What next for Shared Lives? Family-based support as a potential option for older people

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Abstract

With an ageing population and limited resources the challenge for policy makers and practitioners is how best to provide for the care and support needs of older people. This article draws on findings from two studies, a scoping study of the personalisation of care services and another which aimed to generate evidence about the potential use of family-based support schemes (Shared Lives, SL) for certain groups of older people. Forty-three schemes participated in a survey to gather information about services provided and the extent to which this included older people and their carers, and six staffs were interviewed across two schemes about issues for expanding provision for older people in their local areas. It was evident that SL schemes were already supporting a number of older people and there was support for expansion from both schemes and local authorities. Adequate resources, awareness raising, management commitment, and a pool of suitable carers would be needed to support any expansion effort. There is also still a need for SL to be more widely known and understood by care managers if it is to be considered part of mainstream provision for older people.

Keywords: Personalization, Family-based support, Shared Lives, Older people

Introduction

Internationally it has been well documented that with an ageing population and limited resources the challenge for policy makers and practitioners is how best to provide for the care and support needs of older people. Key to current social care policy in England is the personalization agenda with an emphasis on flexible services that give people active choice and control over their care and support.[1,2] There has also been a shift towards 'prevention', with English councils being encouraged to reduce inappropriate admissions to residential care through improving options for community-based provision.[1] In recognition of this, practitioners, commissioners, service users, and their carers need evidence on cost-effective, personalized service options for older people.

The current evidence base in the area of personalization of social care services is limited and the National Institute for Health Research (NIHR) School for Social Care Research (SSCR) funded the *Personalisation of Services Scoping Project* to begin to address this and identify areas for future research that could provide the foundation for greater understanding and knowledge in this field. Through a consultation phase with user-led organizations, policy makers, provider groups, and those responsible for practice development, Shared Lives (SL, formerly known as adult placement) was highlighted as a potentially successful, personalized service, currently most commonly used by service users with learning disabilities. This paper draws on findings from this scoping study and the development phase of follow-up research which aimed to generate evidence about the potential use of family-based support schemes for some groups of older people. Findings from a survey to identify the extent of existing SL provision for older people across England are presented, supplemented by data from interviews with SL staff about the benefits and challenges of providing a service for older people. There follows a discussion of the implications of the findings for implementing or extending SL schemes for older adults.

Adult placement type services have a long history with certain client groups, perhaps the oldest formally constituted service started in Geel in Belgium where for hundreds of years people with long-term mental health conditions and learning disabilities have lived and worked with families in

the community. In England, the Liverpool Personal Service Society has been providing adult family placements for over 30 years. Such schemes are now being widely used for the provision of long-term residential care for people with learning disabilities in the United Kingdom,[3] particularly since the move from residential to community care.

Historically, family placements were defined as 'a scheme in which one, two or three adults with a mental handicap are found a home in an existing household of non-handicapped people which is intended to be permanent'.[4] The Department of Health policy and practice guidance captured this definition but also added to it the notion of extended family ('kinship') support in the community.[5]

Today, Shared Lives Plus (the UK network for family-based and small-scale ways of supporting adults, formerly known as NAAPS) describes SL as 'where an individual or family is paid a modest amount to include an isolated or under-supported older or disabled person in their family and community life. In many cases that person goes to live with a Shared Lives Carer and their family, although Shared Lives is also used as day support, as respite care for unpaid family carers, as home from hospital care and as a stepping stone for someone to get their own place'.[6] Box 1 illustrates a more detailed definition of SL.

Box 1 Detailed definition of SL

SL is a service provided by individuals and families in local communities and is distinguished by the following features:

- Arrangements are part of organized SL schemes that approve and train SL carers, receive referrals, match the needs of service users with SL carers, and monitor the arrangements.
- People using SL services have the opportunity to be part of the SL carer's family and social networks.
- SL carers use their family home as a resource.
- Arrangements provide committed and consistent relationships.
- The relationship between the SL carer and the person placed with them is of mutual benefit.
- SL carers can support up to three people at any one time (up to two people in Wales).
- SL carers do not employ staff to provide care to the people placed with them.
  Source: Shared Lives Plus[7]

SL carers and the person requiring support are carefully 'matched' to ensure compatibility by scheme staff. A key feature is that the SL carer's home is used as a resource, the service user goes to the carer's family home rather than support being provided in the person's own home or in a residential facility.

Shared Lives Plus estimated that in 2012/2013 there were 121 local schemes and around 6720 SL carers in the UK.[7] In 2010, there were 4210 people being supported by SL in England, 575 (14%) of whom were older adults over the age of 65.[8] In 2012/2013 Shared Lives Plus estimated that there were 9660 people supported by SL in England. Although SL forms only a small proportion of adult care and support services, it is rated highly by the Care Quality Commission, with the highest proportion (95%) of services rated as good or excellent of all regulated social care service types, and the best performance in relation to national minimum standards, meeting 93% of them on average.[9]

There has been a limited amount of research in connection with SL and it is only more recently that this type of scheme has begun to attract attention in the literature. There is some evidence of high levels of satisfaction among service users[10,11] alongside cost-savings when compared to traditional services, particularly for people with learning disabilities.[11,12] It has been suggested that SL out-performs alternative care and support options on some key indicators of personalization, such as inclusion, flexibility, choice, and control.[6] It has already been identified as having the potential as an option for older people, including those with dementia.[13–15] SL has been proposed as a potential alternative to traditional respite care, with care provided in a home environment[13,16] and may also provide an alternative to moving to a care home, particularly where the main reason is linked to social isolation or not wanting to be alone overnight. However, there is a lack of robust evidence about outcomes for older people using SL when compared to alternative provision and the benefits highlighted are largely anecdotal.

Methods

The survey of SL schemes

The survey formed part of the development phase of a wider study, the *Outcomes, Processes and Costs of Shared Lives* project. The development phase included: a scoping survey of SL schemes in England; development work with three SL schemes, and the setting up of project and local area advisory groups. The development phase was

Table 1: Description of the 43 schemes: region and type

Type of scheme	Region									Total
	East of England	North West	South East	West Midlands	East Midlands	Yorkshire and Humber	South West*	North East	London	
In-house (council-run)	2	4	7	3	4	4	3	2	6	35
Independent (third sector)		3				2	1			6
Independent (private)		1								1
Other**			1							1
Total	2	8	8	3	4	6	4	2	6	43

*One scheme in the South West covers four local authority areas.
**'Other' was a scheme in the process of becoming a local authority trading company.

granted ethical approval from the Social Care Research Ethics Committee and had support from the Association of Directors of Adult Social Services.

The aim of the survey was to gather information about SL schemes and identify the extent to which SL is currently being used by older people and their carers. The three schemes participating in the wider study and Shared Lives Plus were consulted in the development of the questionnaire (it was piloted to ensure the information requested was readily available and correct terminology was being used). The questionnaire contained a mixture of closed and open-ended questions and covered: background information about the scheme; who the scheme supports; staffing; SL and older people; cost information; and a request to participate in future research.

SL schemes were invited to take part through an email from Shared Lives Plus sent on behalf of the research team in July 2012 (119 schemes are members of Shared Lives Plus). The email explained the purpose of the research and what the information from the survey would be used for. The survey was web-based and accessed through a link contained within the email. Potential participants were asked to respond within 2 weeks and they received one reminder. The final sample included 43 SL schemes (see Table 1) representing a response rate of 36 per cent.

The interviews

Interviews were conducted with SL staff as part of the initial *Personalisation of Services Scoping Project*. During the scoping project SL had been highlighted as a promising, personalized service and so in-depth information was gathered about two schemes, one run by a local authority and one a social enterprise, to inform future research. These schemes were identified and recruited through Shared Lives Plus and were selected because they provided services for a wide range of client groups including older adults. Semi-structured interviews were conducted with six staff across the two areas, an equal number in each (interviews were also conducted with SL carers and service users but not reported here as they were not older adults). Interviews covered the following: description of the scheme; benefits of the SL approach; outcomes for service users; challenges for the sector; and issues with expansion or increase in demand.

Analysis

Data from the survey were downloaded from the online survey software into Microsoft Excel. Descriptive statistics were produced for answers to closed questions and responses to open questions charted.

The qualitative analyses drew on data from the semi-structured interviews. The interviews were audio recorded, transcribed and anonymized (with permission). The data were analysed using a general inductive approach, a systematic procedure for analysing qualitative data where the analysis is guided by specific research objectives.[17] 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 returning to the transcripts and on-going discussion within the research team. NVivo specialist software was used to support analysis.

Findings

The survey of SL schemes

This section first describes the findings from the survey (*n* = 43).

Description of the schemes

As can be seen from Table 1 the overwhelming majority of schemes who took part in the survey were council-run (81%). Of these 35 schemes there were nine where outsourcing was either being considered or definitely going to occur. The main reason given for this was that councils were moving towards becoming 'commissioning only' organizations and would no longer be a provider of services.

The services of 23 of the schemes (53%) were available to both people funded through the local authority and those who funded their own care. Eighteen schemes were available only to those who were funded through the local authority. The majority either offered the service to self-funders in theory or believed there was scope for this. However, in most cases this had not happened, in practice people tended to come through to the schemes through social services and met Fair Access to Care Services criteria.

The number of staff employed by schemes ranged from two to eight with the majority having a full-time manager or co-ordinator (27). Thirty-one schemes (72%) had no plans to change staffing levels. Eleven schemes had plans to increase staff, with only one planning to decrease staff numbers. The schemes usually comprised of an SL manager or co-ordinator, SL workers or officers, and support staff. The number of carers providing services through SL schemes ranged from 11 to 227. The number of carers with each scheme waiting to be matched with someone needing support was between 1 and 65. Twenty-eight (65%) schemes were recruiting carers.

Types of service offered and service user groups

SL schemes can offer different types of support and the definitions of the different types of arrangement are given in Box 2. Schemes were provided with the definitions and asked whether they provided the different types of support and if so, to provide information about the numbers of service users receiving that support by primary client group at the time of the survey.

Box 2 Definitions of types of SL arrangement

Long-term or residential arrangements – an individual lives in the home of the SL carer, and the arrangement is long term. The SL carer's home is used as a resource and they provide accommodation.

Day time arrangements – an individual goes to the home of the SL carer regularly for support during the day time. The SL carer's home is used as a resource.

Respite arrangements/short breaks – an individual stays at the home of the SL carer to give an unpaid or family carer a break. The SL carer's home is used as a resource and they provide accommodation on a temporary basis.

Outreach or 'kinship support' – the carer acts as 'extended family' to someone living in their own home and where both the homes of the people using the service and the SL carers are available for contact.

Rehabilitative or intermediate arrangements – an individual stays at the home of the SL carer on a temporary basis, as a 'stepping stone' to moving on to (or back to) more independent living, or in an emergency. The SL carer's home is used as a resource and they provide accommodation on a temporary basis.

All but one of the schemes provided more than one type of support. Only 1 of the 43 schemes did not provide long-term or residential arrangements; however, in that particular local authority area this was provided by a co-existing third sector scheme. Thirty-five of the schemes provided respite or short breaks, 30 schemes day time support, 6 provided outreach or 'kinship' support and 3 'other' types of arrangement. None of the schemes were providing rehabilitative or intermediate support at the time of the survey.

Table 2:   Number of SL schemes providing different types of arrangement by client group

Type of arrangement	Client group				
	Learning disabilities	Older adults	Physical disabilities	Mental health	Other
Long term/residential	35	26	21	22	7
Day time	26	15	8	8	0
Respite/short breaks	27	15	15	14	11
Outreach/kinship support	5	2	1	3	2
Rehabilitative/intermediate	0	0	0	0	0
Other	1	1	1		

Table 3: Total number of individuals supported across the 43 schemes* by client group

	N	%
Learning disabilities	2742	65
Older adults	727	17
Physical disabilities	394	9
Mental health	246	6
Other	88	2
Total	4197	

*Includes individuals supported through 'other' types of arrangement not covered by the definitions in Box 2.

Table 2 shows the number of schemes providing different types of arrangements for different client groups. The total numbers of individuals being supported across all participating schemes in each client group is shown in Table 3. The majority of schemes provided services for those with learning disabilities, followed by older people, people with physical disabilities, and then those with mental health issues. The smallest group 'other' included vulnerable adults (in these cases usually those in a position to be hurt or taken advantage of) or those with a head injury.

SL and older people
Table 4 shows the number of schemes providing different types of arrangement for older people. Twelve of the 43 schemes (28%) did not provide any services for older people. Nineteen schemes ($n = 34$) had plans to increase SL provision for older people, 4 did not and 11 did not know. This was across all types of provision, respite/short breaks (18), followed by day time arrangements (17)), long-term provision (15), and rehabilitation (10). Small numbers indicated outreach/kinship support and 'other'. Seventeen of the 19 indicated that there was support for expansion from the local authority. Nine schemes felt that they did not

Table 4: Number of schemes with arrangements in place for older people and total number of older people currently placed across the schemes (by type of arrangement)

Type of arrangement	Number of schemes	Total number of older people
Long-term/ residential	26	178
Day time arrangements	15	226
Respite/short breaks	15	89
Outreach/kinship support	2	4
Other	1	230
Total		727

have the capacity to expand the service to older people as there was a lack of appropriate carers, or those with suitable accommodation.

Eleven schemes had tried to increase the number of placements for older people in the past but only four reported that this had been successful. The schemes that had done this successfully attributed this to having a good matching service (the process of matching service users with suitable SL carers), trained carers, adequate funding and staffing, and good information about people's needs. The schemes where this had not worked believed this was due to a lack of: funding; awareness; commitment or support from management; and carers with suitable accommodation.

The interviews
This section describes selected findings from the interviews with staff from two schemes.

Benefits and limits for older people
The staff interviewed worked with schemes that predominantly provided services for those with a learning disability. Interviewees were asked about the benefits of the SL model for older people and all felt that SL could benefit older people in much the same way as for other client groups. Some of the advantages mentioned were that the SL approach promotes social inclusion, integration into communities, gives consistency of people and place, and allows continued use of life skills.

SL carers and service users are matched with people who have compatible interests, skills and experiences, and a suitable home environment. One interviewee described the process for their scheme and this involved talking to an SL carer about a potential placement (as there was an initial in-depth assessment and they also knew their carers well, they would usually have a possible suitable match in mind), discussing the assessment and the needs of the person. If the SL carer felt a placement was a possibility introductory visits would then take place. The service user would usually be supported by their care manager or a family member and SL scheme staff would be there to support the potential SL carer. From there they may meet without other professionals involved and the number of visits or possibly overnight stays before a placement was confirmed was very much on an individual basis. All interviewees saw the matching process as a key element in the success of the SL model and resulted in very few cases of placement breakdown.

Interviewees indicated that there was a particular role for SL in the provision of respite for the family

carers of older people. As one interviewee stated 'instead of putting mum or dad into residential accommodation where they'll be sitting around looking at where they might be in a few years time…think of us'. The staff interviewed also believed SL was well placed to provide a service for people with mild to moderate dementia, allowing them to be in a home not a care environment which people could find unsettling (see Box 3 for an example). Interviewees also reported that there were an increasing number of SL clients with learning disabilities who were developing dementia symptoms as this group were living to an older age than they had in previous generations.

Box 3 Example of the role of SL for older people

George is an older person living with Alzheimer's disease being cared for by his wife. George was matched with an SL carer who provided day support for 2 days each week. On one occasion his wife needed emergency respite care for him and because he had built up a relationship with an SL host family he was able to stay there. Subsequently George has been able to do this on two more occasions.

Interviewees did highlight some of the limitations around providing a service for older people, for example, care managers often needed crisis interventions for older people but unless already known to a SL carer an emergency placement would not be available. There were also likely to be other occasions when a lead-in period while matching took place was not possible. If an older person got up during the night on a regular basis or if ground floor accommodation was required SL may not be able to accommodate them. There was also recognition that a lot rests on whether people liked each other and got along which was much more of a challenge than in other care settings. Interviewees also stated that it was likely that at some point an older person would need residential or nursing care and so any longer-term SL arrangement would inevitably come to an end.

Issues for expansion

The SL staff interviewed could not see any barriers to expanding the service specifically for older people and were unclear as to why referrals for this group were lower than for other client groups. Where referrals did occur they were consistently from the same care managers therefore they could only assume that some did not support the SL

approach or were unsure as to what the scheme could provide. They were aware that the numbers of care home placements were significantly higher than for SL placements for older people.

The issues or challenges to SL schemes expanding or developing their services for older people mentioned tended to apply to service expansion or development of any kind. One of the issues mentioned was around capacity, that there was a limited supply of potential carers, one scheme manager indicated that one in six enquiries resulted in carers who were suitable. As one interviewee commented 'it isn't a job for everyone'. SL in general was always in a position of trying to balance having people to do the work with the work coming in, as a scheme interviewee stated 'it's a chicken and egg situation, do you have lots of carers waiting for referrals to come in….or do you wait until you've got lots of referrals and then you can't meet their needs'. Having people to provide placements across local areas was seen as a potential issue as older people may not want to be placed too far from home.

Another capacity issue mentioned by interviewees was that if expansion meant the need for more scheme staff, this was not always possible for local authority schemes. In-house schemes tended not to charge a management fee whereas schemes out-sourced were able to do this, this then linked to the volume of work and enabled the buying in of more staff. There was also a concern raised that expansion could lead to a dilution of the quality of the schemes so therefore this would need to be planned carefully to ensure quality assurance for the SL model of working.

Discussion and conclusion

There are limitations to the evidence drawn on here. The survey sample was a self-selected group and so may reflect those schemes more likely to provide support or have an interest in older people. The interviews were small in number and at this stage only with SL staff, so care should be taken in generalizing from the findings. Despite these limitations, there are some useful messages to be taken from this snapshot of where SL and older people 'fit' currently both within the SL sector and wider social care provision.

As anticipated the main client group supported by SL schemes was those with learning disabilities as historically this has always been the case.[11] This is due to historical reasons linked to community care and also the model would seem a good fit with the key principles of rights, independence,

choice and inclusivity contained in government strategies for providing services for people with learning disabilities. There is also the likelihood that care decisions for older people often happened at a vulnerable time and situations could deteriorate quickly, people with learning disabilities were likely to have had social care involvement throughout their lives.

However, there were numbers of older people already being supported by SL across all types of provision, and 72% of the schemes surveyed already offered services to older people. A recent survey conducted by Shared Lives Plus estimated the total number of older adults supported by SL as 1600 (this includes those with a learning disability) and 305 supported within this figure who have developed a need for social care in later life. This may mean that if SL is to expand provision for this client group it will mainly be a case of building on existing provision rather than expanding into a new service area.

Day time arrangements, where someone would go to the home of an SL carer on a regular basis was the type of service used by the largest number of older people. This may have enabled the service user to continue living in their own home by giving an unpaid or family carer a break on one or more days during the week, as well as potentially providing meaningful activities and social interaction in a non-institutional setting. Respite and short breaks could also have this benefit and these types of arrangement were recognized by interviewees as a desirable alternative to more traditional respite settings. These types of arrangements were only used by a small number of older people in the study sample and this may be one area to focus on for expansion.

Rehabilitative or intermediate arrangements were not being provided by this group of schemes but there could be a role for this in supporting older people particularly after an in-patient stay in hospital. One scheme provided outreach or kinship support to a large number of older people but this tended to take place in the service user's home, and so would not be considered by Shared Lives Plus as an SL arrangement. This could be another type of provision for SL to explore, a more flexible approach to location while keeping the key aspect of the model, the matching process.

Just under half of the schemes surveyed had plans to expand their services for older people across all types of SL arrangement. Significantly they indicated that there was local authority support for this and this would seem to be important as one of the reasons given for a failure to expand provision

for older people was a lack of commitment from management. The current financial climate did not appear to have had a direct impact on SL schemes as yet with the majority of schemes increasing staff numbers or retaining existing staff. In addition the majority of schemes were actively recruiting SL carers. Having access to suitable carers to support older people was raised as an issue in both the survey and interviews. It is likely that there will be existing or newly approved SL carers willing to support older people but suitability of accommodation and a possible long wait for a suitable match will be the main barriers to this. Targeted recruitment campaigns may be one way to mitigate for these circumstances.

At the time of the survey outsourcing was a possibility for nine of the 35 council-run schemes and this may play a larger part in the future of SL schemes over time mirroring the social care landscape. This is likely to have its own challenges and benefits. There may be issues of continuity for service users, carers and SL carers, and a loss of infrastructure for council scheme staff. It would also require increased marketing of the service to service users and carers rather than relying solely on care manager referrals, at present the main source for most schemes. However, it could also result in more flexibility to respond to demand or needs and enable the accessing of other sources of funding not currently readily available under existing local authority structures. As interviewees stated, fees linked to individuals would give more scope for expansion if it was required, for example, through charging a management fee.

If SL schemes are to expand or introduce support for older adults Fiedler[18] argued that there was a need for SL schemes to raise awareness and become more widely known and better understood by care managers and commissioners, and this would appear to still be the case both from the survey and interview responses. SL schemes do not tend to engage directly with service users and their only link to them is through care managers, who on an individual level may or may not discuss SL as a possible option. If schemes want to expand or develop the service they offer for older people it may be that efforts need to be directed to 'win the hearts and minds' of some care managers or they may need to find ways to build a relationship directly with the service users and carers themselves.

It is evident from this initial work that SL is already supporting a number of older people and there is support for expansion, although it would seem that there is still work to be done before it is

considered part of mainstream provision for older people. There is also a need for adequate resources, awareness raising, management commitment and a pool of suitable carers to support any expansion effort. It also needs to be recognized that SL will not be suitable for all older people. There is also a view that SL is enabling, user-focused, valuable and cost-effective. There is little research evidence to support these claims, particularly with regards older people, apart from anecdotal evidence from social workers and a small number of service user satisfaction surveys. The next phase of the research described here should help to 'unpack' this for older people and their carers through a mixture of face-to-face and self-completion questionnaires capturing their outcomes and experiences. It will also propose estimates of the potential demand for SL among this group, document staff and other stakeholder experiences of the implementation of new or the expansion of existing schemes for older people and estimate the costs involved. The research should help to contribute to decisions locally about whether or how to introduce or expand of SL provision for older people.

Acknowledgements

Disclaimer statements

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