feeling of independence, as one user of day support stated:

I get more choice about what I do. I go out more. Do more things that I want to do. (female, 70 years old, day support).

The majority of respondents referred to the emotional support they received through Shared Lives, directly related to their mental health and well-being. Having someone to talk to about problems or issues was seen as key benefit of Shared Lives. One participant, who was in a long-term placement stated:

Shared Lives keeps me out of hospital. If I am troubled by anything I can talk about it with my carer who encourages me and completely supports me. (female, 68 years old, long-term placement).

Another respondent commented:

If I have things on my mind, I can discuss matters with them. Do not feel isolated. They give you inspiration to carry on life in a better way. (female, 70 years old, day support).

The practical support provided by Shared Lives carers was also frequently mentioned, such as money management, meals, laundry and helping with hospital appointments. Some participants had got into difficulties before using Shared Lives, often financially or not looking after themselves properly, as one respondent in a long-term placement stated:

I was living alone and not looking after myself. I could not cope with money and got into debt. I am now eating and living healthier and I have help with finances. (male, 70 years old, long-term placement).

Occupation

I go out and have lots of new activities and been able to start my sewing again which was my hobby years ago. (female, 70 years old, long-term placement).

This theme referred to how people spent their time, respondents highlighted a range of different activities they were involved with supported by Shared Lives, and there was an emphasis on trying new things. It included three sub-themes of practical activities, talking to someone and looking forward to going out. Service users highlighted getting involved in activities as one of the good things about being part of Shared Lives, including working in the garden, playing games, drawing, sewing and using a computer. Involvement in more or new activities as a result of Shared Lives is illustrated by the following comments:

Every day I have activities to go to without the support of the family I live with I wouldn't be able to do this. (female, 68 years old, long-term placement).

(Shared Lives) helped me to change my day centre so now I don't just sit around all day. (female, 70 years old, long-term placement).

Could not use a mobile phone before Shared Lives and could not go and get money from the bank, but can now. (male, 79 years old, long-term placement).

The users of Shared Lives also often mentioned talking to the Shared Lives carer in the context of "occupation", they found sharing thoughts and experiences and spending time with someone very satisfying, as one user of day support stated:

We talk about current affairs, shared interests and families. It opens up a world outside my own. (female, 90 years old, day support).

Particularly for users of day support services looking forward to going out or spending time with someone from Shared Lives made a big difference to their life. Typical comments were:

It has given me the opportunity to get out with someone other than my family, to some places I have not been before, to walk and get fresh air. (female, 74 years old, day support).

Because I have difficulty walking am house bound and the weekly outings give me an opportunity to be in the outside world again. (male, 83 years old, day support).

Satisfaction with the Shared Lives service

Shared Lives has been life changing for me. I couldn't live without it. (female, 68 years old, long-term placement).

This theme covered more general comments about the Shared Lives service, service users were overall very satisfied with the Shared Lives service (65 per cent). It includes four sub-themes of carer characteristics, the matching process, a life changing experience and the ability to meet changing needs. Respondents often made reference to the carer's personal characteristics describing them as caring, friendly, helpful, considerate and thoughtful. The carer's professionalism was also mentioned frequently, for example:

(my Shared Lives carer) is very good, very professional and she listens to what I say carefully – my speech is affected by a stroke and I'm tired when she comes but she listens patiently to everything I say. (female, 83 years old, outreach service).

Having a support worker I recognise and trust on a regular basis. He understands my needs and takes good care of me. (female, 74 years old, day support).

A matching process is completed prior to a placement to ensure that the service user and Shared Lives carer are compatible. Comments about the matching or the outcome of the process were positive. One respondent stated:

I have been matched with someone I get on really well with. (female, 80 years old, outreach service).

When asked if Shared Lives had changed their life in any way, it was described by many respondents as simply "life-changing", for example, one respondent stated:

Shared Lives has changed my life completely. I am not able to live alone for various reasons. (female, 68 years old, long-term placement).

The only concern raised by older users of Shared Lives and identified as a sub-theme was the ability of the service to keep up with their changing needs linked in part to resources. As participants stated:

They do not appear to have resources to cover health changes in service users. They are governed by their own banding levels. As people get older their needs change and become more demanding of resources. (female, 68 years old, long-term placement).

I need a stair lift and will have to pay for this myself if I want to stay with my carer. (female, 65 years old, long-term placement).

Discussion and conclusion

This paper offers a contribution to the literature regarding older adult views on family-based support in the community. However, this study has several limitations. Shared Lives is a particular type of community-based support and no claims are made that findings can be generalised

beyond this model. However, it does describe the views of service users not represented elsewhere. The questionnaire was self-completed (either alone or with support) and so responses were not followed up to provide deeper insights. Despite these limitations this study does highlight some useful messages and implications for policy and practice.

Although Shared Lives provides differing types and levels of support responses to questions were similar across all respondents. The expectation is that older users of Shared Lives would be at the more able end of the spectrum (i.e. not requiring nursing care), the activities of daily living scores and the fact that the majority were under the age of 85 years old would seem to support this. The views and experiences of older users of Shared Lives who participated in the study were overwhelmingly positive despite a question specifically asking about aspects that may not have been satisfactory. However, as with much research about service provision, it is often difficult to know whether this satisfaction simply reflects being grateful for receiving some support rather than none at all.

Social isolation and loneliness impact on quality of life and well-being with demonstrable negative health effects (Masi *et al.*, 2011). Reducing loneliness or social isolation should therefore improve quality of life and could possibly impact on subsequent health and social care service use, limiting dependence on more costly services. Older people have been identified as one of the groups more vulnerable to social isolation and loneliness and there has been a policy focus on this (Windle *et al.*, 2011). From the older service user experiences reported here it would seem that because Shared Lives involves consistent contact with the same Shared Lives carer and becoming part of or linked to a family or household (and in the majority of cases connected to their networks and local community), this increased opportunities for social contact, with “never feeling lonely” explicitly mentioned as a benefit.

Shared Lives would appear a good “fit” with the on-going personalisation agenda in England which aims to allow greater choice and control for people using care and support services (HM Government, 2007). Most of the respondents cited support from Shared Lives as the reason they felt more independent, due in part to being able to exercise choice and control in a home environment. A surprising number of respondents also specifically highlighted the positive impact Shared Lives had on their mental health and emotional well-being which was exclusively linked to the supportive relationship they had with the Shared Lives carer.

Activity has long been established as being important in later life (Lemon *et al.*, 1972). Research indicates that the quality of social ties and the supportiveness of the social network associated with older adults’ participation in activities accounts for the relationship of activity to well-being. Well-being in later life is less about what older people do, but rather of who with and how they feel about them (Litwin and Shiovitz-Ezra, 2006). The experience of users of Shared Lives would appear to mirror this in that although practical activities were often mentioned, “occupation” could be linked specifically to social interaction such as sharing thoughts and experiences with the Shared Lives carer.

Satisfaction with the Shared Lives service appeared to be directly related to the service user’s relationship with the Shared Lives carer. Shared Lives carers are recruited, vetted and approved by the Shared Lives schemes predominantly located within local authorities. A key aspect of the Shared Lives model is the matching process facilitated by the schemes whereby service users and carers are brought together based on interests, life experiences and needs, for all types and level of support. This should help ensure that service users and carers have a sound basis for a good relationship and for the respondents in this study this would appear to be the case. The only concern the older people using Shared Lives had was about continuing support when there was a change in their needs. Shared Lives is not appropriate for everyone and there may be instances where for example, a requirement for 24 hour care or nursing needs meant a placement could no longer continue, but this would be individual case dependent.

In summary, the views and experiences expressed here suggest that this model of community-based support has a number of advantages for older adults, such as reducing social isolation and loneliness, promoting independence and choice and control, providing emotional support and increase in well-being. Being matched with a suitable Shared Lives carer is a key element in this

regardless of type of support. Shared Lives is not appropriate for everyone but it is suggested that this option should form part of local commissioning strategies and be part of a range of options for social care practitioners to consider in their work with older people. This approach also helps to meet various policy imperatives such as personalisation (HM Government, 2007) and requirements of the Care Act (2014).

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