Shared Lives Plus

Shared Lives in Health

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CordisBright

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Executive Summary

Overview

Shared Lives Plus (SLP) has commissioned Cordis Bright to conduct research in relation to the *Scaling Shared Lives in Health Programme*. This report explores the impact of the Scaling Shared Lives in Health Programme on the use of Shared Lives services to support individuals with a health need in England.

Additionally, this report identifies four case study schemes where individuals with a health need have been supported through a Shared Lives arrangement.

This report builds upon the evaluation of the implementation of the first phase of the Shared Lives in Health Programme, conducted by Cordis Bright, PPL, Innovation Unit and Social Finance in June 2019.

Key findings

Scaling Shared Lives in Health Programme

Without baseline data, assessing the success of the Scaling Shared Lives Programme is challenging. However, data from the State of the Sector survey does provide some insights.

Positively, 44% of schemes that responded to the State of the Sector survey reported that they had heard from Shared Lives Plus about 'The role Shared Lives schemes can play in supporting people with a health need'. Further, 92% of schemes that have identified growth in health-funded arrangements as a strategic priority have heard from Shared Lives about this. While this is still a small sub-group of Shared Lives Schemes, it does suggest that the programme has been well targeted.[1]

The programme also aimed to positively influence the number of Shared Lives arrangements for people with a health need. A majority of Shared Lives schemes (79%) have some exposure to arrangements for people with a health need.[2] While this represents a relatively small number of arrangements overall, it demonstrates a wide-spread engagement with this agenda. A minority of schemes have developed this work further and have a more substantial portfolio of health-focused arrangements.

As a sector, the overall growth of Shared Lives arrangements for people with a health need is difficult to assess. On the one hand, there is evidence that the total

[1] 13 out of 37 schemes reported that growing the number of health-funded arrangements is high or very high priority (35%) 33 scheme did not submit an answer.

[2] 55 out of 70 schemes reported supporting at least one person whose main support need was one of the following: mental health condition; a physical impairment; dual mental health and learning disability diagnosis; profound and multiple learning disabilities (PLMD); sensory impairment/Deaf; HIV/AIDS; acquired brain injury or dementia.

number of arrangements for people with a health need is likely to have grown alongside the sector as a whole. On the other hand, a majority of schemes reported either no change or a decrease in the number of health funded arrangements agreed.[3] Deep-dive evidence suggests that often a Shared Lives arrangement for a person with a health need will still be paid for via local authority.

Going forward, it will be important for Shared Lives Plus and NHS England to clarify its strategic focus: is the aim to expand use of Shared Lives services for all people with a health need or for people with an arrangement that can be *funded* through health funding.

Shared Lives arrangements for people with a health need – deep-dive evidence

Four Shared Lives schemes were identified as showing promising progress at supporting people with a health need via the State of the Sector survey. They were: Ategi Buckinghamshire, Coventry, Derby City and Merton. Consultation was carried out with scheme managers, and also health and care professionals that refer to these schemes. Case studies were also completed by two of the schemes. This evidence provides further insights into the challenges and solutions required to grow Shared Lives offer to people with a health need. Key findings included:

1. **Identifying a local need for Shared Lives:** Examples were given of schemes that failed to gain traction supporting different types of need (e.g. physical disability), often where there was a successful existing service. Shared Lives schemes succeeded particularly where they were able to fill a gap in local provision or aligned to local strategic priorities.
2. **Awareness and understanding of Shared Lives in health settings:** Awareness and understanding of Shared Lives by health professionals remains limited. A very targeted, focused and in-depth approach to developing key relationships with potential referrers was identified as key.
3. **Flexible matching process:** Depending on the needs of the individual and the service that is referring them to Shared Lives, it may be necessary to be flexible with the length of time required to match a person with a Shared Lives carer. This could include a longer or shorter matching period.
4. **Access to health funding:** Where health focused arrangements have been made, it is interesting to note that they appear to be largely funded by social care budgets. There are some exceptions (e.g. short-term health funding for specific situations and the use of personal health budgets in Derby). However, it appears that Shared Lives schemes continue to find it challenging to access Continuing Health Care funding.
5. **Impact of Shared Lives arrangements:** Case study and interview evidence indicates that outcomes for individuals are positive. Further, stakeholders are of the view that the schemes have potential to reduce

[3] 25 of 32 schemes who responded to this question (78%)

health and social care system costs. However more in-depth quantitative research would be valuable to triangulate these findings.

Recommendations

Based on the evidence of this report, we suggest the following seven recommendations are considered. These recommendations are primarily targeted towards Shared Lives Plus and NHS England, but also other Shared Lives schemes.

1. **Document experiments, pilots and projects.** We recommend continuing to ask schemes about people with health needs through the State of Sector survey. For an awareness raising programme such as this, keeping a register of precisely which schemes have been directly engaged and how, would help to demonstrate the likelihood of any changes being linked to the work of Shared Lives Plus.
2. **Gather structured case studies.** We would recommend seeking a wider number of structured case studies from schemes to gather the insights and experiences of the sector in a way which might inform future strategy. A shared case study tool would allow for greater inter-scheme learning. These would differ from the stories that Shared Lives schemes collect for promotional purposes.
3. **Clarify the strategic focus of 'Shared Lives in Health'.** If Shared Lives Plus is to continue to promote growth in support for people with health needs, we would recommend reviewing and clarifying the strategic definition of 'Shared Lives in Health'. In particular, it is noteworthy that the funding landscape is quite different between areas, and therefore it may be challenging for services to grow 'health arrangements' if that is focused on health funded arrangements.
4. **Focus on local priorities.** Shared Lives Plus should encourage schemes to identify service user cohorts that are of strategic local importance, and clear gaps in local provision which Shared Lives could realistically fill.
5. **Social care funding for people with health needs.** There appears to be a continued acceptance that health needs can or will be funded via social care routes. This issue stretches beyond the Shared Lives sector. But it will undoubtedly affect the Shared Lives' ability to grow its engagement with health-funded services. Continued discussions at a local and national level should be prioritised to help tackle this difficulty.
6. **Institutionalise good relationships with referrers.** Further consideration of how to ensure that Shared Lives schemes are able to convert good personal relationships into secure, long-term institutional relationships would help to promote sustainable growth of referrals from health organisations. This might include supporting schemes to identifying referral panels and other decision making forums that they should join.
7. **Gather evidence of impact on the Health and Care sector.** It would be valuable to develop an outcome focused monitoring approach which enables measurement of improvements in individual's circumstances, and costs to the wider health and social care system.

1 Introduction and methodology

1.1 Introduction

Shared Lives Plus (SLP) has commissioned Cordis Bright to evaluate the impact of the Scaling Shared Lives in Health Programme on the use of Shared Lives services to support individuals with a health need in England.

The evaluation is based on an e-survey of Shared Lives schemes and four case studies of schemes where individuals with a health need have been supported through a Shared Lives arrangement. The purpose of these case studies is to identify common challenges to expanding Shared Lives' offer to commissioners, health services and individuals with a health need, and the solutions and good practices that have been implemented by these schemes in response.

This report builds upon the evaluation of the implementation of the first phase of the Shared Lives in Health Programme, conducted by Cordis Bright, PPL, Innovation Unit and Social Finance in June 2019.

1.2 Scaling Shared Lives in Health Programme

Shared Lives Plus and NHS England have been working collaboratively since April 2016 to support the development of a model of Shared Lives to support individuals with health needs. The rationale for this was to test whether the personalised style of support offered by Shared Lives services could be delivered to support individuals with a health condition. Partners wished to understand:

- The impact on health outcomes for individual service users.
- The relative costs of Shared Lives services compared to "conventional care" alternatives.
- The impact of using Shared Lives services on service users' subsequent use of other health care services.

The Scaling Shared Lives in Health programme was originally intended to run from 2016 to 2021 with seven sites being funded to develop and implement a local model of support. This phase of activity was concluded early in 2018 in response to low numbers of successful arrangements in pilot sites over a period of 18 months between January 2017 and December 2018.

Following this period of piloting in local schemes, the Scaling Shared Lives in Health Programme has sought to promote the role that Shared Lives services can play supporting individuals with a health need through a programme of awareness raising and promotional activities. This programme aimed to boost awareness within the sector and share lessons from the earlier work of the programme.

1.3 Research rationale

This research has two aims:

1. To assess the impact of the Scaling Shared Lives in Health programme on the provision of Shared Lives arrangements for people with a health need, including any growth in overall numbers of arrangements.

2. To understand the nature of the support provided by Shared Lives schemes for individuals with a health need, including:

    a. The type of support provided by Shared Lives.
    b. The type of needs that Shared Lives has supported.
    c. How that support was arranged and funded.
    d. The impact of Shared Lives arrangements on the individuals.

This evaluation builds upon the findings of the evaluation of the first phase of the Scaling Shared Lives in Health programme.

1.3.1 Methodology

This evaluation has taken a mixed methods approach to addressing the key aims set out above. This included:

1. E-survey of Shared Lives Schemes
2. Deep-dive study of four Shared Lives Schemes supporting individuals with health needs.

E-survey

To capture the impact that the Scaling Shared Lives Programme has had across the sector, additional health questions were included in the annual State of the Sector survey which is sent to Shared Lives schemes. In total, 70 schemes responded to the State of the Sector survey.

The majority of schemes included in the analysis were based in the South East, Greater London and North West, but there was representation from every region of England (see Figure 1).

Figure 1: Number of schemes from each region of England and the percentage they make up of the sample

Region	Number (%)
North West	16 (23%)
South East	13 (19%)
Greater London	9 (13%)
Yorkshire and the Humber	7 (10%)

Region	Number (%)
North East	7 (10%)
West Midlands	6 (9%)
South West	4 (6%)
East Midlands	4 (6%)
East of England	4 (6%)
Total	**70 (100%)**

61% percent of the schemes were local authority-run services, with the remainder set up as independent organisations (17%), charities (10%), local authority trading arms (7%), one community interest company (1%) and one health trust (1%).[4]

Deep-dive study

Based on responses to the State of the Sector e-survey, a number of Shared Lives schemes were identified as exhibiting signs of promising practice in respect of supporting individuals with a health need.

Deep-dive studies were conducted with four of the schemes, including interviews with scheme managers, local health or care professionals with experience of Shared Lives arrangements for individuals with health needs, and case studies. The following qualitative consultation was conducted as part of the deep-dives:

Figure 2 Summary of deep-dive approach

Scheme	Type of scheme	Interview with scheme manager	Interview with health and care professional	Case studies
Ategi Buckinghamshire	Charity	✓	✓	3
Coventry	Local authority	✓	×	2
Derby City	Local authority	✓	✓	n/a
Merton	Local authority	✓	✓	n/a

[4] This data was not available for one scheme (1%). Percentages do not add up to 100% due to rounding.

1.4 Structure of report

This report is structured as follows:

- **Section 2** considers the impact of the Shared Lives in Health programme on the Shared Lives Sector.
- **Section 3** reviews evidence from the deep-dives. It explores the lessons to be drawn from the experience of promoting Shared Lives for people with a health need, and the impacts and outcomes from implementing this approach.
- **Section 4** provides a summary of findings and a consolidated overview of recommendations.

2 Scaling Shared Lives in Health Programme

2.1 Overview

The following chapter provides a summary of the evidence in relation to the impact of the Shared Lives in Health Programme. This is primarily based on responses to the additional health questions incorporated into the annual State of the Sector Report.

2.2 Overview of Shared Lives in Health

Health needs being met by Shared Lives services

In total 4,852 people were reported to have a Shared Lives arrangement in the 70 schemes that responded to the State of the Sector survey, including those with a social care and/or health need. The majority of arrangements are live-in arrangements (51%), followed by short breaks (20%) and day support (9%).[5,6] 20% of arrangements are unspecified.

Of these arrangements, schemes reported the primary support need of 4,816 people[7]. Responses showed that the large majority of individuals fit a traditional Shared Lives profile:

- 3,193 (67%) people were supported for learning disabilities
- 325 (7%) were supported for needs associated with old age
- 294 (6%) people were supported for autism/Asperger syndrome

In total **836 people (17%) had a health need** recorded as their main support need. This included:

- 235 (5% of the total sample) people with mental ill-health.
- 182 (4%) people with a physical impairment.
- 139 (3%) people with dementia.
- 112 (2%) people with a dual mental health and learning disability diagnosis.

[5] Percentages do not add up to 100% due to rounding.

[6] The day support figure includes 68 people supported by the Gateshead scheme. Their figure was originally 7,440 but, presuming this was an error, we calculated 68 based on their total given figure (85) minus their figures for live-in arrangements (17) and short breaks (0).

[7] Some schemes reported the primary support needs of a slightly higher or lower number of people than they had reported having a Shared Lives arrangement.

- 76 (2%) people with an acquired brain injury (ABI).
- 62 (1%) people with profound and multiple learning disabilities (PMLD).

While the overall numbers of arrangements for people with a health need remains a relatively small proportion of the overall number of Shared Lives arrangements, it is noteworthy that:

- 57% of schemes reported that they supported at least one person with a mental health condition.
- 29% of schemes reported that they supported at least one person with dementia.
- 19% of schemes reported that they supported at least one person with ABI.

This would suggest that a significant proportion of services are engaged in this agenda, even if the number of people supported is small.

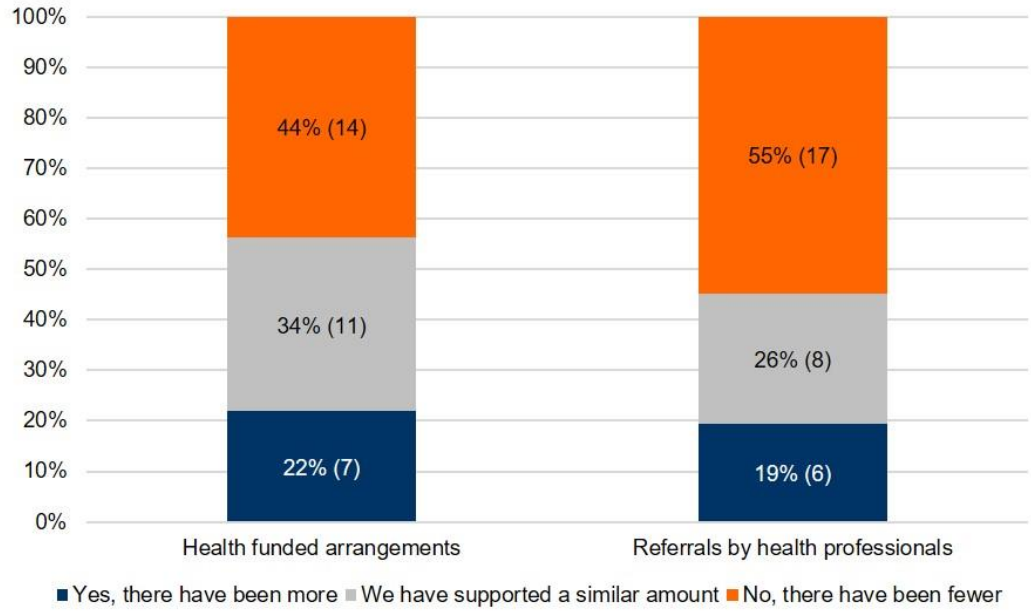
Growth of health needs in Shared Lives

There is mixed evidence about the extent to which Shared Lives is supporting more people whose primary support need is health related.

Figure 3 shows that a majority of schemes are not reporting an increase in referrals by a health professional or health funded arrangements. As discussed in greater detail in relation to the deep-dive case studies, this does not preclude that schemes may be supporting more people with a health need (only that the source of funding and referrals does not come from within the NHS). It shows:

- 25 schemes (81% of schemes responding to this question) reported either no change, or a decrease in the number of referrals received by health professionals. Six schemes (19% of schemes responding to this question) reported an increase.
- 25 schemes (78% of schemes responding to this question) reported either no change or a decrease in the number of health funded arrangements agreed. Seven schemes (22% of schemes responding to this question) reported an increase.

Figure 3: Reported change in number of health funded arrangements and referrals from health professionals between April 2018 and March 2019 (n = 32, n = 31)[8]



However, there is other data which leads us to question these assumptions. Proportionally, the 2018/19 State of the Sector responses show a similar breakdown of main support needs as in the 2016/17 State of Sector report (prior to the Scaling Shared Lives in Health programme)[9]. This would suggest that the sector has not significantly diversified since the programme begun. However, there is evidence to suggest that the sector as a whole has grown during this period, so assuming the proportion of people with a health need has remained relatively consistent, we may *very cautiously* predict that the absolute number of arrangements would have also increased.[10] Additionally, what is not captured here are the individuals who have a health need in addition to their primary care need (e.g. learning disability and dementia).

Referrals by health professionals

In total, the schemes in this analysis reported receiving 109 referrals from health professionals in the last year. Twenty-seven percent of these (29 referrals) resulted in completed arrangements (although it is not known how these arrangements were funded).

[8] 38 and 39 schemes did not respond, respectively.

[9] Shared Lives Plus (2018) *State of the Sector 2016-17.*

[10] Shared Lives Plus (2019) *State of the Sector 2017-18.* [online] available at: https://sharedlivesplus.org.uk/wp-content/uploads/2019/06/Shared-Lives-in-England-2017-18-full-report.pdf

It was noted that one scheme made up over half of these referrals with a total of 52, resulting in 13 completed arrangements (45% of total completed arrangements). It is also noteworthy that only 15 schemes (21%) responded to this question. We would therefore suggest caution interpreting this result, but it would suggest that only a small number of schemes have developed a clear route into Shared Lives via health professionals. These findings, in keeping with the findings outlined in Figure 3 above, suggest that certain sites have found it easier to make progress with the Shared Lives in Health agenda but it is not a consistent experience across all sites.

Health funded arrangements

Most support offered by Shared Lives schemes was funded by traditional social care procurement. This was the case for live-in arrangements (92%), short breaks (96%) and day support (94%). For live-in arrangements and short breaks, the second most common funding stream was joint commissioning by health and social care (4% of live-in arrangements and 3% of short breaks). The second most common funding streams for day support were the Continuing Health Care Fund and self-funding (both 2%).

While health funding streams represent only a small proportion of total arrangements, we also note that 41% of schemes have health funded-arrangements in some form (i.e. they have at least one arrangement which is not funded via traditional procurement or self-funded).

Figure 4: Summary of funding sources

	Live-in support	Short breaks	Day support	Total
Continuing Health Care Fund	2%	1%	2%	2%
Section 117 Aftercare	1%	0%	0%	1%
Other NHS funding	0%	0%	0%	0%
Jointly commissioned by health/social care	4%	3%	1%	3%
Traditional Social Care procurement	92%	96%	94%	93%
Self-funded	1%	1%	2%	1%
Total	**100%**	**100%**	**100%**	**100%**

2.3 Organising arrangements for individuals with health needs

The survey suggests that almost three-quarters of schemes have confidence that Shared Lives staff can organise an arrangement for someone with a health need. Specifically, 29% of schemes believed their staff to be very confident and 41%

believed them to be mostly confident. In total, just over a quarter of schemes believed staff to be not so confident (22%) or not at all confident (7%).[11]

However, schemes have more mixed perceptions of the understanding of local health professionals about what services Shared Lives can provide and how to refer to them. Specifically, 26% of schemes felt that health professionals mostly understand what Shared Lives does and how to refer clients, while over half of schemes felt that health professionals are mostly unsure (45%) or do not understand (29%).[12]

Schemes' own internal bias may encourage them to be more positive about their own understanding, and more critical of their partners' understanding. However, this reported lack of understanding amongst healthcare professionals about the work of Shared Lives reinforces the picture suggested earlier, that only a proportion of schemes have well-established pathways into their service from health.

2.4 Impact of the Scaling Shared Lives in Health Programme

In the State of the Sector survey, there is evidence to suggest that the Scaling Shared Lives in Health programme has reached a proportion of Shared Lives schemes, although the information is not yet fully understood across all sites. It shows that:

- 44% of schemes reported that they had heard from Shared Lives Plus about 'The role Shared Lives schemes can play in supporting people with a health need'.
- 26% of schemes reported that they heard from Shared Lives Plus about 'How to successfully organise Shared Lives arrangements for people with a health need using health funding'.
- 21% of schemes reported that they heard from Shared Lives Plus about 'How to work with health professionals to encourage referrals to Shared Lives from health services'.

In the deep-dive schemes, there was similarly mixed evidence. For example, one of the four schemes reported hearing about the role Shared Lives can play in supporting people with a health need, how to work with health professionals to encourage referrals, and how to organise placements for people with a health need, whereas another reportedly had not heard from Shared Lives Plus about any of these.

That said, in each of the four deep-dive schemes, staff identified that they did receive regular communications from Share Lives Plus. Specifically, they

[11] n = 41 due to 29 schemes not responding.

[12] n = 38 due to 32 schemes not responding.

reported receiving communications via member emails and through direct communications with Shared Lives Plus staff. Those who had such direct communication reported finding this ad hoc access to advice and guidance helpful. Scheme managers also identified that they make use of peer-support networks, using Google Groups. While this was not explicitly linked to the Scaling Shared Lives in Health programme, it was identified as one of the sources of information that they might turn to if they were looking to access further support or information on how to support individuals with a health need.

2.4.1 Health service users as strategic priority

Approximately one third of those who answered this question (35%, 13 respondents) reported that securing health-funded Shared Lives arrangements is a high or very high priority. The majority (65%, 24 respondents) reported that it is a low or very low priority.[13] This may in part explain the differential experiences between schemes reported in Figure 3 above: schemes are unlikely to make significant progress in attracting health referrals and arrangements if they do not perceive it to be a strategic priority. Shared Lives Plus' role may be influential, however: of those highlighting that health-funded referrals and arrangements is a growth priority, 92% (12 out of 13) reported that they had heard from Shared Lives Plus about 'The role Shared Lives schemes can play in supporting people with a health need'.

Without a baseline, it is challenging to assess whether this represents progress, but it would appear that of those schemes that have prioritised people with a health need as an area of strategic focus, the Scaling Shared Lives in Health Programme may have been a contributing factor.

[13] n = 37 due to 33 schemes not responding.

3 Shared Lives in health: Key schemes

3.1 Overview

The following chapter includes analysis of the experience of four Shared Lives schemes involved in providing services to individuals with a health need. The schemes were identified via the responses to the State of the Sector survey.

This chapter includes evidence from telephone interviews with scheme managers, health and care professionals that have been involved in organising Shared Lives arrangements for individuals with a health need, and case studies of individual service users.

This chapter includes evidence in relation to:

- How schemes have established an offer for individuals with a health need.
- How the referrals, matching and arrangement process is conducted for individuals with a health need.
- The funding of health arrangements.
- The impact of health arrangements of service users and the wider health and care system.

3.2 Developing an offer for service users with a health need

3.2.1 Introduction

To develop a service offer for service users who have some form of health need, service managers identified a number of key considerations and actions that informed their approach. These included identifying groups of people who would benefit from a Shared Lives service and were not already being effectively served by another service locally. Linked to this, scheme managers and other professionals identified that it was important to ensure that the schemes had the right carers and properties at their disposal to provide support.

Once a cohort of service users had been identified, the scheme managers described a process of proactively promoting Shared Lives in specific teams as well as embedding the scheme within key decision-making forums to generate referrals.

3.2.2 Identifying a need for Shared Lives

The types of identified need

Mangers identified a range of conditions but principally they were focused on individuals with a mental health condition (Merton, Coventry, Derby, and Ategi

Buckinghamshire); dementia and related conditions such as Korsakoff Syndrome (Derby and Coventry) and acquired brain injury (ABI) (Derby).

Taking time to understand the local provision and gaps in services

Coventry, Merton and Derby's experience all demonstrates the value of understanding the local landscape and gaps in provision very carefully.

Coventry initially sought to expand their offering for service users with physical needs. This was in response to local carers having homes which would be suitable for reablement (e.g. bungalows). The Coventry team began working closely with the hospital discharge team to promote their services. However, the local authority already had a strong offering for people in need of reablement and therefore it was not possible to gain traction in this area. The change to a more successful focus on mental health was informed by discussions with the hospital discharge team who described a lack of local support for individuals discharged from mental health rehabilitation services.

Similarly, research in Merton identified that there was existing provision for individuals with high levels of need linked to a mental health condition. It was also clear that there was a range of support for people with lower levels of need such as Independent Living schemes or floating support. However, there was no service that could support individuals who were below the threshold of high needs services but not yet able to live a more independent life. This gap in local provision represented an opportunity for the Merton scheme.

In Derby, it was identified that there were services for individuals with an ABI, such as extra care housing or sheltered housing, where an individual could live independently with visiting support. However, Shared Lives were able to offer a service with an 'enabling' element since a Shared Lives carer could also do activities such as *"go with to shops, help write shopping list, act as sounding board, make sure they do their exercises, go to their medical appointments with them".* Interviews with health and care professionals identified that the personalised approach taken by Shared Lives services could set it apart from alternative combinations of care and support, which were already available to people with a health need.

In each of these examples, schemes have clearly identified a cohort that they were able to support where there was a local need. In Merton and Derby in particular, it is noteworthy that Shared Lives arrangements were often an alternative to services such as independent living, extra care or sheltered accommodation. In this regard, Shared Lives is providing a similar option for individuals with a health need as it does for its established client group of individuals with a learning disability or autism.

Promoting Shared Lives for people with health needs

Strategies to promote Shared Lives for people with health needs included awareness-raising campaigns to inform health professionals of the availability and capabilities of Shared Lives services, and joining meetings of teams that Shared Lives is seeking to work with. Each of the deep-dive schemes offers

evidence to suggest that on-going in-person interaction with health professionals has been key to schemes' success.

For example, in Merton the scheme manager and a Mental Health Team Manager both noted that Shared Lives staff regularly attend mental health team meetings, to discuss potential referrals that can be made from the ward to Shared Lives. This has helped to build understanding of Shared Lives' capabilities within the team, as noted by the team manager:

> *"Before people saw it as sort of like fostering, home for life, now there are more clients who are expecting to move on and have outcomes to meet. Shared Lives officers are now working with both groups, and gently trying to move older groups through and out into independent living."*

This example chimes clearly with the previous evaluation of the Shared Lives in Health programme, which found that it was important to secure a strong partnership with key teams involved in the referral process and that this could be boosted by having an active physical presence within that team.

Similarly, staff at Ategi Bucks reportedly also attend meetings attended by health professionals where discharge plans are coordinated between the ward staff and community teams. In Buckinghamshire, this is coordinated by a social worker based within the hospital who is the source of a number of referrals to Shared Lives. It was noted by the Hospital Social Worker that generally awareness and understanding of Shared Lives services is low, amongst health colleagues and also potential service users, and that they were required to often explain the service's offer. This also resonates strongly with previous findings that it is important to identify and cultivate 'champions' in key positions who are willing and able to promote Shared Lives within the health system – especially where other staff or potential service users are not familiar with the service that Shared Lives can provide.

The need for champions is reinforced by the experience of Derby Shared Lives. The scheme manager reported that the scheme has carried out generalised promotion of their services by placing rolling advertisements for Shared Lives on hospital screens, as well as speaking at team conferences. However, the scheme has had its greatest success in relation to supporting people with acquired brain injury (ABI). It was identified that this was facilitated by a historical connection between a Shared Lives staff member who had previously worked in a local specialist ABI charity and maintained strong professional links to the Head Injury Team in the hospital. It was reported that general awareness and understanding of Shared Lives outside of the acquired brain injury team remains low, highlighting again the importance of targeted relationship building with key teams and the value of local champions that provide access and promote Shared Lives.

Lastly, schemes highlighted that it was important to explain the benefits of the Shared Lives approach, as an alternative to more established and familiar services. As noted by one health professional who now refers into the service regularly:

"It took me a while to wrap my head around it as it seems too good to be true, it's so different from anything already existing."

It was stressed that it is important not only to explain what Shared Lives is and does but also the relative strengths of the service compared to other alternatives.

3.2.3 Obstacles to establishing Shared Lives for people with health needs

Schemes identified two key challenges in establishing Shared Lives as a service option for people with a health need.

Identifying key stakeholders and building awareness of Shared Lives

As noted above, success appears to rely on building awareness of Shared Lives in health, identifying key stakeholders who can help make referrals and developing very targeted and in-depth relationships with these key individuals. The deep-dive research identified that these tasks are challenging to deliver.

In particular, scheme managers identified that awareness is often quite limited amongst health professionals. Where schemes are operated by local authorities, they are organised with the adult social care services and resultantly do not interact frequently with health colleagues. It was also noted by one scheme manager that, for example, they would be interested in the potential of expanding the service into physical disability or health needs, but it is not clear which stakeholders would need to be engaged to allow the scheme to promote itself effectively.

Carer availability and skills

Two scheme managers identified carer availability as a key challenge for expanding Shared Lives as a service for people with a health need. However, some of those challenges – such as having sufficient male carers or carers with a property with ground-floor living arrangements – are not specific to individuals with a health need.

It was noted that for some schemes, such as Derby and Coventry, it has been necessary to provide additional training for carers. For example, Derby reported that they are commissioning additional training in identifying the signs of sepsis and health colleagues in Coventry are offering additional training in epilepsy and diabetes. As such, Shared Lives scheme managers we interviewed felt confident that their carers could support service users with more complex health needs than typical Shared Lives service users.

3.3 Making a Shared Lives arrangement for a person with a health need

3.3.1 Types of arrangements

The deep-dive schemes were most commonly organising live-in arrangements lasting more than four weeks, with a smaller number of service users supported with short breaks and day support. The length of service users' arrangement

depended on whether their goal was to be supported into independence (and how this could be achieved) or whether they required more long-term support.

In terms of the support provided by a Shared Lives carer, it was noted that this is very similar to the support that might have been provided to a Shared Lives service user without a health need. Service users tend to be referred into Shared Lives on the basis that their carers will provide emotional and social support, with some personal care support. While the nature of the personal care required may be linked to a health condition, examples of Shared Lives carers involved in medical support were not identified. In some instances, additional support was provided alongside Shared Lives by other health and care professionals depending on the need of the individual, such as a physio or district nurse. In relation to an individual's health needs, the carers' key role was primarily to support them to take their medication and attend medical appointments.

3.3.2 Referral process

Overall, the evidence suggests that minimal changes to the referral processes have been required in order to accommodate service users with a health need. Shared Lives scheme managers report similarities between the process for taking a referral for a person with or without a health need. For them, the key distinction is that the referral source may come from a team outside the usual adult social care or learning disabilities team that refer people to Shared Lives. Also, of course, the individual may be accommodated in a health service rather than living in the community.

In most cases, the process starts with an initial discussion between the scheme manager and the referring partner to establish a person's suitability for the scheme. If their suitability is agreed, the referring partner fills out a referral form which details service users' specific care history and needs. The importance of the initial conversation to assess the suitability of the individual was highlighted as an important step for referrals by health professionals, particularly where they had less familiarity with Shared Lives' capabilities. This also highlights the importance of the relationships between Shared Lives staff and relevant referring professionals, in that they know who to contact in the event that they are unsure about a potential referral.

In Merton the process differs slightly. A local referral panel is convened, led by the local authority's Head of Adult Social Care and attended by heads of other local authority teams, including those which look after mental health and learning disability provision. At this forum, the professional wishing to make a referral gives a presentation on the person they are referring, and those in attendance advise on where best to place that person. As a local authority service, Shared Lives Merton is one of a range of care options which is considered when assessing the person's needs and level of risk. This highlights the importance of being integrated into key local decision-making groups. In Merton, as a council-operated service, this is a straightforward process however this may be an obstacle to independent Shared Lives schemes.

3.3.3 Matching process

Like the referral process, the matching process is similar for Shared Lives staff whether a service user's needs are health or care related. The process starts with the scheme manager getting to know the service user's case and choosing one or two carers based first on the person's need and then on their personal preferences. This is followed by a period of facilitating meetings between the service user and the carer, usually also including the service user's case worker.

However, this matching process is a bespoke and tailored activity, which varies in length and complexity. There appear to be few common factors which help to predict those which are likely to be more complex. For example, one scheme reported that the matching process for service users with mental health conditions is usually longer than for service users with learning disabilities, as it can take longer to build up trust with the carer, especially if the service user is leaving a restricted care setting. However, another scheme reported that the matching process for service users with mental health conditions is usually faster, as service users are keen to leave the hospital setting and see their placement with Shared Lives as a necessary stage in their recovery.

This finding differs from the findings of the previous evaluation of the Scaling Shared Lives in Health programme, which suggested that for most health professionals speeding up the matching process would be a requirement for increasing arrangements. However, the evidence from schemes here suggests that the matching process does not need to be quicker in all circumstances. The matching process will need to be flexible to meet the different needs of individuals and the services that are making the referrals.

This finding indicates that the scheme's adaptability to the needs of the individual during the matching phase is likely to be key to their ability to support service users with a range of health needs to access their service. A "standard" or "one-size fits all" approach is unlikely to increase the rate of health referrals or arrangements.

3.3.4 Health funding sources

In the majority of deep-dive schemes it was reported that arrangements for most people with a health need were funded by social care.

It is true that for a number of the schemes, funding decisions were taken by panels which included representation by health and social care representatives, so it was not always clear which specific funding stream was used to fund a service user's arrangement. For example, one scheme manager said:

> *"We have found people with [a positive] CHC checklist, we try not to let that delay the process, we make the arrangement then we let the LA and NHS fight out about the funding. We try not to get involved in that process, usually the Local Authority will fund the arrangement in the interim."*

However, where scheme managers and professionals did have more specific knowledge, it was usually the local authority who were funding the arrangement. This is consistent with the findings of the State of the Sector survey and

stakeholder interviews which found that traditional social care funding through the local authority is still the primary source of funding to support Shared Lives arrangements.

It was noted that for people with a health need which required time-limited support, funding was typically provided by health services. However, in these cases, the costs of rent or care for non-health conditions were not covered via health funding and were more typically funded through traditional social care procurements.

For example, individuals with Shared Lives arrangements may also have received regular input from professionals such as a district nurse, occupational therapist or psychiatric nurse, while Shared Lives carers typically supported individuals with matters linked to personal care. Health and care professionals identified that if Shared Lives arrangements were to be funded, for example with Continuing Health Care (CHC) funds, it would likely require Shared Lives schemes and/or carers to offer the types of care typically provided by visiting medical professionals.

Whilst in most cases, social care funding was most commonly used, the experience in Derby differs. In Derby, Personal Health Budgets (PHB) were used to fund arrangements for individuals with an ABI. The example was given of one young person whose placement was successfully funded by a PHB:

> *"In May 18 we [the referrer] started talking to Shared Lives, meanwhile the individual is in own accommodation, (in this case extra care housing). I wrote to the funding panel around July. Panel approved PHB in September - £250 per week. By November, a carer was lined up; the carer and service user meet in December; the carer trained through December, first aid (general stuff), but also specific training from us around brain injury."*

There are, however, a range of challenges associated with the use of PHBs for Shared Lives arrangements. These include:

- Calculating the amount to claim: Since there is neither an hourly rate associated to Shared Lives nor a fixed amount of care and support provided per day, it is challenging to apply for PHBs. Application forms are designed for services that can be more easily described in those terms.

- Highlighting the 'health' care: The care provided by Shared Lives arrangements could arguably be classified as a health care or social care activity in many instances (e.g. safeguarding). To access a PHB, applications needed to be carefully tailored to focus on health outcomes. Examples given included: support with healthy eating and diet; support to complete exercises at home; completing documents linked to health, such as keeping a sleep diary. In some instances, to do this Shared Lives staff need support to identify a 'health' benefit when completing funding applications.

- Funding period: PHB funding is linked to outcomes in a plan. Often people will need a longer placement than will be funded by PHBs. Over time, ideally as

people achieve more positive health outcomes, if an individual is to continue in a Shared Lives Arrangement this will eventually need to be transitioned into a Social Care funded package.

An important observation about PHBs was that in Derby, the budget and application process to receive a PHB was separate from the CHC funds. In other areas of the country, CHC eligibility is a prerequisite for receiving a PHB, but in Derby this was reported not to be the case as there was a distinct budget specifically for PHBs. By comparison, a health professional noted that

> *"I've tried [to arrange a PHB] in Nottinghamshire, Lincolnshire, Leicestershire and Derbyshire and been told they need to get CHC funding first."*

This illustrates the importance of a clear understanding of the local context and that any scheme seeking NHS funding to support arrangements for people with a health need will need to understand the local funding strategy and ensure that they are targeting a cohort that is suitable for Shared Lives **and** likely to be eligible for funding.

3.4 Impacts and outcomes

Evidence from interviews and service user case studies indicates Shared Lives arrangements for people with a health need have achieved positive results for the individuals concerned and contributed to positive developments in the wider health and care system.

3.4.1 Impact on people with a health need

A number of examples and case studies were provided by schemes which highlighted that prior to joining a Shared Lives arrangement, individuals were accommodated in inappropriate settings, where the care was either insufficient, or too inflexible. This includes individuals, for example with a mental health need, living in supported living accommodation, Bed and Breakfast hotels, or independently who required more support with the activities of daily life. There were also instances of individuals who were living in highly restrictive hospital-based care settings, not necessarily merited on the basis of their needs, but because they were deemed to be too at risk for the available alternatives.

For example, a case was described concerning an individual with a "*moderate*" mental health need. Without the Shared Lives arrangement, options for this individual included staying unnecessarily in an acute mental health treatment setting or entering independent accommodation with intermittent floating support, which may not have been sufficient to prevent relapse.

Particularly for individuals that have been sectioned unnecessarily, Shared Lives provides an immediate benefit of supporting the promotion of their individual liberty and independence. Shared Lives schemes tackle this issue by facilitating regular monitoring of service users' recovery in a setting which promotes independence. For example, carers often support service users to access health

appointments and take their medication. This improves their long-term physical recovery and enables improvement in other outcomes. An illustration of this is provided in the case study below.

Steve's[14] story

Steve is 51 years old and has been diagnosed with paranoid schizophrenia. Steve would regularly display anxious and paranoid behaviour and would occasionally disappear from home for long periods of time. Steve was admitted to a psychiatric hospital where staff identified that he often forgets to take his medication and attend appointments, contributing to his difficulties prior to being admitted to hospital.

After two years of rehabilitation, a health professional referred Steve into Shared Lives where he was matched with a carer over the course of 10 weeks. Amongst other types of support, Steve's carer ensures that his medication is administered as prescribed and takes Steve to his monthly hospital appointments. At these appointments, health professionals take Steve's blood pressure and issue a new prescription of his medication.

Steve's regular access to medication and health monitoring have dramatically reduced his anxious episodes and he has not been back to hospital since starting his Shared Lives arrangement. This has given him the stability that he needs to rebuild relationships with his family and regain some independence. As he explains:

"I've got my confidence back, I can travel independently now and visit people I want to see… My brother and I still enjoy watching the football together and most importantly I have been able to maintain contact with my son"

Another advantage of Shared Lives arrangements over traditional care options such as residential homes is that they offer a more personalised and flexible service. Interview and case study evidence suggests that this allows service users to build their skills and work towards independence in a way which would not always be possible in more communal care settings. The example below illustrates this:

Peter's[14] story

Peter is 57 and is diagnosed with a form of early-onset dementia as a result of his alcoholism. He was admitted to a Mental Health Hospital in his mid-forties, before later moving into a residential care home for six years. In Peter's words,

"Social workers felt I needed 24-hour care, so I went to live in a residential care home that looked after the elderly with dementia. I liked it at the home,

[14] Names have been changed

but I did not talk to the other people living there as they were much older than me. I liked talking to the staff who would take me out shopping. I did not like being told when I could have a fag and not having my own money. The front door was always locked, and I could not go out on my own. I did not see my family very much which I didn't like."

After introducing a potential Shared Lives carer to Peter and his family at his care home, a live-in arrangement was organised. He has been living with his Shared Lives carer for four years now.

Peter's carer helps him to order and administer his medications, attend medical appointments, maintain a healthy diet, and to keep in touch with his family. Peter is able to attend local authority day services for support with his dementia. Peter is supported to go to unfamiliar places, arrange social activities and events, and allowed to join the carer's family holidays. Peter says:

"I enjoy my carer's children and grandchildren visiting, they are always pleased to see me and often shout for me as they live opposite and see me sitting outside"

As Peter and Steve's stories both indicate, an additional benefit of Shared Lives arrangements has been the support with key health activities such as taking medication at the right time, attending appointments, as well as support with maintaining a healthy lifestyle (such as diet and exercise).

3.4.2 Impact on the health and care system

Scheme managers and health and care professionals were of the view that Shared Lives would be contributing to cost efficiencies for the system as a whole. In their view, savings could be identified for the NHS in terms of funding a more appropriate and less costly Shared Lives arrangement than, for example, continuing to support someone in a mental health hospital placement. In some cases, the cost burden is transferred from NHS to social care. However, stakeholders also provided examples of potential efficiencies for local authorities: stakeholders identified numerous cases of individuals that may have otherwise been supported into inappropriate supported living arrangements, where placement breakdown would have been costly and presented risk for the service user.

4 Key findings and recommendations

4.1 Impact of the Scaling Shared Lives in Health programme

Without robust baseline data, attributing changes to the Scaling Shared Lives in Health programme is challenging. There is a mixed picture about the possible impact of the programme: 44% of schemes report hearing from Shared Lives Plus about the role Shared Lives schemes can play in supporting people with a health need. However, 92% of schemes that have made health arrangements a priority reported that they have heard from Shared Lives Plus. This may suggest that the programme is amongst the factors that are influencing local schemes' strategic decisions about whether or not to prioritise people with a health need as an area of growth.

Recommendation: We would recommend documenting experiments, pilots and projects carefully. This would include continuing to ask schemes about people with health needs through the State of Sector survey. For a programme such as this, keeping a register of precisely which schemes have been directly engaged and how, would help to demonstrate the likelihood of any changes being linked to the work of SLP.

We would also recommend seeking a wider number of structured case studies from schemes to gather the insights and experiences of the sector in a way which might inform future strategy.

4.2 Growth of Shared Lives arrangements for people with a health need

There is mixed evidence regarding the growth of Shared Lives arrangements for people with a health need. On the one-hand, the proportion of individuals with a health need supported by Shared Lives has remained relatively constant in recent years. Given the growth of the sector this does suggest there has likely also been growth in the overall numbers of people with a health need supported[15]. Positively, 47 out of 70 schemes reported that they support at least one person with a mental health need, dementia, or an ABI. While for most schemes this is a smaller part of their service, it does suggest that a majority of schemes are engaged in some health-related activity.

On the other hand, in 2018/19 44% of schemes that responded to the survey reported supporting fewer arrangements funded by health funding. Only 22% reported supporting more people in arrangements funded by health funding. That being said, deep-dive evidence suggests that this may not reflect the number of people with a health need being supported, as a majority appear to be funded by local authorities.

[15] Shared Lives Plus (2019) *State of the Sector 2017-18.* [online] available at: https://sharedlivesplus.org.uk/wp-content/uploads/2019/06/Shared-Lives-in-England-2017-18-full-report.pdf

Recommendation: If Shared Lives Plus is to continue to promote growth in support for people with health needs, we would recommend reviewing and clarifying the strategic definition of 'Shared Lives in Health'. In particular, it is noteworthy that the funding landscape is quite different between areas, and therefore it may be challenging for services to grow 'health arrangements' if that is focused purely on health *funded* arrangements.

4.3 Organising arrangements for people with health needs

Qualitative consultation illustrated that Shared Lives schemes have the potential to organise a Shared Lives arrangement for individuals with a health need. There is not a consistent experience of how referrals and matching processes may be adapted, but in the deep-dives case studies the existing mechanisms were broadly sufficient. There are however existing barriers to making arrangements:

- **Identifying local needs:** Examples were given of schemes that failed to gain traction supporting different types of need (e.g. physical disability). This resonates with the experience of some schemes in the first phase of the Scaling Shared Lives in Health programme. Identifying local needs and priorities, including gaps in local provision which Shared Lives could fill was essential. **Recommendation:** Shared Lives should identify service user cohorts that are of strategic local importance, and where there are clear gaps in local provision which Shared Lives could realistically fill. Where established services are in place and work well, it is challenging to promote Shared Lives as an alternative. Working in isolation and attempting to bridge the gap between health and social care independently has proven challenging. Instead, Shared Lives needs to be incorporated into local change and delivery programmes.

- **Awareness and understanding of Shared Lives in health settings:** Evidence suggests that awareness or understanding of Shared Lives by health professionals remains limited. Building understanding has been achieved by persistent interactions with key staff. The importance of maintaining regular in-person presence with teams that should refer to Shared Lives and of 'champions' within health teams has been highlighted. **Recommendation:** Further consideration of how to ensure that Shared Lives schemes are able to convert good personal relationships into secure, long-term institutional relationships would help to promote sustainable growth of referrals from health organisations.

- **Funding sources for Shared Lives:** Building on the findings of the evaluation of the first phase of the Scaling Shared Lives Programme, there is evidence that service users with health needs have their Shared Lives arrangement routinely social care funded. Use of Personal Health Budgets are locally variable and may only be used for a time-limited period, and for certain conditions (e.g. ABI). **Recommendation:** There appears to be a continued acceptance that health needs can or will be funded via social care routes. This issue stretches beyond the Shared Lives sector. But it will undoubtedly affect Shared Lives' ability to grow its engagement with health-funded

services. Continued discussions at a local and national level should be prioritised to help tackle this difficulty.

4.4 Impact of Shared Lives arrangements for people with a health need

Qualitative consultation and case studies highlight that there are benefits of a Shared Lives arrangement for both the individual with a health need and the health and care system. In respect of the original rationale for the Scaling Shared Lives in Health programme, this report finds positive evidence to contribute to the case for promoting Shared Lives as an option for people with a health need:

- **Impact on health outcomes for individual service users:** there is evidence of a more appropriate level of support, often in-between hospital-based care or supported living arrangements. People with a health need benefit from support with health-related tasks, as well as promoting their independence through a more personalised service.

- **Relative costs of Shared Lives services compared to "conventional care" alternatives:** It was consistently reported that the costs of a Shared Lives arrangement would be less than placement on psychiatric wards or in care homes. However, it was noted that often additional health professionals would be required to support individuals alongside Shared Lives.

- **Service users' subsequent use of other health care services:** By providing a more appropriate service, it was noted that the risk of placement breakdowns and subsequent use of further health services was reduced in Shared Lives. This was a risk particularly highlighted for individuals with a mental health condition who were offered lower levels of support.

- **Recommendation:** Evidence concerning individual and system-wide outcomes are encouraging but based on relatively uncorroborated evidence. It would be valuable to develop an outcome focused monitoring approach which enables measurement of improvements in individual's circumstances, and costs to the wider health and social care system.

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