Shared Lives Intermediate Care

Evaluation Report

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1. Executive Summary

Introduction

Shared Lives Intermediate Care is a pilot programme that aimed to develop Shared Lives as a 'home from hospital' service for older people. It offered short term support in a family home to people who are well enough to leave hospital but are unable to return to their home/live independently.

Intermediate care is a short-term intervention that aims to reduce the length of hospital stays and/or prevent the need for admission to hospital or long-term residential care by providing alternative support for a limited period.

The pilot ran from October 2016 to March 2019 and initially involved seven existing Shared Lives schemes (called pilot sites). These sites worked with local hospitals and Clinical Commissioning Groups (CCGs) to develop referral pathways into Shared Lives for people with a range of health needs.

As part of the programme, pilot sites monitored their activity and fed back to the Shared Lives Plus Development Officer and the evaluation team. Shared Lives Plus produced an Intermediate Care Guidance document based on this learning (in autumn 2018) for dissemination to other Shared Lives schemes wanting to develop their Intermediate care offer.

Methods

The evaluation is based on a mixed methods approach drawing on quantitative and qualitative data including:

- Interviews - with individuals, carers, schemes and health & social care practitioners
- Project monitoring data - numbers of referrals/placements, profile of people
- Workshops with pilot and non-pilot Shared Lives schemes
- Change stories – provided by schemes and written up into case studies.

Findings

At the start of the programme it was expected that Intermediate care referrals would be older people who are most at risk of delayed discharge from hospital. Pilot sites expended time and resources on seeking NHS referrals, but found it difficult to access health teams, and health funded placements did not materialise in any numbers. The biggest challenges were in getting health professionals to understand and trust the Shared Lives model and make referrals, especially as this required system and culture change.

Pilot sites responded flexibly to barriers and difficulties, and utilised their existing contacts and reputation within the social care sector, gaining mainly social care funded intermediate

care referrals. New contacts were made with mental health teams who referred the largest number of people into the project. People with complex and multiple needs benefitted from this pilot, often when traditional service were not appropriate. This included younger people after a stroke, people with mental ill health and individuals whose housing circumstances and health needs made returning home difficult.

Numbers of referrals were low overall and there were capacity issues, with concerns about insufficient carers to meet potential demand. The pilot sites reported a total of 31 home from hospital Shared Lives arrangements in the period October 2016-April 2019. Similar arrangements were made throughout the pilot outside the programme in non-pilot sites; these are not included in this evaluation as they were not made by the Shared Lives Intermediate Care pilot sites.

Pilot sites showed flexibility, adapting their processes and systems to the nature and speed of home from hospital referrals. Shared Lives carers involved in the pilot demonstrated their capabilities and skills in supporting peoples physical and emotional health. Most were existing carers who, with appropriate ongoing support and training, proved themselves capable of providing support for people with a wide range of health needs.

People in Shard Lives arrangements told us that having 'a life' and feeling connected is important to their health and happiness. The individual stories in this evaluation highlight how people are being supported to recover from ill health and stay well. Some people welcomed the chance to go home after a short Shared Lives stay, others chose to remain on a permanent basis, both of which were successful person-centred outcomes.

Conclusion

Shared Lives systems can be adapted to respond to intermediate care referrals but this offer is not well known or used. Culture change is slow and Shared Lives Intermediate Care has yet to become routinely offered by health teams. Some health and social care professionals recognise the potential savings to the system of Shared Lives, especially the value that one dedicated carer can bring to overseeing and supporting independence and self-care. This pilot demonstrates the potential benefits of Shared Lives Intermediate Care for the health outcomes of people with multiple or complex needs, in particular, people with mental health issues.

Shared Lives schemes and carers inside and outside the pilot are supporting people leaving hospital, preventing ill health and hospital admission and reducing strain on NHS resources as part of their *'business as usual'*. The Shared Lives model is person-centred and inclusive - it can be an option for anybody whose needs can be met in a Shared Lives carers family home. All five Shared Lives schemes remaining in the pilot said they were continuing with their intermediate care offer, but within their core service. There was agreement that promoting Shared Lives as a unique personalised service was important in raising awareness across sectors. Involving all Shared Lives staff and carers by integrating new initiatives and sharing the learning is important to increase the diversity of people who are benefitting from Shared Lives.

2. Introduction

Shared Lives Plus received funding to develop an intermediate care service offering short term support to people who are well enough to leave hospital but are unable to return to their home and live independently.

The aim of intermediate care is to reduce the length of hospital stay, and or to prevent the need for admission to hospital or long-term residential care by providing alternative support for a limited period of time. This project supported the development of Shared Lives as an intermediate care service, with a focus on home from hospital, enabling people to regain their health and independence in a supportive family home.

The Shared Lives Intermediate Care (SLIC) pilot project ran from October 2016-March 2019. It initially involved seven sites across England (see below) who tested new ways of working to offer an intermediate care service and fed back on challenges and success:

- Durham Shared Lives
- New Directions Sefton
- PSS Midlands
- Positive Steps Shropshire
- Shared Lives South West
- Tricuro – Bournemouth (withdrawn)
- Wigan Council shared Lives (withdrawn).

Two sites withdrew from the pilot (see above) but they contributed learning to the evaluation.

Evaluation Methods

The National Development Team for Inclusion (NDTi) was commissioned to conduct the evaluation of the Shared Lives Intermediate Care pilot programme in January 2017. The purpose of the evaluation was to look at the impact of the programme in relation to the agreed project outcomes. It does not seek to evaluate each individual pilot site but uses data and findings from fieldwork in each site to indicate what worked and what didn't work for the pilot programme overall.

NDTi captured Stage 1 of the evaluation in an interim evaluation report (July 2018). It draws on fieldwork with all seven pilot sites and two non-pilot sites between May and June 2018, as well as project monitoring data and change stories provided by the sites.

This final report - Stage 2 of the evaluation - builds on the interim report. It includes additional qualitative data from fieldwork with people in Shared Lives arrangements, Shared Lives carers, health and social care professionals, plus end of project interviews and data

gathered from the remaining pilot sites. It also includes change stories gathered by schemes over the length of the project.

This evaluation uses a mixed methods approach - drawing on quantitative and qualitative data including:

- Feedback from workshops – with pilot and non-pilot schemes (2 workshops)
- Conversations with pilot and non-pilot sites (14 interviews)
- Analysis of project monitoring data – spreadsheet provided by Shared Lives Plus
- Case Studies (13 Change Stories - written as Case Studies by Shared Lives Plus)
- Interviews with people in Shared Lives arrangements (3 individuals)
- Interviews with Shared Lives carers (5 carers)
- Interviews with health & social care professionals (4 professionals).

This report first considers the delivery and reach of the pilot, and then reports on progress towards the 8 programme outcomes that were developed with Shared Lives staff and pilot sites.

NDTi would like to thank the pilot sites who contributed to this evaluation by collecting and recording data, attending workshops, giving us contacts and by sharing their views and experiences. We also would like to thank the Shared Lives carers and people in Shared Lives arrangements we spoke to, for sharing their views and experiences, as well as the health and social care professionals who took the time to talk to us.

3. Shared Lives Intermediate Care Delivery and Reach

Background

Shared Lives schemes that opted to become Shared Lives Intermediate Care pilot sites received funding from Shared Lives Plus to set up a home from hospital service in their locality. This involved working with their local hospitals and Clinical Commissioning Groups (CCGs) to develop referral pathways, recruiting and training Shared Lives carers and raising awareness of Shared Lives as an option for people with health needs leaving hospital. It also involved adapting their referral processes and paperwork to ensure that referrals could be dealt with in a flexible and timely manner.

Pilot sites recorded and monitored their intermediate care activity throughout the project and sent this data to Shared Lives Plus. A 'Change Story' template was also completed by carers and pilot sites. This data was made available to the evaluation team.

OUTCOMES FOR PEOPLE SUPPORTED BY SHARED LIVES

Outcome 1. Personalised support that enables people to maintain and recover their health and lead a full life in non-institutionalised settings

Outcome 2. Diversity of people with a range of needs supported through Shared Lives intermediate care

OUTCOMES FOR SHARED LIVES CARERS

Outcome 3. Carers are valued, recognised professionals with skills & expertise

Outcome 4. Carers have security of role and income benefiting carers & the system/locality

OUTCOMES FOR SHARED LIVES SCHEMES

Outcome 5. Shared Lives schemes are seen as knowledgeable, skilled and responsive

Outcome 6. Part of local offer/network of support

OUTCOMES FOR HEALTH AND SOCIAL SYSTEMS

Outcome 7. Contributed to reduced length of stay (and speedier discharge)

Outcome 8. Evidence of costs and benefits, including potential savings, by focussing resources on prevention and self-care/management, in line with NHS priorities

The burden of data collection was an issue for the pilot and provided learning for the evaluation team. Some of the monitoring data provided by pilot sites was incomplete and a questionnaire NDTi created for benchmarking at the start and end of placements was not returned in sufficient numbers so could not be used in the evaluation (see Wider Learning section, page 44).

Summary of Programme Activity

The data for this section comes from the monitoring and recording spreadsheets completed by the pilot sites involved in the intermediate care programme. These sites jointly reported a total of 31 successful home from hospital arrangements in the period October 2016 to April 2019 from 58 referrals (see Table 1).

The interim report included data on number of carers available and being assessed for Intermediate care placements, but this recruitment activity was reduced as the low numbers became evident, so data on numbers of carers recruited is not included in the final report.

Monitoring data did not indicate delays to placements that were caused by Shared Lives systems. Two Section 117 placements took longer than expected, due to their complexity rather than issues with Shared Lives processes.

TABLES

Table 1. Number of Referrals and Successful Arrangements

Area	Number of referrals	Number of successful arrangements
PSS Midlands	12	4
Positive Steps Shropshire	10	8
Durham Shared Lives	10	7
Shared Lives South West	24	10**
New Directions Sefton	2	2
Wigan Council Shared Lives*	0	0
Tricuro Bournemouth*	0	0
TOTAL	**58**	**31**

*These sites left the pilot.

**5 cases of hospital avoidance were removed from this figure

In some areas there was a significant difference between the number of referrals and the number of successful arrangements. This was mainly due to inappropriate referrals being made into the pilot. The reasons for this are explored further in relation to Outcome 5.

One pilot site included some people in existing Shared Lives arrangements who avoided hospital due to being in Shared Lives – these were removed from the total in order to maintain the focus on home from hospital.

Table 2 gives a profile of the 31 successful arrangements that occurred in the pilot sites.

Table 2. Profile of Participants

Age	Number
> 65	25
65-74	1
75-79	2
80-84	2
< 85	1

Funding	Number
Health	2
Social care	28
Self funder	1

Client group	Number
Old age support need	3
Learning Disability	8
Mental Health	12
Physical Impairment	3
Other	5

There were unanticipated outcomes from the outset of the intermediate care programme in terms of the profile of participants. These were outlined in the interim report and are re-iterated here. Table 2 shows the following:

- A high number of people were under 65 years old

- A high number of people had mental health conditions
- A high number of people were supported via social care funding.

The two people supported by health funding received it via section 117 of the Mental Health Act. This is funding for people leaving hospital or a psychiatric institution after a period of mental ill health for aftercare support needs in the community.

Within these broad 'client group' categories in Table 2, there was a diversity in terms of individuals supported. Figure 2, page 22 gives a detailed breakdown of specific health issues that people supported by the pilot experienced. The issues around diversity are explored in more detail in the discussion relating to Outcome 2, page 21.

4. Progress towards outcomes

At the Shared Lives Intermediate Care programme inception workshop in March 2017, NDTi developed a Theory of Change with the pilot sites and other Shared Lives staff. At a second workshop in October 2018 this was amended and refined. It became a Vision for Change, based on pilot sites' experiences of the programme so far (see Appendix 1). The Vision looked towards the future for Shared Lives Intermediate Care after the project end in 2019. It included some revised project mechanisms and enablers based on learning so far and produced similar but more focused outcomes.

These eight outcomes form the structure of this evaluation report. The sections below explore the progress towards each outcome, building on data from the interim report with the new data gathered from fieldwork, interviews, and final project monitoring data (to March 2019). This included data from qualitative interviews with individuals who were discharged from hospital into a Shared Lives arrangement, Shared Lives carers and health and social care professionals, as well as end of project interviews with pilot sites.

Please note that when we cite fieldwork findings, we have tried to be as specific as possible without compromising confidentiality of individuals.

OUTCOMES FOR PEOPLE SUPPORTED BY SHARED LIVES

Outcome 1. Personalised support that enables people to maintain and recover their health and lead a full life in non-institutionalised settings

Outcome 2. Diversity of people with a range of needs supported through Shared Lives intermediate care

The interim evaluation report (July 2018) drew on data provided by pilot sites about the progress towards these outcomes for individuals. Illustrative case studies derived from 'Change Stories' provided by pilot sites were also included.

This section of the evaluation report builds on the evidence provided by pilot sites by providing qualitative data from interviews with three individuals in Shared Lives arrangements. This explores first-hand, peoples' experiences of maintaining and recovering their health and living within Shared Lives. This section also explores progress towards this outcome by drawing on interviews with five Shared Lives carers and with four health and social care professionals, giving their perspective on the impact of Shared Lives on peoples' health outcomes.

Due to the short-term nature of Intermediate care, people had moved on and interviewees were hard to find. We therefore draw on 5 of the 13 Case Studies produced by pilot sites over the life of the pilot as illustrative examples. These have not been verified by NDTI but have been checked and written up by Shared Lives Plus.

Outcome 1. Personalised support that enables people to maintain and recover their health and lead a full life in non-institutionalised settings

The interim report gave case study examples and accounts from Intermediate care pilot sites of how the care and support in Shared Lives has impacted positively on peoples' lives and relationships, easing social isolation and loneliness and improving health outcomes.

In Stage 2 of the evaluation three people who had been referred from hospital into a Shared lives arrangement were interviewed. These individuals described improvements in their quality of life, happiness and well-being that resulted from living in a Shared Lives arrangement. The impact on peoples' health in terms of recovery, support for self-care, prevention and potential savings to the system emerged as strong themes in the case studies and interviews. However, these individuals gave improvements in their social networks and relationships, and feelings of happiness and connection in Shared Lives, more prominence than their health status.

People in Shared Lives arrangements described how being supported to do ordinary things and making their own decisions led to gaining confidence and coping skills. All those interviewed said they were enjoying their life with the Shared Lives carer/family.

> ***"I can cook for myself if I want to…I can go out with my friends. [Carer] helps me get things organised, including my tablets."***

> ***"It's definitely helped me…helped my confidence. I feel better, I'm getting good support…I'm in a good headspace now."***

Some were specific about the ways that Shared Lives enabled them to recover, and then to stay well.

> ***"Being here has helped me a lot…with my [appointment] letters, my injections, and my tablets and that"***

All interviewees said that seeing their family and friends, and getting out and about in the community were important to them; two people had been hospitalised for some time and one had been isolated at home.

'I'm pretty happy here... I've got more friends to talk to…I've got my mates…I only had one friend at my flat.'

The Shared Lives matching process brought a sense of connection with the carer and housemates that was important to people.

"She [carer] has the same sort of interests, she has got a dog, she likes animals and is very down to earth, like me."

"There's three of us in the house and x the dog…we get on pretty well together…every time I go back [home] I look forward to it."

Feeling included, valued and able to reciprocate was also important– one interviewee told us how he contributed to his living situation.

"I like cooking, I like washing up, I'll clear the plates and wash up for [carer] and x [co-resident] after our meal…I took the dog out when [carer] had the flu"

Although interviewees were keen to talk about their life in Shared Lives rather than their health issues, progress towards improved health and independence was evident by the way that individuals talked about feeling '*better*', '*more organised*' and *'able to cope'* with day to day life. One interviewee mentioned Shared Lives had given her '*headspace*', another that he felt *'on top of things'* because of the support he was getting.

Shared Lives carers we spoke to highlighted the connections between physical and mental health and aimed to support the whole person in the context of their life. They said that emotional as well as practical support was important for recovery.

"X's physical and mental health problems have gone hand in hand…"
Shared Lives carer

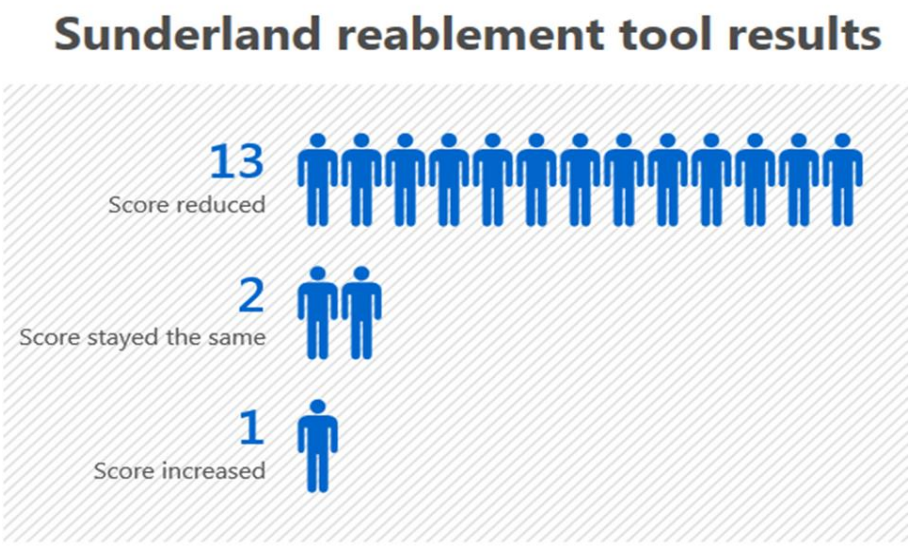
"I'm mainly giving emotional support to help her deal with her anxiety."
Shared Lives carer

One interviewee said getting the right support for her ongoing mental health issues made all the difference.

"I'm sorting things out so I can go back to my bungalow.. it gets quite stressful but [carer] helps me and I don't feel so anxious…."

The Sunderland Community Reablement Tool measures an individual's ability to care for themselves. It includes aspects of personal care, mobility, cognition, food preparation and medication. Pilot sites were asked to complete the tool at the start and end of each intermediate care placement to give an indication of the impact of being in Shared Lives on these areas. Due to capacity issues, pre and post assessment data was provided for only 16 out of the 31 Intermediate care placements. Although this is incomplete data, the Sunderland scores demonstrates that most peoples' ability to care for themselves was significantly improved by the end of their Shared Lives placement. A reduced score demonstrates an improvement in an individual's ability to care for themselves

Figure 1: Sunderland Community Reablement Tool Scores



N.B The person whose score increased was inappropriately referred into Shared Lives.

The focus of intermediate care on promoting an individual's health and recovery was taken very seriously by the carers we interviewed. They said there was a lot to do when people left hospital – several people had become institutionalised and needed intensive support, especially at the beginning. Carers were proactive, helping people get their paperwork organised, registering with health services, going to medical appointments, assisting with medication, healthy eating and general self-care.

> ***"I kept him going with the quitting smoking programme, got him eating properly and taking his meds."***
> **Shared Lives carer**

One carer said the person he supports does not read so keeping on top of his multiple medical appointments would be impossible without help.

"X has numerous health issues (diabetes and mental health) and lots of appointments to juggle – eye clinic, lymphedema, podiatrist, diabetic nurse…he had been in hospital more than 6 months and had dropped off all the relevant lists, GP, dentist, pharmacy…"
Shared Lives carer

Carers in the pilot were also proactive around peoples' medication, reminding them to keep to their schedule, liaising with pharmacists, GPs and other professionals over concerns and issues. The impact of medication on daily life was noted and acted upon by carers. One described the person she supported as *'zombie like'* all day before his depot injection was changed to tablet form, with an immediate improvement in his quality of life. Similarly, another noticed the impact of a morning antipsychotic drug on the person she supported, and after discussions with his psychiatrist this was changed. She said:

"He's on 19 tablets a day…the tablets made him very sleepy...now he takes his morning tablet in the evening which is better...the next thing is to reduce his meds, but re-arranging them helped."
Shared Lives carer

One carer who supported a man with multiple health issues said that with the help of the local pharmacist, they now have a routine that works. The carer said:

"He gets confused about whether he has taken it [insulin]or not he simply wouldn't be able to manage on his own."
Shared Lives carer

Food, cooking and eating was important to individuals supported in Shared Lives. Several carers said peoples' diets had been poor and noted the impact this had on their health. The link between diabetes and diet was something that carers were aware of; they supported people to take part in shopping, cooking and making healthier food choices. Several carers commented on the health benefits.

"X won't cook for herself like a lot of older people…I've had to get used to it, she's a faddy eater...being in Shared Lives means x is eating more and better."
Shared Lives carer

Self-neglect was a feature of several individuals supported in Shared Lives Intermediate Care. One carer described how she felt the person she supported– who had had drug and alcohol issues – had benefitted.

> ***"I think it [Shared Lives] helped from the way he was living which was quite chaotic…it was a fresh start…he could have died, what we gave him was breathing space."***
> **Shared Lives carer**

Shared Lives Intermediate Care was not always plain sailing. The individuals we spoke to had no complaints about their Shared Lives arrangement but as in any living situation there were clashes of lifestyles. There was some resistance to contributing to the household from people who had been institutionalised and were used to being looked after.

> ***"He was a young man who wanted to live life his way…I struggled to get him to do basic household tasks…he would have said I was a nag"***
> ***Shared Lives carer***

Some people were strong characters. The carers we interviewed appeared to take everything in their stride, but said it helped if they could see a change or difference they made.

> ***"X is very strong-willed person who has led a full life. She won't accept help or advice easily...I just got on with it…she's calming down now and listening a bit more"***
> **Shared Lives carer**

Carers demonstrated empathy and understanding about peoples' feelings and situation.

> ***"X can be quite difficult, but I can relate to her feeling things are out of her control. She has lost her independence, all due to a 6-week hospital stay. I can understand"***
> ***Shared Lives carer***

All three interviewees were happy with their living situation and one said she now felt able to return home due to the support she had received. Two had made the decision to remain in their Shared Lives placement long term; one had given up his flat where he was not happy.

> ***"I'm in no particular hurry to go anywhere else or change things.'***
>
> ***"I want to stay where I am, I'm happy here...I don't want to go back to my flat."***

Carers and pilot schemes pointed out that personalised decisions about where the person went after Shared Lives Intermediate Care were important in terms of long-term recovery.

Sending somebody home before they were ready or ending up in the wrong setting had implications for relapse and further use of services.

One interviewee who felt able to go home after Shared Lives said:

> ***"I couldn't have gone home straight from hospital, it would have been too quick, the time needs to be right, it has been really positive living with x [carer]."***

One interviewee who was happy in his Shared Lives placement was sent home, despite it being evident to the Shared Lives carer that he could not manage. He was re-admitted to hospital until returning to the same Shared Lives carer as a long-term placement.

> ***"Having enjoyed a high level of support it fell right off, he became very poorly very quickly - he wasn't taking his insulin and his diet was poor. They, the authorities, finally realised living in his own flat wasn't an option for him"***
> **Shared Lives carer**

The case studies and interviews found that people had different needs and wishes regarding their next step after Shared Lives. Steve's story (page 19) demonstrates how Shared Lives offers personalised support for moving towards independence. Trevor's story (page 20) illustrates how ongoing support may be needed to maintain recovery.

STEVE'S STORY

Steve had had a stroke and was taken into intensive care. He was hospitalised for 4 months and had two minor heart attacks while in hospital. Steve had depression and thoughts of suicide. He had a significant cognitive impairment, his memory had severely deteriorated and he became very frail with very limited mobility. He needed support with all daily living tasks

The hospital discharge social worker referred Steve to Shared Lives, believing that he would need long-term care. He was unable to return home and was frightened about his future. The social worker did not feel a residential care home would be the best option for him, and Steve was determined to recover further. Hospital staff were uncertain about how much Steve would be able to improve.

Steve wanted to remain living in the local area. The Shared Lives scheme found a suitable match for Steve, with carers who shared his sarcastic sense of humour, had dogs (he missed his dog), and lived very close to his town with public transport links.

Steve's mobility and memory were severely affected by the stroke, but with the carers help he set himself goals and gradually started to regain his independence and confidence. He was able to manage his medication and his mood improved. He was supported to take a holiday abroad. Steve had been anxious about living alone but started to look forward to it. A suitable flat was found and Steve was supported to make a successful transition.

TREVOR'S STORY

Trevor is a 67-year-old man who was referred to Shared Lives following multiple admissions to hospital due to falls that were caused by alcohol misuse. Trevor had experienced abuse during his childhood and had developed an unhealthy relationship with alcohol as a coping mechanism. Trevor lived alone in the community with no support network and as a result suffered from loneliness and isolation.

Trevor was admitted to hospital regularly and would always follow the detox plan until he returned home. After his last admission Trevor was referred to Shared Lives and successfully matched with Shared Lives carers that owned a farm with lots of land and animals. This was a great match for Trevor as he had spent his working life as a groundsman and loved being outdoors.

The Shared Lives arrangement started as a twenty-eight-night period to help him get back on his feet and continue his abstinence. Trevor is also being supported by the Drug and Alcohol Service who provide a twelve-week support service after a hospital admission.

So far Trevor has continued to be free from alcohol and is much healthier and happier being supported in Shared Lives.

Outcome 2. Diversity of people with a range of needs supported through Shared Lives intermediate care

Section 1 outlined the profile of people who were discharged from hospital into the Intermediate care programme. The range of health conditions are displayed in the tables below and indicate that progress towards this outcome was made in the pilot.

Table 3. Profile of Participants

Client group	Number
Old age support need	3
Learning Disability	8
Mental Health	12
Physical Impairment	3
Other	5

The diversity of people supported by this pilot programme is presented in Figure 2 below. It is important to note that several people referred into the programme had multiple health conditions, often a mental health issue combined with a physical or learning disability.

Figure 2. Diversity of health issues

Shared Lives Intermediate Care has not been used as initially anticipated – it has not been tested on the group it was intended for. Fewer older people than expected were referred and fewer people with straightforward conditions requiring intermediate care, such as those recovering after hip surgery. Younger people who have had a stroke and people with a learning disability and multiple health issues have benefitted. As well as a broader range of conditions and ages, Shared Lives Intermediate Care has been utilised when people are well enough to leave hospital but their accommodation is not ready or suitable.

Most of the referrals received into the pilot have been for people with complex needs, where traditional services were not suitable. The largest number of referrals into the programme were people with mental health issues; several of these had multiple issues. One person had surgery for cancer but was unable to return home due to hoarding making her home unsafe as well as suspected domestic abuse.

Pilot sites and social workers told us that more time and attention is given to the discharge of people when traditional services don't fit their needs due to their level of complexity. In contrast, we were told that block contracts for residential care were the quickest and often the cheapest routes for more 'straightforward' patients and the incentive to find alternatives was not there.

The pilot demonstrated that with support, Shared Lives carers are willing and able to support a diversity of people and needs. However, it was important for schemes and carers to have full information in advance and for ongoing support and team-working to operate throughout the placement. Full disclosure was important to schemes and to carers. Although carers said medical labels could be off putting, they felt they needed to know all the facts. Carers felt that meeting and making a connection with the person was the most important factor for a successful placement overall.

"I was a bit nervous…because of what the mental health team were saying about him…they were giving me dire warnings about relapse… but I've found he's very amenable."

Shared Lives carer

Table 4 shows the destination of people at the end of their Shared Lives Intermediate Care placement. Due to the nature of the intermediate care (i.e. people move on), limited follow up information is available. The high number returning to their own home is generally considered a successful outcome in terms of reablement and independence as that is the focus of intermediate care. Where the decision to enter a long-term Shared Lives placement following a Shared Lives Intermediate Care placement is a result of the individual's personal choice, and an alternative to residential care or nursing home, this can be considered a successful outcome. The high number of people moving into a long-term Shared Lives placement, therefore, can also be considered a successful outcome for these people.

Table 4. Destination at end of placement

Destination at end of placement	Number
Long term shared lives	11
Own home	10
Residential or nursing home	3
Died	1
Other/no response	5
Placement ongoing	1

Outcome 2 is being met to some extent but there is clearly room for more diversity in terms of referrals into Shared Lives from health and social care practitioners. Pilot sites agreed that anybody should be able to access Shared Lives if their needs can be met in a Shared Lives carers home – but this is dependent on people knowing about and asking for Shared Lives, as well as health and social care practitioners being willing to refer people into it. Pilot sites said that risk aversion by professionals was an issue and there was still some nervousness and suspicion from families and individuals new to the idea of Shared Lives.

Pilot sites found that after publicising the intermediate care offer some referrals were inappropriate for a family home and had to be refused. In terms of diversity, they told us

that it was easier to tell health and social care practitioners what type of referrals would be inappropriate than those that were appropriate, as the latter was so broad. Some pilot sites had created referral checklists and protocols to help with this issue (see Outcome 5, page 32).

Apart from two placements where the person referred was too ill for Shared Lives, the few placements that broke down were not to do with the nature of the person's condition but other issues such as lack of professional support, poor communication, family issues or challenging behaviour not appropriate for a family home.

OUTCOMES FOR SHARED LIVES CARERS

Outcome 3. Carers are valued, recognised professionals with skills & expertise

Outcome 4. Carers have security of role and income benefiting carers & the system/locality

The interim evaluation report detailed concerns about supply and demand and the challenges faced by sites in recruiting carers with a clinical background or interest to the Intermediate care pilot. Shared Lives pilot sites had concerns about practical issues such as the unsuitability of carers' homes, and reported a lack of confidence from new carers about this new area of work, including worries about the health needs of people discharged from hospital.

There was a shift in emphasis as the project progressed. By Stage 2 of the evaluation most carers involved in the pilot were existing rather than new carers. Site leads told us that they were not focusing on recruiting new carers to the pilot because the numbers of referrals were lower than expected and because they had found that existing carers were willing and able to take on intermediate care placements. Pilot leads told us they would now offer all new referrals to all appropriate carers, and some had changed their application form for new carers to indicate if their areas of interest would include health placements.

This section of the evaluation fills in the gaps around the carers role and experience of the intermediate care pilot by reporting on interviews with five Shared Lives carers, as well as health and social care professionals who have referred into Shared Lives from a hospital setting.

Outcome 3. Carers are valued, recognised professionals with skills & expertise

The Shared Lives carers interviewed by NDTi for Stage 2 of the evaluation reported positive experiences of the pilot programme with the majority saying they would do it again. These were all existing and experienced Shared Lives carers, and they had a range of backgrounds and skills. Some were new to giving specific health support, others had a health or mental health background, including nursing, hospital auxiliary, social work and one had been a Samaritan.

All five carers interviewed said that any Shared Lives carer could take on a home from hospital placement, although several said it helped to understand the medical jargon used. The consensus was that clinical or specialist skills were not required for this role unless the person supported has a lot of medical issues.

Schemes and carers agreed that a health background was useful rather than essential, whereas having a connection, motivation and interest in the person was crucial. Pilot leads told us that their carers had shown themselves more than capable of offering appropriate support to people with a range of health needs.

> ***"New carers with clinical expertise were not needed – in some cases it just happened they had relevant expertise – some of my best carers have never worked in care services at all"***
> ***Pilot site lead***

Carers said they focussed on getting to know the person and making a connection, rather than on their diagnosis or medical treatment. They valued the Shared Lives ethos with the matching process as an essential ingredient for their role.

> ***"Carers are different with different life and work experiences, matching is very important, but any Shared Lives carer could do Home from Hospital"***
> ***Shared Lives carer***

Carers said that to provide the best support they needed to be aware of and knowledgeable about the person's health issues and receive training and support where needed, but they were not put off by medical labels. They acknowledged matching may have to be quicker than usual, but said that meeting and home visits before a placement are vital to ensure success.

> ***"Paperwork is all very well but it's essential to meet the person…the matching process, the introductory meeting and visiting you at home. Getting to know people gradually…there's value in that, that's why we hardly ever have placements that go wrong."***
> ***Shared Lives carer***

Several carers said that the basic training and ongoing support they receive from Shared Lives was excellent, some had undergone additional diabetic training and other bespoke training where needed. One of the carers interviewed had no medical background but successfully supported somebody with complex medical needs.

Carers interviewed said that close ongoing contact with schemes, social workers and other professionals enabled them to support the person and do their job well. Several carers gave examples of the benefits of close working relationships with GPs, pharmacists and psychiatrists.

"The pharmacist and psychiatrist are very good, they listen to me, they really do, we suggested reducing his meds to stop him being so sleepy in the morning, they swapped it to the evening dose"
Shared Lives carer

Carers valued being part of the team and getting a response when issues arose; this was important to them and indicated recognition of their role.

"I got good support from the hospital social worker, every time I emailed or contacted x he was on it, he got back to me straightaway and was very helpful."
Shared Lives carer

However good communication did not always happen, some people were placed in Shared Lives and then forgotten about, some carers struggled to get a response from professional teams when needed, and this did have a detrimental impact (see Wider Learning section, page 44).

Professionalism was important to the carers we spoke to but Shared Lives carers also talked about the importance of their role in terms of being a supporter and enabler, with their remit clearly being the person as a whole, rather than their medical condition or label.

Several carers had an interest in mental health and found it motivating and rewarding to be able to support people in a unique way by spending time with them.

"He tells me things…about his past…you start to find out what's really going on…it makes it very interesting [work] and I think you can help people better…"
Shared Lives carer

Most carers enjoyed the company of the person they supported and focused on their abilities and assets rather than difficulties.

"I'm fairly non-judgemental, people try and live their lives and sometimes they don't manage well."
Shared Lives carer

This non-judgemental support, at the heart of the Shared Lives model, was of crucial importance to people supported. One care coordinator said that for somebody with hoarding issues, the fact that she and the carer was more than a professional relationship, had made all the difference.

> ***"It was important to her that the carer hadn't seen the house and wasn't involved in the stress and embarrassment of that…it meant quite a lot, that un-judgemental support. It was important to her that the carer was on her side."***
>
> ***Care coordinator***

Pilot leads said there were clear differences in the carers role in a short-term intermediate care placement with a focus on reablement. They said it was important to be clear with carers about what was required at the start and how intermediate care differed from other Shared Lives arrangements, so that carers could decide if it was what they wanted to do.

Shared Lives carers we spoke to explained how they experienced their role in intermediate care.

> ***"It's different to a long-term placement, not just about keeping the person safe, they need to be ready to go home, you're promoting their independence…, they need to be prepared to go home".***
> ***Shared Lives carer***

One carer with a clinical background pointed out how different it is supporting somebody at home compared to a hospital setting. She said the '*usual rules'* don't apply.

> ***"His degree of independence was a surprise but after a while I relaxed about it…you have to let people with mental capacity make their own decisions…it took a few days but we sized each other up."***
> ***Shared Lives carer***

Carers described how they had to be *'even more on the ball'* as there was a lot of work that had to be done at the start of an intermediate care placement.

> ***"There is quite a lot of running around to do because of the person being in hospital…that is the only difference in regular and HfH placements…it's intense at first".***
> ***Shared Lives carer***

Health and social care services interviewed, who had referred into Shared Lives were positive about the carers contribution and skill, often emphasising the difference that carers made in helping the person regain their independence.

> ***"The placement probably exceeded my expectations…the carer was absolutely brilliant, she went above and beyond…and very much supported the person's independence…it was a really positive interaction…it set the person up for going back home…"***
> ***Mental Health social worker***

"I would like to applaud the two Shared Lives carers involved, they have been so instrumental in getting her ready to move back home…giving her time… their kindness has lifted her mood and enabled her to deal with the rest of her life it's a real success story."
Care coordinator

Carers told us that making a difference to somebody's life brought its own rewards. All those interviewed said they could see the benefits of the intermediate care pilot for the people they supported, and that that this gave them a sense of satisfaction and value;

"I would do it again…it is satisfying because it's easy to see what benefit he is getting from being here"
Shared Lives carer

"For me it's about making a difference…I need to feel as though I've done something, seeing a change."
Shared Lives carer

Carers in the pilot had many challenges which they took in their stride; those we interviewed told us that these were part and parcel of being a Shared Lives carer. Family relationships were a challenging area where they showed sensitivity and skill. In one instance the person indicated that a relative was taking money from her; the carer involved the social worker and the matter was resolved. In another, the carer skilfully challenged a mother about the next step, for the best interests of her son.

Shared Lives carers were valued and their skills and professionalism was recognised by schemes and health professionals who came into contact with them. Due to the nature of intermediate care, people moved on and carers did not always have feedback or ongoing contact. Carers we spoke to did not expect it, but said that when recognition came it was appreciated.

"You know you're managing quite well but it's nice when other people say [good] things"
Shared Lives carer

Outcome 4: Carers have security of role and income benefiting carers & the system/locality

As outlined in Section 1 of this report, a feature of the Intermediate care pilot was the low numbers of referrals. Recruitment activity was conducted at the start of the pilot but the low numbers led to concerns about newly recruited carers waiting for Intermediate care referrals and leaving the service if they did not materialise due to lack of income.

It was clear that carers wishing to do only intermediate care work would not have a secure role or income. One carer said:

> ***"Home from hospital has been slow to get off the ground…I know carers interested, but you can't keep people waiting too long – they move on".***
> ***Shared Lives carer***

Pilot sites said they stopped recruitment of carers specifically for health-related work and utilised existing carers instead. However, some reported that good people were lost to the pilot or that carers interested in Intermediate care had taken another placement for financial reasons. Several site leads said the ability to pay a retainer would help progress towards this outcome.

> ***"I lost an excellent carer who was waiting for a suitable placement because there were no referrals… it would be good if you could pay people a retainer to get them to wait around."***
> **Pilot site lead**

Health and social care staff referring into Shared Lives were concerned about the small pool of carers that made matching more difficult and successful referrals less likely. This resulted in schemes talking of a 'chicken and egg' situation in terms of supply of referrals and sufficient carers (see Outcome 6 page 35).

Shared Lives carers were pragmatic about their insecure position; some said long waits for a placement and financial insecurity were part and parcel of their role. Whilst some carers said they were happy with irregular placements, others needed a regular income and said they would take any suitable match that fitted their situation. Several had previously offered respite or short breaks which they said was similar to intermediate care in offering a sporadic income.

Several carers we spoke to had not sought out an intermediate care placements but found it worked for them – one offered short breaks and another liked the mix of long- and short-term placements. One carer said she was looking for a permanent place but would do intermediate care again, whilst waiting. Another who had two people on permanent placements, took the occasional intermediate care placement as well. She said an advantage of having gaps in-between was the opportunity for recuperation, especially after a challenging placement.

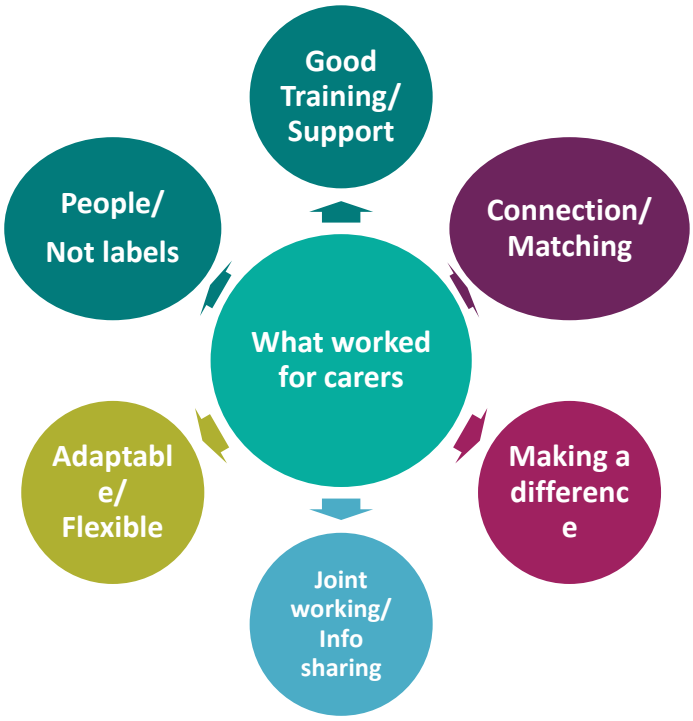
> ***"I knew there was an end in sight and I would get a breather…you can put up with things if you know they will end."***
> ***Shared Lives carer***

Pilot sites were aware of the skill and expertise of their carers and understood what was required for a successful intermediate care placement. One site said the pilot did not get off the ground as their local commissioners were offering carers the same pay as they would for respite/short breaks.

> ***"One of the issues was that they wanted to pay a very low amount of money to carers…they wanted the service for cheaper than we wanted…what they were expecting of carers…it just wasn't fair."***
> ***Pilot site lead***

The lack of a secure income has implications for the ability of Shared Lives schemes to attract and retain carers and it was clear that this outcome is not being met. Carers told us long gaps with empty spaces are problematic, but it was clear that their motivation was not financial.

> ***"It's not about the money…what people get from Shared Lives is one to one, they get the best that you can give them."***
> ***Shared Lives carer***



OUTCOMES - SHARED LIVES SCHEMES

Outcome 5. Shared Lives schemes are seen as knowledgeable, skilled and responsive

Outcome 6. Part of local offer/network of support

In the interim report, site leads talked extensively about the work they were doing to develop relationships in the health sector and the challenges they faced gaining access to appropriate health funded referrals via NHS routes. Some sites were struggling with capacity issues for developing this new work in health and lack of resources meant that two pilot sites withdrew from the programme (Bournemouth and Wigan).

In stage two of the evaluation, pilot sites described the continuing uphill struggle to gain inroads into NHS and to build relationships with health teams, where they were not known.

This section of the report draws on data from in depth interviews with the five remaining pilot leads (March 2019). Data is also drawn from the workshop with Shared Lives schemes and interviews with staff from health and social care services.

Outcome 5. Shared Lives schemes are seen as knowledgeable, skilled and responsive

Pilot sites spoke of a steep learning curve in terms of understanding NHS systems and health funding streams – staff with a health background said they were at an advantage when making contact with health services, understanding the jargon and the different funding pots. One pilot lead with a health background said she spent time '*upskilling'* staff to ensure no potential health referrals were missed. Another said her knowledge had increased as the project developed.

> ***"Some schemes have a better understanding of funding than others – some don't know about section 117 or Continuing Healthcare (CHC)C funding – they are very different things…I have learnt a lot about funding streams and eligibility"***
> **Pilot site lead**

We were told that sites spent a long time working out the details of how to deliver the programme and said it would have been helpful if clear guidance from Shared Lives Plus had been in place at the start of the programme. A Guidance document was produced - based on learning from the project - in September 2018 and was well received. However, some pilot leads felt that they had been at a disadvantage at the beginning, and that the lack of guidance had been detrimental in achieving this outcome.

> ***"We spent months talking about what should happen…how to deliver the project, carer payments etc…we should have had clear guidance at the beginning, not at the end…it was too late".***
> **Pilot site lead**

Site leads commented on the impact of local circumstances on implementing the pilot; the turbulence of the health sector, with cuts and staff changes in CCGs and trusts a major destabilising feature in many areas. Each area was different and several sites commented that it would have helped them if scoping had been done before the pilot, identifying where an intermediate care offer was most likely to be well received and local factors affecting its implementation (see Wider Learning section, page 44).

Finding a 'way in' to health teams was problematic for all sites, there was agreement that face to face meetings and keeping up the contacts on a regular basis was important for relationship building and trust. However, these connections often relied on one or two people, with frequent staff changes making them insecure.

Several sites said they needed more time and that due to turbulent local circumstances the pilot was only just getting going.

> ***"We are hoping for more time to develop it [the SL service]…there is so much change locally, people being made redundant, financial constraints over the last 3 years have had a huge impact...the CCG and hospital went into special measures."***
> **Pilot site lead**

There were concerns detailed in the interim report about the Shared Lives paperwork and processes being a potential barrier in terms of schemes' responsiveness to health referrals. As the pilot progressed, pilot sites adapted their existing systems, rather than creating new ones, and these adjustments meant they could accommodate health referrals in a timely manner. Pilot leads told us they '*streamlined*' their systems and paperwork in order to be able to respond quickly to discharge teams who were used to a quick turnaround. There was agreement that it was important to '*keep the process simple*' using clear paperwork and templates. One pilot lead said she goes out to do a pen picture within 24 hours. Another asks for safeguarding information at referral stage so she can assess risk to carers. One had created a checklist that helped to reduce inappropriate referrals. Flexibility was important, pilot leads told us how they speeded up the matching process for hospital discharge, and in one unusual situation it was waived (see Jason's story, page 40).

When health and social care professionals did refer into Shared Lives, it was often via existing networks, due to individual relationships, reputation or simply the physical proximity of services. Health and social care staff with experience and understanding of

Shared Lives were positive about the knowledge and skill of carers and schemes but there was risk aversion from those who did not understand or trust the model. One pilot lead said it helped that one of her carers had been a social worker and could *'talk their language.'*

Successful placements had created 'champions' in discharge teams who understood, valued and promoted the Shared Lives service. Proactive and enthusiastic staff provided a *'way in'* for pilot sites. One pilot site described how a mental health social worker became an Shared Lives champion within her team.

> ***"The mental health team are on board… and discuss success stories at their team meetings."***
> **Pilot site lead**

The two interviewees who had referred into Shared Lives Intermediate Care both had a positive experience. One said:

> ***"The matching process happened pretty quickly and so did the discharge. The Shared lives worker was easy to keep in touch with, she was always available, very on the ball".***
> **Mental health social worker**

We were told that success stories have helped progress towards this outcome by enhancing the reputation of Shared Lives schemes locally, but the number of people placed was too low to make an impact. One social worker who was enthusiastic about the potential of Shared Lives and wanted to promote it to colleagues said there was a long way to go to gain the confidence and trust.

> ***"I think is such a good idea, just getting one [referral] through the door would really help."***
> **Acute hospital social worker**

There were ongoing concerns that Shared Lives would not be able to respond to referrals due to not having enough carers. The limited geographical spread of Shared Lives carers was also a concern affecting the responsiveness of schemes in a large area.

> ***"It's a shame there aren't as many carers as you would ideally like…if these two hadn't bonded things might have been more difficult as there were only two possible carers"***
>
> **Mental health social worker**

Outcome 6. Part of local offer/network of support

The lack of awareness of Shared Lives and the intermediate care offer was a major hurdle for schemes in terms of this outcome. The low numbers of people supported by the Shared Lives Intermediate Care pilot indicates that it was not taken up in any significant way by health and social care practitioners.

A Care coordinator who had a positive experience of a successful placement said that getting to know the service and Shared Lives carers would help staff understand and promote the service as part of the network of support available locally.

> ***"The home from hospital service is a really well needed resource…something to be promoted…the majority of my colleagues would think of Shared Lives for learning disability…the teams need to know what can be offered."***
> **Care coordinator**

She went on to say that it provided an alternative option for discharge when residential care was inappropriate.

> ***"The alternative would have been a residential home with elderly people. I don't think she would have stayed there…It happens a lot, people of a similar age…there's people of that age (50 and 60) they're not old and residential care is not suitable'.***
> **Care coordinator**

Pilot sites said that progress had been made but had taken longer than expected to make inroads locally; they talked of the need to build on work they have started.

> ***"The pilot has raised the profile of Shared Lives and what it can achieve…we have better connections with Social Work teams, we are included/invited to things now that we weren't before"***
> **Pilot site lead**

They said that having a presence in team meetings and keeping the momentum and ongoing contact was important. In one area, renewed contact between the discharge team and Shared Lives has resulted in them meeting weekly to go through the caseload.

> ***"It involves a culture change and that takes time – the social work team need to understand how Shared Lives works…with something new it's difficult to get off the ground…it all went quiet and Shared Lives went out of our minds"***
> **Acute hospital social worker**

It was evident that health and social care services found it difficult to change their usual practices. Several site leads mentioned how it was difficult to introduce something new. In one pilot area the programme *'never really got going'* due to a lack of interest by commissioners. This lack of interest in some areas was explained by the focus on block contracts and other models for discharge such as 'Discharge to Assess' and 'Step Down' beds. The CCG had committed their money into these contracts and initiatives that offered an easy route for discharge. One site lead explained that having block purchased residential care beds in their area meant that health commissioners were not interested in Shared Lives for intermediate care.

> ***"They have already put their money into social care for Intermediate care and Home from Hospital.. they're not going to pay for it twice".***
> ***Pilot Site lead***

We were told that the costs were uppermost in commissioners minds, and that costings for Shared Lives would be needed to be compared with residential care.

> ***"We have to justify everything …we have to do a best value, we send a form to our brokerage team and it comes back with costings next to it, we would have to have Shared Lives on the form, with costs…to see what is the cheapest."***
> ***Acute hospital social worker***

Pilot leads told us that the Intermediate care pilot project has been useful in raising the profile of what Shared Lives can offer to people who have health issues, but some felt it was not helpful to *'hive off'* intermediate care as a separate area of its work. Shared Lives schemes outside the pilot are already offering home from hospital and health related support, some pilot sites felt it has been confusing and counterproductive to separate it off as a different offer. Several schemes said it would be better to simply to publicise what Shared Lives can do as an inclusive service that can benefit anybody who can be supported in a family home (see Wider Learning section, page 44).


Health Knowledge & Understanding
Clear,flexible &quick processes
Checklists
Finding a 'way in'
Success stories
Champions
Balancing supply & demand
What worked for schemes

OUTCOMES – FOR HEALTH AND SOCIAL SYSTEMS

Outcome 7. Contributed to reduced length of stay (and speedier discharge)

Outcome 8. Evidence of costs and benefits, including potential savings, by focussing resources on prevention and self-care/management, in line with NHS priorities

The numbers of people discharged from hospital and supported via the Shared Lives Intermediate Care programme are too low for the pilot to have made any noticeable impact on the local health and social care system. However, the qualitative data from case studies and interviews provides examples of timely discharge and reduced length of stay; and there are indications of potential savings to the system from improved self-care and prevention of ill health.

This section draws on interviews with commissioners, care co-ordinators and social workers, interviews with the Shared Lives pilot site lead and pilot schemes, as well as case studies. This data illustrates the potential of Shared Lives and give an indication of progress towards these outcomes.

Outcome 7. Contributed to reduced length of stay (and speedier discharge)

The problem of 'bed blocking', was one of the issues that this programme aimed to address by offering Shared Lives as an option for intermediate care when people are able to leave hospital but not ready to go home. Several people came into Shared Lives Intermediate Care whilst waiting for their home to be ready, or for reablement after a stroke (see Steve or Tina's story). Marjorie (see below) is an older person who came into Shared Lives whilst waiting for an extra care placement. These people would otherwise have been placed in residential care or remained in hospital.

There were concerns in the interim report that Shared Lives processes the matching process, would not be able to adapt to the short turnaround required for discharge teams. As previously discussed, pilot sites were able to adjust their systems and procedures to avoid delaying discharge. This went some way towards meeting Outcome 7. The interim report reported how the discharge of people with complex needs (especially section 117) often takes longer to arrange than more straightforward discharge but delays were not overly problematic in this pilot.

A bigger problem was the reluctance of discharge teams to utilise the Shared Lives offer and to refer people with health needs into Shared Lives. We were told that teams were *'set in their ways',* and that it was easier (and sometimes cheaper) to do what they normally did.

> ***"Part of the problem is that discharge teams are used to working at speed and referrals happen quickly within 48 hours) I keep nagging at people [saying] for speed you do what you are used to…but people will lose a beneficial option."***
> **Acute hospital social worker**

One adult social care commissioner who was supportive of the pilot programme, had not seen any successful placements in her area; she expressed her frustration that they had not been able to assess whether Shared Lives could help speed up hospital discharge.

> ***"Unfortunately there have been no placements…so it has not been successful up to now…we have been unable to test the model so commissioners do not know it can work."***
> **Adult social care commissioner**

One unusual case study (see Jason's story) demonstrated that Shared Lives can be flexible and fast, when a young man with a learning disability was admitted to A&E and then discharged into a Shared Lives intermediate care placement as an emergency. Although this was the only case of its kind in the pilot, it demonstrates the potential of Shared Lives in terms of speedy hospital discharge.

It is important to note that this pilot did not capture data on the impact of being in a Shared Lives arrangement on hospital admission or discharge into a pre-existing Shared Lives arrangement. Pilot schemes and carers pointed out that when somebody is supported in Shared Lives, they are likely to utilise health services appropriately, and have shorter hospital stays. Those who are already in Shared Lives return back home far quicker due to the ongoing support they are receiving (see also Outcome 8, page 41).

MARJORIE'S STORY

Marjorie is in her early 80's. After being admitted to hospital during a period of ill health it was decided she would be unable to safely return to her own home. Extra care housing was identified but was not available immediately. Instead of remaining in hospital until the extra care housing became available Marjorie was discharged to Shared Lives where she could continue to increase her recovery and regain her independence. Marjorie was able to continue to do the things she normally did in the community like visiting her hairdresser once a week. The alternative to Shared Lives was a stay in a residential home where the likelihood of deterioration and the need for long term care would be higher. After 12 weeks Marjorie was able to move into her new home.

JASON' STORY

Jason is a young man with a learning disability who has lived alone since his father's death. He was admitted to A&E after a suspected seizure. The social worker requested an emergency Intermediate Care Placement with Shared Lives until Jason had a formal diagnosis. Due to the nature of this emergency it was necessary to forgo any matching visits and make an immediate arrangement. All paperwork including Jason's care plan was already in place Having this information at the start of the placement enabled the Shared Lives carers to meet the high level of care Jason needed. They supported Jason with all his daily routine living needs, including monitoring his medical issues. Jason was able to continue with his normal daily activities, for example going to his day care three times a week and spending time with his befriender. Jason's diet has also improved- he said he does not eat well at home-usually pot noodles.

There appeared to be big changes for Jason in his short time with Shared Lives. The main difference is in his mental health and well-being. Jason said that he had felt very isolated and lonely before, with the only involvement in his life being from professionals. Jason is vulnerable and said he felt very much on his own, was often distressed and uneasy with a low mood The carers' extended family have embraced Jason, who said; *'this is the best time of my life being with you guys'.*

Jason now has a formal diagnosis of epilepsy and has been prescribed medication to manage this. He will stay with his Shared Lives carers until he has had an MIR and Brainwave scan as an outpatient.

Outcome 8. Evidence of costs and benefits, including potential savings, by focusing resources on prevention and self-care/management, in line with NHS priorities

As discussed in relation to Outcome 3, Shared Lives schemes and carers who participated in the intermediate care pilot were clear that their focus was on supporting peoples' independence and self-care/management. The benefits of having one carer providing personalised support after hospital discharge was outlined in relation to Outcome 1 (page 13).

Shared Lives carers ensured people accessed appropriate services in the community, supported them with medication regimes and attending medical appointments, and took action on signs of illness or relapse early, avoiding hospital re-admission and resulting in savings to the system. For people with complex and multiple needs, the benefits of having support for their physical and mental health meant improvements in confidence, independence and coping skills. Several carers gave examples of how as they got to know the person they supported, they could spot changes in their health early and take action to avoid relapse or re-admission.

The reduced Sunderland Reablement Scale scores (see page 15) indicate that most peoples' ability to care for themselves was significantly improved by the end of their Shared Lives Intermediate Care placement. Although the data is incomplete, it is backed up by the interviews and case studies that provide many examples of improvements in self-care and management, prevention of ill health and hospital avoidance, indicating that Shared Lives Intermediate Care placements can meet this outcome. Trevor's story (page 20) illustrates potential savings from Shared Lives support reducing multiple admissions to hospital.

In this small pilot programme there were examples of dramatic improvements in peoples' health that clearly reduced the strain on services.

> ***"His diet is critical due to his diabetes…the chips and pies he ate before exacerbated his problems…he's now eating appropriate food and showing steady improvement. The Lymphedema clinic said they will be discharging him."***
> ***Shared Lives carer***

The savings to the system were clear to individuals, carers and to schemes, who wondered why the Shared Lives offer had not been more widely taken up.

> ***"The level of support that he would need to remain in his flat, administer his medication, deal with correspondence…imagine the cost of that…I don't know why they're not clamouring for Shared Lives"***
> **Shared Lives carer**

Tina's story (page 43) clearly indicates savings to the system of Shared Lives Intermediate Care, relating to reablement after a stroke. Tina's recovery was expected to take 3 months but she was able to return home after just 7 weeks in Shared Lives. The pilot site calculated that the savings to the system of this placement amounted to over £10,000.

The impact of Shared Lives on promoting independence and self-care and the resulting savings to the system were evident to practitioners who had referred into the pilot. Health and social care practitioners we spoke to were enthusiastic about the way that people had been supported to recover and return home to live independently, often more quickly than expected, as in Tina's case.

One social worker who had referred somebody on a section 117 into Shared Lives had said she had gone home successfully after six weeks and that the service *'set the person up for going home'*. She said she is keen to refer into Shared lives again.

> ***"Shared Lives is always a consideration…short term support in a family home is ideal for promoting independence and reablement when somebody is medically ready to leave hospital but needs support. It is often the least restrictive option."***
> ***Mental health social worker***

As discussed in relation to Outcome 6 (page 36), there were ongoing issues regarding the costs of Shared Lives. Evidence was needed for brokerage teams who often went for the cheapest option. One Care Co-ordinator described how she made a case for Shared Lives for somebody with complex needs.

> ***"The placement worked brilliantly, it was a turnaround for her… The alternative would have been a residential home…I don't think she would have stayed there, she would have been out the door in a week. I had to present my appeal to the brokerage team…there has to be evidence you have looked at all the options. She's almost ready to move home now, it's a real success story."***
> ***Care coordinator***

As discussed in relation to Outcome 1, intermediate care is by definition short term support with a focus on living independently afterwards. However, an important part of personalisation is that people's wishes, abilities and needs are continually reviewed. The data collected by this evaluation on the destination of people at the end of their Shared Lives Intermediate Care placement highlights savings to the system that are relevant to this outcome. Table 4 (see page 23) shows that the majority of placements had become long term Shared Lives placements (11 people) and that 10 people returned to their own home. Only 3 people were placed in residential or nursing homes after Shared Lives.

The pilot demonstrated the importance of person-centred care, with people not being sent home before they are ready. In some cases, the most appropriate step was a long-term Shared Lives placement rather than independent living. One person whose health had improved enormously in a home from hospital placement was sent home with disastrous results and costs to the system.

> ***"He was sent back to his flat even though it was clear he wouldn't manage, he lasted a few days, then was admitted to hospital."***

Pilot sites gave further examples of the benefits to peoples' health and savings to the NHS once people are being supported by an ongoing Shared Lives arrangement. Some of these case studies are detailed in the interim report and include examples of people returning home more quickly after an operation and the reduced use of emergency services for people in Shared Lives.

TINA'S STORY

Tina is in her early 40's and was admitted to hospital following a stroke. After being in an acute ward for 2-3 months she was transferred to a rehabilitation unit. Tina was referred to Shared Lives by a social worker at the unit. After 2 months rehabilitation Tina had regained her mobility but continued to have difficulties with impaired memory and poor concentration skills. Tina was matched with a Shared Lives carer who had experience of working with people after a stroke. It took under 3 weeks between the referral to Tina being discharged to Shared Lives.

The Shared Lives carer supported Tina to regain skills/activities of daily living that she had forgotten, such as cooking. She and Tina also followed the occupational therapy and physiotherapy programmes successfully. The carer supported Tina with travel training so that she could travel independently when she returned home.

The health and social care team had predicted that Tina would require Shared Lives for around 3 months but she was able to return home to her flat after just 7 weeks. Following Tina's return home the Shared Lives carer continued to support her for a couple of weeks to ensure that transition was smooth and Tina was coping.

Tina's placement cost £400 per week in Shared Lives. The cost of a hospital bed averages £300 per night therefore over the initial 6 weeks the savings to health were £10,200.


Responsive schemes
Simple/ Fast process
Buy in
Culture change
Success stories
Cost savings
What worked for health & social care systems

5. Wider learning

This section considers the Shared Lives Intermediate Care programme overall in addition to the findings that have been discussed in relation to the eight agreed programme outcomes.

It includes data from pilot sites, including those that have withdrawn and two non-pilot sites that were involved in the interim evaluation.

What worked well:

- **Having a flexible and inclusive Shared Lives offer**

Shared Lives pilot sites told us that in order to make a success of the intermediate care pilot programme, they had to be flexible and adaptable, depending on local circumstances. Sites described referrals coming from unexpected sources, often based on chance rather than design. They said it was important to be able to respond flexibly, rather than being tied to prescribed client groups or funding sources. Sites concluded that the best way to do this is to focus on offering an inclusive and personalised service for anybody whose needs can be met in a family home.

Schemes inside and outside the pilot said that the national Intermediate care pilot project had been useful in raising the profile of what Shared lives can do for people with a diversity of health needs. They pointed out that many schemes are broadening their scope and offering an service to new groups of people and said there is transferable learning for other projects from the intermediate care pilot about how to expand their offer whilst remaining inclusive.

- **Supporting people with complex and multiple needs**

The intermediate care pilot had been envisaged for straightforward discharges from hospital but these were often catered for by block contracts already paid for by commissioners. It appeared that health and social care professionals were more likelty to *'think outside the box'* when people had complex or multiple needs. Schemes found that these discharges were not as rushed and there was time for visits and matching. Savings to the system were also clearer when the person had multiple needs and traditional services had failed or were inappropriate. The costs of care for people in this group were often very high and Shared Lives was cheaper than the alternatives, making it an attractive option.

The pilot found that Shared Lives carers were willing to take on people with challenging issues whose paperwork was off-putting, especially if they made a connection and if they could see the benefits of their input. With appropriate training and support for their role, Shared Lives carers were uniquely placed to offer one to one support for all aspects of a person's physical and mental health. They could spot and act early on behaviour changes

that indicated a potential issue or problem and said they gained satisfaction from seeing the difference they made in supporting independence and self care.

- **Communication, team work, and ongoing support**

The importance of team work and communication between everybody involved in supporting an individual in Shared Lives Intermediate Care, was a theme running throughout this evaluation. For pilot sites, and carers, working collaboratively with health and social care professionals meant an increased liklihood of appropriate referrals, and successful arrangements. Full disclosure of information about a person's medical condition was of crucial importance. Team work was found necessary for success; there were examples of poor practice where people were placed into Shared Lives without appropriate support, where full facts about people referred were not shared, and/or when professionals did not respond to concerns raised by schemes or carers. On a few ocasions placements broke down due to lack of support and poor communication.

Support from within Shared Lives was praised by carers and schemes who appreciated the guidance they got from from their locality and from the wider project team at Shared Lives Plus. Sharing learning at workshops and other events was important to site leads and they said an online forum to discuss issues and concerns was needed.The change stories were a popular way to communicate sucess as the project gained momentum. Site leads said these stories got the message out of what Shared Lives schemes and carers were capable of – and they boosted morale of the pilot sites when numbers were low.

What didn't work well

- **Lack of scoping of local context**

Pilot sites in some areas struggled to get going with intermediate care programme due to local circumstances. There is learning here for Shared Lives Plus and schemes about scoping a local area for enablers and barriers before a project starts. Some pilot leads spent time and resources at the start of the pilot, exploring an avenue that was not fruitful and then having to start again from scratch.

Knowledge at the start about local services, what they were called and what they offered would have been helpful in some sites. Others said it would have been useful to know that funding had been committed to other initiatives, allowing no possibility of the Shared Lives offer gaining inroads. One pilot lead who discovered funding or home from hospital placements was already committed to 'Step Down' beds said:

> ***"To be honest it [Shared Lives Intermediate Care] wasn't taken up by our commissioners…they weren't interested, weren't receptive".***

- **Narrow focus of pilot**

Pilot and non pilot schemes said that introducing the intermediate care pilot as something new was problematic and created confusion within Shared Lives schemes and amongst carers. Several said it had been a mistake to *'hive off'* home from hospital arrangements as something new or different to Shared Lives *'business as usual'.* One pilot lead said:

> ***"If we could take somebody from hospital we would do it anyway…it doesn't need to be under a separate umbrella."***

Others agreed and one said that *'marketing'* the pilot as intermediate care or home from hospital was a mistake. One site who later withdrew from the pilot, said that the intermediate care offer was similar to respite and that presenting it to schemes and carers in that way may have avoided some of the problems experienced by the pilot.

> ***"The offer does have similarity to emergency respite placements of which we have experience and the offer of Shared Lives is versatile…to make it specific puts pressure on the service but also places a different view in the minds of the officers and carers, potentially creating anxiety."***

Several schemes spoke of the need to broaden the offer to include prevention and hospital avoidance. They suggested promoting their offer via GP surgeries and similar community routes to identify people at risk of hospitalisation or admission to residential care was important, as well as promoting to hospital teams for home from hospital referrals.

- **Lack of resources, staff time and capacity**

Some pilot sites were able to appoint extra staff to work on the intermediate care pilot, others took on this work as an 'add on' to an existing role. Pilot sites said dedicated staff were important in setting up the pilot; some said they simply did not have the time and resources to do the work required. Some sites said that guidance from Shared Lives Plus was lacking at the start and they had to '*reinvent the wheel.'*

Two sites withrew because of workload and capacity issues. In one area the commissioners were on board but due to challenges of time, staffing and resources at the site, the work could not be done to accommodate referrals. This pilot lead said it was the '*right service, at the wrong time'.*

There was agreement that designated staff were needed in the pilot sites to lead the project, but that the workload needed to be shared and supported by other staff and management, especially as referrals increased. One site lead said that during the pilot other

staff in the scheme did not engage with health referrals, but passed them on to her, meaning that opportunities were missed when she was unable to respond.

Learning emerged relating to the administrative burden and paperwork involved in the pilot and in the evaluation. The monitoring paperwork required for the pilot added to the workload of schemes; some said it was confusing and at times unhelpful. Some schemes recorded hospital avoidance referrals, others did not. One pilot lead said that an issues log would have been useful for schemes to share experiences and learning from the pilot.

> ***"Somewhere to share issues…there was supposed to be a google group but that never happened…we met up separately/informally"***

Questionnaires designed by the evaluation team – to provide benchmark and follow up data for the pilot - were not used by the pilot sites, despite adjustments being made at an early stage. The reasons for non-completion were that the administrative burden was too great for schemes and carers.

6. Conclusions and Recommendations

By the end of the Shared Lives Intermediate Care Pilot programme in April 2019, there had been 31 home from hospital referrals into a Shared Lives arrangement via this pilot. The five sites remaining in the programme had made good progress towards the eight agreed outcomes in the Vision for Change.

Schemes had worked extremely hard at making inroads into health teams locally and promoting the Shared Lives offer for intermediate care. Pilot schemes told us that making new links took time but that they were starting to see results and would be continuing to develop this offer under their core business.

For Individuals

This evaluation found that people in Shared Lives arrangements focus is on the life they are living, rather than their health condition/s. People told us that their social connections and relationships are an important part of feeling well and happy and they value the personal connection, non-judgemental and asset-based support of Shared Lives carers.

The interviews and case studies illustrate how living in a family home with one to one support enables people to maintain and recover their health and to live a full life (Outcome 1). The physical and mental health benefits of Shared Lives emerged clearly in this evaluation. The low numbers reached by this pilot indicate that people who could benefit are missing out on this option.

Fewer people were referred into Shared Lives from hospital than envisaged, but these people were diverse individuals, often with multiple and complex physical and mental health issues (Outcome 2). Most people referred were those for whom traditional services were not appropriate and a bespoke Shared Lives arrangement enabled them to be discharged from hospital in a timely manner. The time taken to place people with complex needs into Shared Lives was not an issue (Outcome 7).

Many individuals in the pilot responded to personalised support by improving their health status and independence, developing self-care and self-management skills, with potential savings and cost benefits for the system (Outcome 8).

Success in terms of intermediate care is that people return home. However, returning people home too soon after a short-term intermediate care placement could undermine potential savings to the system (Outcome 8). Several people opted for long term Shared Lives placements as this met their needs.

For Carers

This evaluation indicates that Shared Lives carers are valued professionals with the skills and expertise to deliver intermediate care (Outcome 3). Most carers who had an intermediate care placement were existing Shared Lives carers, some had an interest in health, or a clinical background, others received training to improve their confidence and specific skills where needed. Most carers said they enjoyed their health-related placements and would support an individual discharged from hospital again. Carers interviewed said the person and the connection achieved through matching was more important than client group or medical condition. They said they got a sense of satisfaction from making a difference to peoples' lives and enjoyed the emphasis on promoting independence and self-care (Outcome 8).

Pilot sites and health and social care professionals recognised their skill and praised the quality of support provided by carers, citing the practical and emotional care provided, the difference to peoples' well-being, and the benefits to the system by having one person overseeing all aspects of a person's care. Shared Lives carers and schemes told us that all carers should be offered the option of health referrals, as any carer with an interest could do this work (with additional training where necessary). Some sites felt that the emphasis on clinical skills and different role had put some carers off participating in the pilot.

When placements worked best, the carer and scheme worked together with the ongoing support and input of relevant health and social care professionals. There were concerns about lack of carers to fulfil potential demand and the lack of geographical spread. Job security is an ongoing issue, although Shared Lives carers said they were not doing this work for the money. Shared Lives schemes were protective of their carers as a precious resource, and said they needed to be paid properly and given appropriate support and guidance in this demanding role (Outcome 4).

For Shared Lives Schemes

Pilot site leads worked hard to get inroads into local health services, hospital discharge teams and CCGs. Most were successful in building positive ongoing relationships with health and social care professionals, particularly in mental health. Those practitioners with experience of the pilot said that Shared Lives intermediate care pilot leads were hard working, knowledgeable, skilled and responsive (Outcome 5).

Site leads said they were on a steep learning curve with the intermediate care pilot. As the pilot progressed, schemes developed their knowledge and adapted their systems/processes enabling them to respond to referrals in a flexible and timely manner. They said they would have benefitted from scoping in advance and understanding their local health landscape better, and that the Shared Lives Plus Guidance would have been helpful earlier.

Sites said progress was being made towards Shared Lives intermediate care being part of the local offer/network of support (Outcome 6) but there were organisational and cultural

barriers in a time of uncertainty and change in the health sector. Discharge teams were set in their ways and block contracts and other initiatives meant that money for intermediate care had already been committed elsewhere. This made it difficult to find a 'way in' to new teams and gain health funded referrals.

Pilot sites and health and social care services were concerned about having insufficient carers available to meet potential demand and schemes had a balancing act locally. Some pilot leads felt they were now consolidating their hard work, and all the pilot schemes said they would continue to offer intermediate care as part of the generic Shared Lives offer.

It was acknowledged that culture change is difficult and churn within health and social care system was problematic for changes in practice. Where successful placements were made, health and social care professionals were keen to recommend Shared Lives as an option to their colleagues or teams. Pilot sites said that practitioners who did not know Shared Lives were cautious and risk averse, admitting it is easier to do what has always been done in terms of discharge from hospital.

For the Health and social care services/system

Pilot sites showed they could adapt their usual processes where necessary, avoiding delays in home from hospital discharges into Shared Lives. Some people spent less time in hospital or another institution, some were discharged into Shared Lives instead of residential care, others utilised Shared Lives as a stepping stone before returning home (Outcome 7).

Overall, people in Shared Lives arrangements maintained and recovered their health; Shared Lives carers in this pilot had a strong focus on supporting people towards independence by self-care and reablement. There were clear indications in the case studies and interviews of improvements that led to the prevention of ill health and hospital avoidance, reducing strain on the system (Outcome 8). The fact that most people either returned home at the end of their Shared Lives stay, or remained in a long-term Shared Lives placement also suggests reduced strain on services – as few people were re-admitted to hospital or went into a residential or nursing home from Shared Lives.

There was agreement that evidence of savings - especially cost/benefit analysis was needed for commissioners. However, the focus of the pilot on home from hospital referrals meant that broader savings to the health and social care system were not captured as part of this programme. Case studies and interviews demonstrate the impact of Shared Lives on peoples self-care and management, hospital avoidance and the appropriate use of services and remain vital in getting the message across to practitioners but quantitative data is lacking (outcome 8).

Recommendations for Shared Lives Schemes

- Maintain an inclusive, flexible and responsive referrals process
- Maintain/develop relationships with old and new health and social care teams
- Highlight individual stories - and promote carer's contribution.

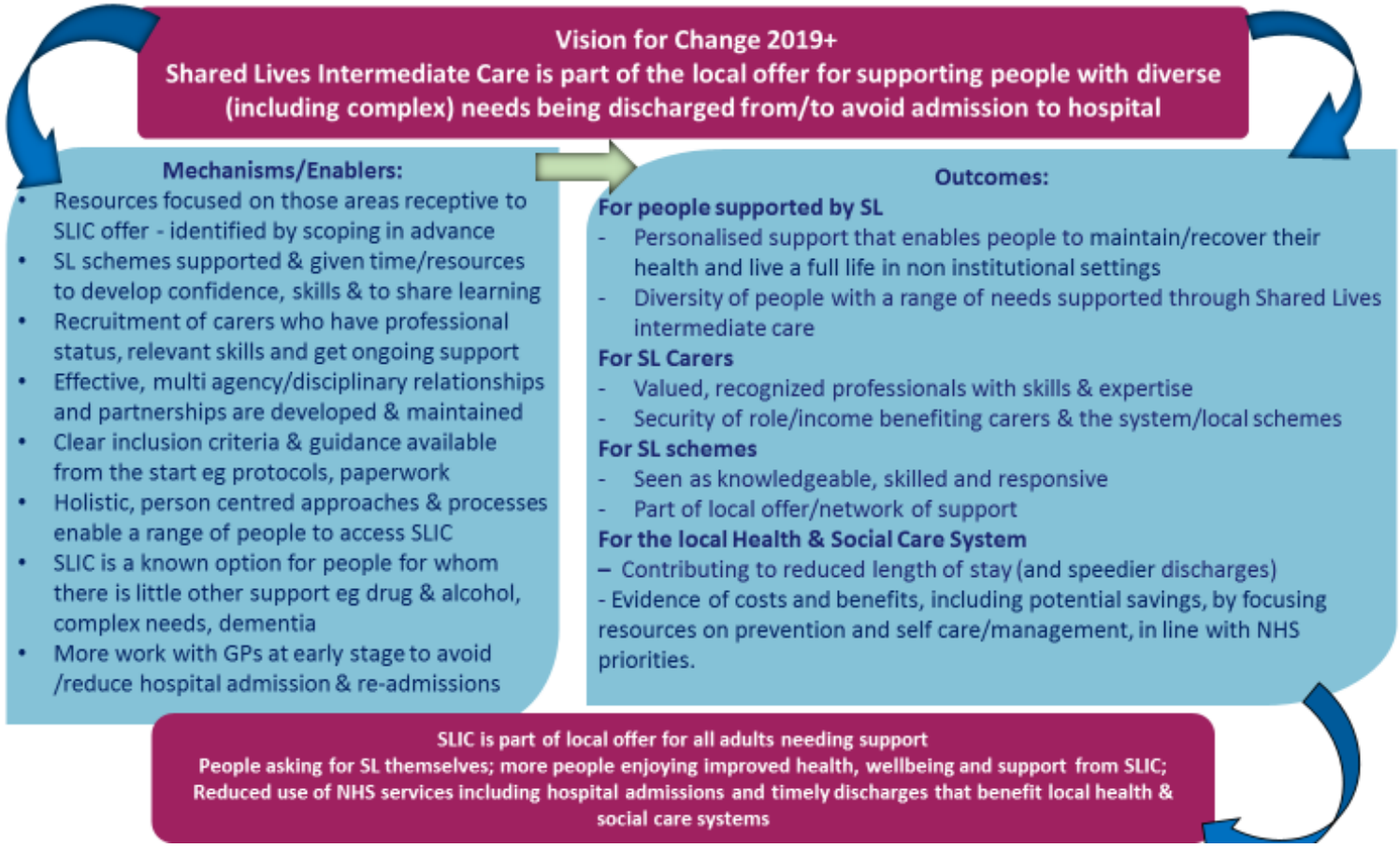
Recommendations for Health and social care services/systems

- Think of Shared Lives as an option for people with complex and non-complex health and social care needs
- Consider quality of life and the impact on health outcomes of one to one support in a family home
- Look system wide -at savings due to self-care, prevention of ill health and hospital avoidance – rather than unit costs.

Recommendations for Shared Lives Plus

- Raise awareness of Shared Lives as an option for diversity of people via ongoing national publicity
- Scope localities in advance of a new programme - to identify receptive areas
- Integrate new Shared Lives projects into the existing Shared Lives offer
- Provide support, guidance and training at implementation of a new project
- Produce cost benefit analysis/evidence of impact of Shared Lives on prevention of ill health and self-care/management

Appendix 1


Vision for Change 2019+
Shared Lives Intermediate Care is part of the local offer for supporting people with diverse (including complex) needs being discharged from/to avoid admission to hospital
Mechanisms/Enablers:
• Resources focused on those areas receptive to SLIC offer - identified by scoping in advance
• SL schemes supported & given time/resources to develop confidence, skills & to share learning
• Recruitment of carers who have professional status, relevant skills and get ongoing support
• Effective, multi agency/disciplinary relationships and partnerships are developed & maintained
• Clear inclusion criteria & guidance available from the start eg protocols, paperwork
• Holistic, person centred approaches & processes enable a range of people to access SLIC
• SLIC is a known option for people for whom there is little other support eg drug & alcohol, complex needs, dementia
• More work with GPs at early stage to avoid /reduce hospital admission & re-admissions
Outcomes:
For people supported by SL
- Personalised support that enables people to maintain/recover their health and live a full life in non institutional settings
- Diversity of people with a range of needs supported through Shared Lives intermediate care
For SL Carers
- Valued, recognized professionals with skills & expertise
- Security of role/income benefiting carers & the system/local schemes
For SL schemes
- Seen as knowledgeable, skilled and responsive
- Part of local offer/network of support
For the local Health & Social Care System
– Contributing to reduced length of stay (and speedier discharges)
- Evidence of costs and benefits, including potential savings, by focusing resources on prevention and self care/management, in line with NHS priorities.
SLIC is part of local offer for all adults needing support
People asking for SL themselves; more people enjoying improved health, wellbeing and support from SLIC;
Reduced use of NHS services including hospital admissions and timely discharges that benefit local health & social care systems