Evaluation of the Shared Lives Mental Health Project

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Executive Summary

Shared Lives is a form of social care which has historically been used primarily for people with learning disabilities. In Shared Lives, an adult who needs support or accommodation is matched with an approved Shared Lives carer, who supports and includes the individual in their family and community life. The Cabinet Office has funded Shared Lives Plus to deliver a project to support the development of Shared Lives as an option for people with mental ill health. The project has supported seven local Shared Lives schemes[1] to develop, demonstrate and market a financially viable and commission ready approach to Shared Lives mental health support, and to generate learning about what works.

The National Development Team for Inclusion (NDTi) was commissioned to conduct an independent evaluation of the project. Drawing on data collected through a mixed methods evaluation approach, this report describes the impact and learning from the project. It is hoped that the findings reported will be of use to Shared Lives schemes looking to develop support for people with mental ill health, for Shared Lives Plus supporting schemes to develop in this area and for commissioners and mental health professionals who are interested in learning about how Shared Lives can support people with mental ill health.

Progress towards outcomes

Five outcomes covering outcomes for individuals, outcomes for schemes and outcomes for the mental health sector were developed for the project. Progress towards the outcomes can be summarised as follows:

Increased understanding of Shared Lives as a viable option for people with mental ill health in the mental health sector

Including:

- **a) Greater awareness and understanding of Shared Lives among people and organisations working with people with mental ill health; and**
- **b) better relationships/partnerships with people and organisations working with people with mental ill health**

Through the project, all seven schemes undertook awareness raising activities in order to promote Shared Lives to professionals and organisations who support people with mental ill health. Despite some difficulties in making in-roads in making contact with mental health teams, all schemes made progress in this area. Key to facilitating progress has been finding a "way in" to mental health teams through making the most of existing contacts or links, sustained attempts to secure invitations with mental health teams, or making contact with

[1] Bradford, Derby, East Sussex, Lincolnshire, North Somerset, Rochdale and Telford and Wrekin

those with more strategic responsibility. Where mental health professionals become aware of what Shared Lives can offer, it is often met with significant enthusiasm. Seeing the positive outcomes in an individual case rather than hearing about the model in theory is key to convincing professionals that Shared Lives is a viable option for people with mental ill health. Harnessing the enthusiasm of mental health professionals to act as ambassadors or champions within mental health teams is an effective way of promoting Shared Lives.

Increased capacity within the Shared Lives sector to support people with mental ill health

Including:

a) **More people with mental ill health in Shared Lives arrangements**
b) **More and better supported Shared Lives carers**

The target for the project was for the schemes to grow their mental health support by 100 Shared Lives arrangements across the seven schemes. Given that by the end of September there were a total of 71 new arrangements across the seven schemes it seems likely that the target will be met, or close to being met, by the end of December 2016. While all schemes have made progress towards increasing the number of people in Shared Lives arrangements, the experience of the Shared Lives schemes was varied, with some schemes experiencing higher levels of referrals than anticipated, and other schemes struggling to reach their targets. Key factors in generating higher numbers of referrals were becoming part of the process where decisions are made about support packages (through being part of panel meetings, brokerage or being on a preferred provider list) and seizing opportunities to fulfil demand, such as gaps in certain types of provision or drives to move away from traditional forms of support.

The target for Shared Lives carer recruitment for the project was to increase the number of Shared Lives carers offering mental health support by 31 across the seven project schemes. This was exceeded by the end of September. Across the schemes there was strong and consistent evidence of Shared Lives carers being supported well by Shared Lives schemes through recruitment, assessment, induction and ongoing support through placements. This support is key to the success of individual arrangements and to the Shared Lives model.

Individuals with mental ill health have better choice and control over their lives and their support, and improved mental health and wellbeing

Across the schemes there was evidence of people in Shared Lives arrangements having choice and control over whether Shared Lives was the right support option for them, and considerable evidence of people in Shared Lives arrangements being enabled to pursue personal interests and activities within the community that they may not have had the opportunity to do in more traditional settings. Although careful matching between individual and Shared Lives carer took place in all schemes, there was less evidence of

people having a choice of Shared Lives carer or arrangement. For some people in long-term live-in arrangements, there were also some restrictions on what they were able to do with their days due to the expectation that they would be out of the house during the daytime in the week.

The evaluation, qualitative accounts of Shared Lives carers and mental health practitioners, stories of people in Shared Lives arrangements, and case studies provided by schemes have provided a rich insight into the impact that Shared Lives can have on the lives of people with mental ill health. Individual cases have shown how Shared Lives - day support, short breaks and long-term arrangements - can work to improve general wellbeing and improve mental health through preventing crisis and hospitalisation, and supporting maintenance and stability for people with mental ill health. It is not an option that will be right for everyone – there were a small number of cases which had not worked out – but it is clear that for some people, at the right point in their mental health recovery, Shared Lives is form of support that can deliver positive outcomes in terms of mental health and wellbeing.

Shared Lives is part of local mental health promotion and prevention services/support

This outcome reflects the long-term vision that Shared Lives will become part of the landscape of mental health services or provision in the local areas. Through a combination of the three support options (day support, short breaks and long-term arrangements), across the seven schemes there was evidence of Shared Lives working well as a mental health intervention in the form of: planned prevention; facilitated discharge from hospital; as a step towards independent living and maintaining stability. In addition, there were a small number of examples where Shared Lives has been used in responses to crisis/emergency. However, while the project has demonstrated that Shared Lives *can* be part of the landscape of mental health support, there is some way yet to go in all of the areas before this outcome is realised. As the number of people experiencing positive outcomes through being in Shared Lives arrangements increases, as champions of Shared Lives within mental health teams continue to spread the word, and as health and social care processes change to incorporate consideration of Shared Lives as an option as routine, it seems likely that this will start to change.

Increased skills, knowledge and contributions of people accessing, experiencing and delivering Shared Lives

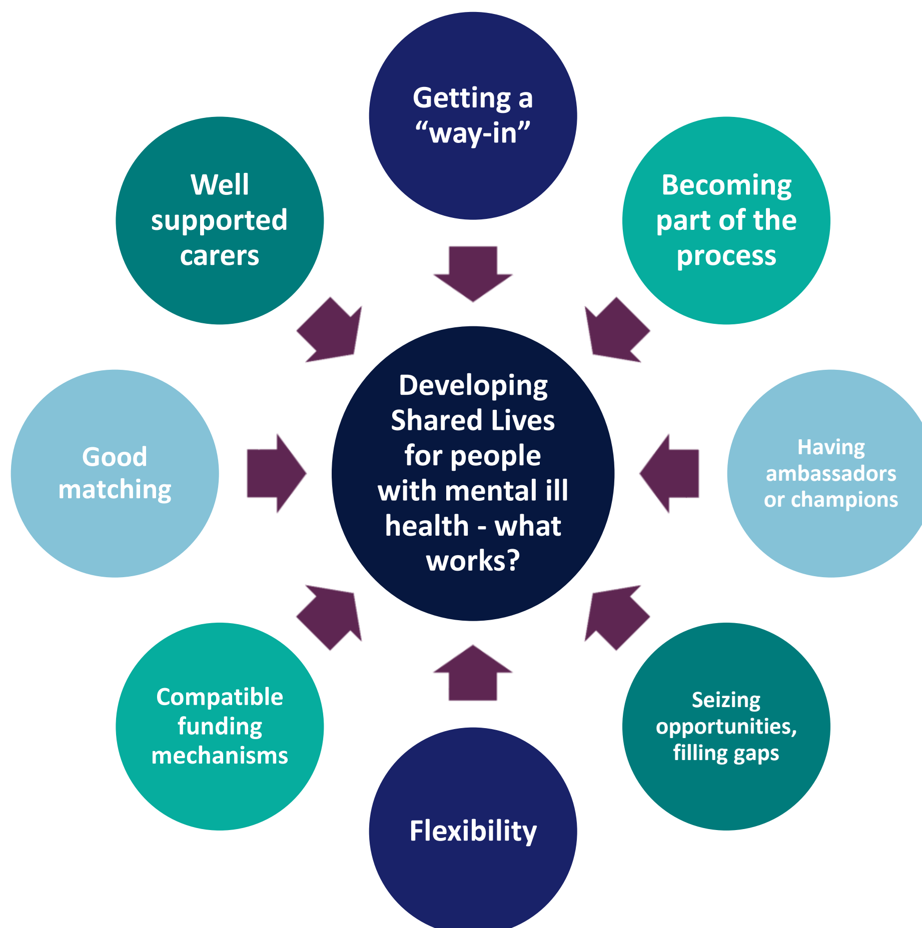
This final outcome cuts across all of the other areas and recognises the broader outcomes generated through this project – not only for those who are directly receiving support through Shared Lives but also those delivering Shared Lives as carers, as staff or as volunteers. There was evidence of an increase in knowledge about mental health both by Shared Lives staff and Shared Lives carers and a recognition that supporting people within families and in the community can help to break down the stigma of mental health.

The project recorded a total of 356 social action opportunities and 45 volunteering opportunities that were created as a result of the project. Volunteering opportunities includes people volunteering to support Shared Lives – for example through promotion, events, recruitment of carers and being on Shared Lives panels – as well as people in Shared Lives arrangements volunteering.

Summary: Developing Shared Lives for people with mental ill health – What works?

There is great variation in how Shared Lives has been delivered to support people with mental ill health across schemes, and there are many factors which have both challenged and enabled the development of the support for people with mental ill health. There is variation in: type of arrangement offered by schemes; the scheme itself (whether independent or local authority); local health and social care systems; funding mechanisms; and the support needs of individuals. As a result of such variation, there is no one single recommended model of delivery. Instead eight key factors for supporting the development of Shared Lives as a form of support for people with mental ill health have been identified:

Developing Shared Lives for people with mental ill health – what works?



1. **Getting a "way-in"** – finding a "way in" to mental health teams in order to promote Shared Lives to potential referring practitioners is crucial. This could be through making the most of existing contacts or links, sustained attempts to secure e.g. invitations to mental health team meetings, or going to the 'top' and making contact with those with more strategic responsibility.

2. **Becoming part of the process** – although this can be a challenge, especially for independent providers, becoming integrated into the process where decisions are made about support packages (whether this is through being part of panel meetings, brokerage or being on a preferred provider list) is key to growth happening at any pace.

3. **Having ambassadors or champions** – having enthusiastic ambassadors or champions *within* mental health teams can be very effective at promoting Shared Lives.

4. **Seizing opportunities, filling gaps** – making the most of local opportunities such as gaps in certain types of provision or drives to move away from traditional forms of support – i.e. fulfilling demand – can lead to growth at a faster rate.

5. **Flexibility** – being flexible about the type of arrangement that can be offered, to whom, and being flexible about the role of Shared Lives (e.g. as planned prevention, facilitated discharge or maintenance) at least at the early stages of development can open schemes up to a greater number of opportunities.

6. **Compatible funding mechanisms** – although this is not always within control of Shared Lives schemes, especially in-house local authority schemes, to maximise opportunities, schemes need to ensure the local funding mechanisms (block contracts, personal budgets etc.) fit with the schemes processes. Ultimately, being able to accept all forms of funding through whatever route or mechanism will maximise opportunities.

7. **Good matching** – a fundamental element of the Shared Lives model for people with all support needs is the importance of good matching between Shared Lives carer the person being supported, and this is no different for people with mental ill health. Good matching leads to positive outcomes and referrals follow good outcomes.

8. **Well supported Shared Lives carers** – the Shared Lives carer is key to making a Shared Lives arrangement work. Good support for Shared Lives carers through recruitment, assessment, induction and ongoing support through placements ensure they can fulfil their roles.

Conclusion

Although all seven project schemes experienced challenges and frustrations in developing support for people with mental ill health, this evaluation has found evidence of the positive impact that having support through a Shared Lives arrangement – whether it is day support, short breaks or long-term arrangements – can have on the lives of people with mental ill health. Examples have been seen of improvements in general wellbeing and increased participation in community life, as well as specific examples where people's mental health has stabilised and hospital stays have been prevented. Shared Lives will not be right for everyone, but for the right person, at the right point in their mental health recovery, Shared Lives can offer an individualised, person-centred form of support at the heart of the community. As such, it has the potential to play an important role as one option, among other types of accommodation, short breaks and day support on offer to people with mental ill health.

Updated context from Shared Lives Plus

The Shared Lives Plus mental health development project was funded by the Cabinet Office for nine months from January to September 2016. This evaluation reports on that timeframe.

However, the project ran for twelve months to the end of December 2016. The final outcomes are described below:

- **7** Shared Lives schemes took part for the full term of the project.
- **95** new Shared Lives arrangements with a further **11** in progress making a total of **106** Shared Lives mental health support arrangements for the duration of the project (31 long term, 37 short break, 22 day and 16 unspecified)
- **119** new and existing Shared Lives carers offering mental health support (28 long term, 30 short break, 37 day and 24 unspecified).
- **61** family carers accessed short breaks
- **572** new social action opportunities, including day, short break and residential
- **114** new volunteering opportunities
- **249** mental health organisations contacted
- Commission ready pack of **15** documents including a business case, commissioning guide and training resource.
- **2** development seminars
- **3** workshops attended by **52** different people and **24** different schemes.

1. Introduction

In February 2016, the National Development Team for Inclusion were commissioned to undertake an evaluation of the Shared Lives Mental Health Project on behalf of Shared Lives Plus. Funded by the Cabinet Office, seven local Shared Lives schemes have been awarded grants of up to £15,000 to support the further development of Shared Lives to support people with mental ill health[2]. Operating for 12 months to December 2016, the project has supported development activities in Shared Lives schemes in the following areas:

- Bradford
- Derby
- East Sussex
- Lincolnshire
- North Somerset
- Rochdale
- Telford and Wrekin

Drawing on data collected through a mixed methods evaluation approach, this report describes the impact and learning from the project. It is hoped that the findings reported here will be of use to Shared Lives schemes looking to develop support for people with mental ill health, for Shared Lives Plus supporting schemes to develop in this area and for commissioners and mental health professionals who are interested in learning about how Shared Lives can support people with mental ill health.

2. Background to the project

Shared Lives

Shared Lives (formerly Adult Placement) is a regulated form of social care delivered by Shared Lives carers who are trained and approved by a registered Shared Lives scheme. In Shared Lives arrangements, adults (or sometimes young people aged 16 – 17) who need support or accommodation are matched with compatible Shared Lives carers and families who support and include the individual in their family and community life. Support is provided in three types of arrangement:

- **Long-term accommodation and support**: an arrangement where the person moves into the home of the Shared Lives carer. These arrangements can be an alternative

[2] The term 'mental ill health' was agreed by those involved in the project as the preferred term to use to refer to people with lived experience of a range of mental health conditions, and has therefore been used throughout this report

to residential care, supported accommodation, or living with their own family. This can be a step towards independent living, or could be a longer-term arrangement for individuals who are unlikely to be able to live independently.

- **Short breaks**: an arrangement where the person stays in the home of the Shared Lives carer for a limited time. This can be utilised as a form of intermediate care, or for family carer respite.
- **Day support:** involving the sharing of home and family (and/or community) life of the Shared Lives carer during the day. This can be used as an alternative to other forms of day support, such as day centres.

Half of the 12,000 people currently supported by Shared Lives are living with their Shared Lives carer as part of a supportive household; half visit their Shared Lives carer for day support or overnight breaks. People in Shared Lives arrangements can also receive a combination of types of support, for example, someone may receive Shared Lives day support and also have short breaks with the same Shared Lives carer, or they may live in a long-term arrangement and have day support with a different Shared Lives carer.

As an alternative to traditional models of social care, including day centres and residential care, the focus of the Shared Lives approach is on providing people with the support they need to live life to the full in their community. Shared Lives carers share their own homes and family lives and support people to develop independent living skills, friendships and roots in their community, providing person-centred support that is tailored to the specific needs and choices of individuals. Shared Lives carers are paid a modest amount to cover their time and expenses.

Shared Lives schemes operate in the majority of local authorities in the UK. Historically, these arrangements have been used primarily to support people with a learning disability. More recently local schemes have developed their provision to offer support to people with other support needs, including older people, people living with dementia, people with mental ill health, and young people in transition.

Shared Lives Plus

Shared Lives Plus is a national charity and the UK network for shared living approaches to care and support for adults. Shared Lives Plus helps members to work together to survive and thrive, influencing local and national policy makers and providing support, training, events, resources, research programmes and access to insurance. Members include 152 Shared Lives schemes and 5,000 individual Shared Lives carers across the UK.

Shared Lives Plus major supporters include the Big Lottery, Nesta, Department of Health and the Cabinet Office who are providing support to double the size of the Shared Lives sector in England.

Shared Lives for people with mental ill health

In the two years to 2014/15 the number of people using Shared Lives grew by 27%, to more than 11,500 people[3]. Over that same period, the use of Shared Lives by people with mental ill health increased by 17%, to a total of 760 individuals[4]. The support continues to be utilised predominantly by people whose primary support needs are related to a learning disability (76%), while the proportion of people with mental ill health currently stands at around 7%.

Current policy context

The current policy context in the NHS and local government provides a strong foundation from which to develop person-centred community-based support for people with mental ill health. The Care Act 2014[5] strengthens the role of personalisation in social care and places wellbeing as the central principle of the provision of social care. The Five Year Forward View for Mental Health[6] states that people with mental ill health have a right to choice and control and to receive care that is safe, effective and personal, and emphasises the need for commissioning for prevention and quality. Integrated Personal Commissioning (IPC) is a new approach to joining up health, social care and other services at the level of the individual[7]. It enables people, carers and families to blend and control the resources available to them across the system in order to 'commission' their own care through personalised care planning and personal budgets. IPC also supports people to develop their knowledge, skills and confidence to self-manage through partnerships with the voluntary and community sector, emphasises the role of community capacity building and advocates greater use of alternatives to traditional forms of health and social care. People with significant mental health needs are one of the groups included in the IPC pilots. All of these policies are centred around the principles of personalisation – individualised and person-centred care and support that offers individual's choice and support – principles that are in-line with the Shared Lives approach to support.

Shared Lives Mental Health Project

[3] Shared Lives Plus, (2016), The state of Shared Lives in England report 2016, Liverpool: Shared Lives Plus
[4] Shared Lives Plus, (2016), The state of Shared Lives in England report 2016, Liverpool: Shared Lives Plus
[5] Department of Health (2014), The Care Act, London: The Stationary Office
[6] The Mental Health Taskforce (2016), The five year forward view for mental health, London: The Mental Health Taskforce
[7] www.england.nhs.uk/commissioning/ipc/

Building on recent growth, the aim of the mental health project is to support the development of Shared Lives as an option for people with mental ill health. The project has supported seven local Shared Lives schemes to develop, demonstrate and market a financially viable and commission ready approach to Shared Lives mental health support, and to generate learning about what works. Learning from the project will be shared across the Shared Lives sector to support the growth and development of Shared Lives nationally.

Operating across seven areas in England, each scheme has been awarded a grant of up to £15,000. The sites and their targets, based on the proposals they submitted for the project are summarised in the table below. As shown, four of the seven schemes planned to deliver support to people with mental ill health in all three of the types of arrangement (day support, short breaks, long-term arrangements), while one scheme (East Sussex) has a sole focus on long-term support and one other (Bradford) does not plan to offer provision of this kind as part of the project. Two of the five schemes (Lincolnshire and East Sussex) have experience of supporting people whose primary support needs are related to mental ill health that precedes the project. Two schemes are run by independent organisations, the other five schemes as part of the local authority.

Table 1: Summary of the seven Shared Lives Mental Health Project sites

Scheme	Offering Day (D), short break (SB) or long term (LT)	Local authority or independent	Number of new Shared Lives carers target	History of supporting people with mental ill health	Number of people in new arrangements (target)
Shared Lives Bradford	D, SB	LA	5	No	10
Derby City Council Shared Lives	D, SB & LT	LA	9	No	14
East Sussex Shared Lives Scheme	LT	LA	4	Yes	7
ASA (Adults Supporting Adults), Lincolnshire	D, SB & LT	I		Yes	15
North Somerset Shared Lives	D, SB <	LA	4	No	10
PossAbilities, Rochdale	D, SB <	I	5	No	13
Telford and Wrekin Shared Lives Scheme	D, SB <	LA	4	No	10-15

3. The Evaluation

Aims and purpose

The purpose of this evaluation is to identify the impact of the project in the following areas:

1. The number of additional (new) people with mental health problems provided with Shared Lives services
2. The awareness raising activities carried out by local schemes and by Shared Lives Plus and their effectiveness and impact
3. The extent and effectiveness of engagement with people with mental health problems and their families, clinicians and other relevant stakeholders
4. The tools and resources produced which could be of use for the wider sector
5. The effectiveness of links made and relationships with local mental health and care commissioning organisations, referral teams, user-led and family organisations or groups, volunteering, peer support and other social action related organisations
6. How Shared Lives helps people take part in social action, both through providing Shared Lives and through receiving Shared Lives

In addition, the evaluation aims to explore and make recommendations with regards to:

1. The opportunities for developing and scaling Shared Lives as a mental health intervention nationally
2. The barriers to developing and scaling Shared Lives as a mental health intervention nationally
3. Any areas of Shared Lives practice which may need developing or changing to reflect the goals, wishes and needs of people with mental health problems and its fit with the recovery model and commissioners' expectations.

Methodology

In order to capture the learning from the project and demonstrate effectiveness and impact, the evaluation has been designed to reflect a broad range of perspectives. The findings draw on quantitative and qualitative data and insights gathered through the following methods:

- Theory of Change workshop, bringing together delivery leads from the seven project schemes, people with lived experience of mental ill health, Shared Lives carers, Shared Lives Plus staff and mental health professionals
- Initial telephone interviews (total n=16: Shared Lives leads (7), mental health professionals (3), Shared Lives carers (3), people in Shared Lives arrangements (2), person with lived experience of mental ill health (1))
- Fieldwork visits to four project sites, involving semi-structured (face to face and telephone) interviews (total n=46)
    - Shared Lives delivery staff (n=12)
    - People in Shared Lives arrangements (n=8)
    - Shared Lives carers (n=11)
    - Mental health professionals and practitioners (n=8);
    - Others including representatives from key partners and referring agencies, people with lived experience of mental ill health and family members (n=7)
- Analysis of project monitoring data
- Analysis of data collated through the My Shared Lives outcomes measurement tool
- Change stories (a type of case study focusing on change to individuals) completed by schemes
- Follow up interviews with Shared Lives leads in non-fieldwork schemes (n=2)

Ethical approval was granted for the research through NDTi's internal ethics process. Interview participants were provided with information sheets about the research and advised that participation was voluntary. In order to encourage openness and honesty and to enable discussion about aspects that have been challenging or not gone well, the content of the interviews have been kept confidential within the NDTi research team and quotes in this report have been kept anonymous. In order to ensure anonymity the findings described in this report have not been attributed to particular schemes but are reported as general findings.

Due to some limitations of the data collected through the My Shared Lives outcomes tool the findings from the tool are reported separately in section 6 alongside discussion of these limitations.

Theory of Change

At the start of the project a Theory of Change was developed through a workshop with a range of stakeholders for the project. A Theory of Change captures: the issue to be addressed by the project; the underlying assumptions or rationale behind the project; the context the project is operating in; the mechanisms or activity which will create the change; the drivers supporting the change; the desired outcomes for the project and the longer-term impact. The Theory of Change developed for the project can be found in Appendix A.

The outcomes agreed through the workshop are:

1. Increased capacity within the Shared Lives sector to support people with mental ill health including:
    a. More people with mental ill health in Shared Lives arrangements
    b. More and well supported carers
2. Individuals with mental ill health using Shared Lives have:
    a. Better choice and control over their lives and their support
    b. Improved mental health and wellbeing
3. Increased understanding of Shared Lives as a viable option for people with mental ill health in the mental health sector including:
    a. Greater awareness and understanding of Shared Lives among people and organisations working with people with mental ill health
    b. Better partnerships/relationships with people and organisations working with people with mental ill health
4. Shared Lives is part of local mental health promotion and prevention services/support
5. Increased skills, knowledge and contributions of people accessing, experiencing and delivering Shared Lives

The findings of the evaluation are reported in four sections. The first section describes how Shared Lives has been delivered as a model for people with mental ill health, the second part reports on progress towards these agreed project outcomes, the third part looks at the findings from My Shared Lives and the fourth part briefly reflects on the cost of Share Lives compared to other support options.

4. Models of Delivery

A key aim of the evaluation is to capture learning from the project to support the development and scaling up of Shared Lives nationally. Shared Lives schemes vary across the country as does support and services for people with mental ill health and the health and social care processes and structures that both operate in. Before looking in detail at the outcomes of the project, this section describes how the funding was used and the range of ways that Shared Lives has been delivered by the seven schemes to provide support for people with mental ill health.

The grants could be used flexibly to meet the costs of undertaking additional activities to develop Shared Lives to support people with mental ill health, with an overarching emphasis on developing links with clinicians, mental health organisations, user led organisations and commissioners. The specifics of development activities varied across the seven sites, although all had targets around the numbers of new people and carers that they intend to reach. Across the schemes the funding has been used for:

- Promotion and marketing of Shared Lives
- Recruitment of new Shared Lives carers
- Induction of new Shared Lives carers
- Resourcing staff time to develop relationships with mental health teams and organisations
- Resourcing staff time to develop processes
- In one case trialling a “try before you buy” voucher scheme

Across the seven schemes all three types of Shared Lives arrangements were used to support people with mental ill health:

- **Long-term accommodation and support**: across the schemes there were examples of people in long-term arrangements as an alternative to residential care, supported accommodation, inpatient care, living with their own family or living independently. There were examples of people using long-term Shared Lives arrangements as a step towards independent living, and as a longer-term arrangement for people who are unlikely to be able to live independently.

- **Short breaks:** across the schemes there were examples of short breaks being used for carer respite, for crisis prevention, to facilitate hospital discharge and in a small number of cases as a crisis intervention as an alternative to inpatient care.

- **Day support:** across the schemes there were examples of day support being used as an alternative to other forms of day support such as day centres and as a way to support independent living.

There were several examples of people accessing a combination of these forms of support, for example living with one Shared Lives carer in a long-term arrangement and having day support and short breaks from another, or having regular day support and planned short breaks with the same Shared Lives carer. There was also movement between these arrangements, for example someone who has been in a long-term arrangement, moving on to living independently and receiving day support from the same Shared Lives carer to provide support to maintain independence. The indications are that this flexibility, the ability to change arrangements as someone's mental health and support needs fluctuate, works well to support people with mental ill health.

Through a combination of the three support options, across the seven schemes there was evidence of Shared Lives working as a mental health intervention in the form of:

- Planned prevention
- Facilitated discharge from hospital
- Step towards independent living
- Maintenance
- Crisis/emergency response

Through the evaluation we heard about Shared Lives being used to support people with mental ill health in all of these ways and examples are included in later sections of this report showing the positive outcomes for people. The exception to this is the case of Shared Lives as a response to crisis. Although there were a small number of examples where this has happened, schemes have not generally planned to offer this sort of support and the cases were usually in response to specific requests and agreed on a case by case basis. It was generally acknowledged that being able to respond as quickly as a crisis intervention requires is not a good fit with the careful matching process that is a crucial part of the Shared Lives model. There was also wariness around the risks associated with placing someone in a household for the first time at a point of crisis without the time usually taken to collect full information, complete detailed assessments and form a relationship. This does not necessarily mean that Shared Lives is not suited to this sort of provision but schemes

wanting to provide crisis/emergency support may need to make some significant changes to processes and procedures and to the support offered to Shared Lives carers providing support in these contexts.

The people who have been supported in Shared Lives arrangements through this project have had a range of diagnosed mental health conditions including bipolar disorder, schizophrenia, obsessive-compulsive disorder, personality disorder, depression and anxiety. Because most people were eligible for health or social care funding (we did not come across anyone self-funding through the evaluation although it is identified as an option), they tended to have diagnosis of a serious mental illness and were receiving secondary care services.

In terms of referral routes, the schemes can essentially be divided into two categories:

- Those that receive referrals from mental health teams
- Those that can receive referrals from any source including health professionals, voluntary sector organisations and self and family referrals

This broadly reflects whether the schemes are in-house local authority schemes or independent providers, with independent providers having more flexibility to receive referrals from any route. Some of these potential sources of referrals – such as voluntary sector organisations – have not yet been used.

Closely linked to the referral system and diversity of referral routes are the mechanisms by which Shared Lives arrangements for people with mental ill health are funded. Day support and short breaks are usually a set cost per session or per night and are funded by social care, health, self-funding or a combination. Long-term Shared Lives arrangements are usually funded by three sources:

- **A care and support payment** which is paid by social care, health or someone self-funding their care/support. The care and support payment usually covers support in the evenings, weekends and first thing in the morning.
- **A payment for accommodation** provided (the room the person using Shared Lives rents from the Shared Lives carer). This is usually paid for by housing benefit (if the person is eligible).
- **A contribution from the person** living in the Shared Lives arrangement towards board and lodgings (often known as the service user contribution), this is to contribute to the cost of bills and food

The evaluation identified a range of mechanisms that have, or could have been used to fund Shared Lives arrangements for people with mental ill health:

- Block contracts
- Council managed personal budgets
- Direct payments
- Direct payments via independent brokerage
- Section 117 aftercare on discharge from section
- Personal Health Budgets
- Self-funders

As with referral routes, some of these are identified funding sources or mechanisms that could be used and have not yet been. Schemes differed in their readiness or ability to work with these mechanisms (as discussed in more detail below) again depending on whether they are in-house local authority or independent, and some mechanisms are more commonly used than others.

The purpose of this section has been to describe the different ways Shared Lives has been used to support people with mental ill health and to emphasise the variability. There is no one single model that works as a mental health support – different combinations of arrangement types can work to support people at different stages of their recovery and this can change over time as the person's needs change. This flexibility means that Shared Lives is able to provide an individualised person-centred form of support for people with mental ill health.

Recommendation for Shared Lives schemes: Be prepared to be flexible. Offering flexibility in the ways that Shared Lives can be delivered (by arrangement type, referral route and funding accepted) will both maximise the opportunities for Shared Lives as an option and offer more personal individualised support.

5. Progress towards outcomes

This section describes the progress towards the five outcomes for the project that were developed as part of the Theory of Change workshop. The five outcomes cover outcomes for individuals, outcomes for schemes and outcomes for the mental health sector. The discussion of the progress towards outcomes follows a logical order: firstly exploring the extent to which Shared Lives has become known and recognised as an option in the mental health sector; secondly exploring how and whether this has led to an increase in the use of Shared Lives for people with mental ill health; thirdly looking at the impact of being in a Shared Lives arrangement for people with mental ill health; and fourthly looking at progress towards Shared Lives becoming part of the landscape of mental health support and provision. Finally, cutting across the other four outcomes we consider the skills, knowledge acquired and contributions made by people accessing, experiencing and delivering Shared Lives.

OUTCOME: Increased understanding of Shared Lives as a viable option for people with mental ill health in the mental health sector

Including:

a) **Greater awareness and understanding of Shared Lives among people and organisations working with people with mental ill health; and**

b) **better relationships/partnerships with people and organisations working with people with mental ill health**

While Shared Lives is established and well known among people and organisations working with people with learning disabilities, the same cannot currently be said for people and organisations working with people with mental ill health. This was well recognised by the schemes, and increasing the awareness and understanding of Shared Lives in the mental health sector was a key focus for their activity throughout the project.

Under the project, all schemes have undertaken awareness raising activities in order to promote Shared Lives to professionals and organisations who support people with mental ill health (who will potentially refer to Shared Lives). Schemes used a range of methods to do this including securing invitations to mental health team meetings, meeting with individual commissioners and mental health team leads, putting on events and visiting voluntary sector organisations and user groups. Two schemes have offered and provided inductions or training for newly qualified social workers so that they are aware of Shared Lives as an option from the start of their careers.

A number of the schemes reported frustrations in trying to make in-roads into contact with mental health teams:

> *"The biggest battle has been to break into the mental health team itself, people are not responding to contact"* Shared Lives lead

Schemes are maximising existing relationships and 'ways in', for example through former colleagues and success has often hinged on a pre-existing relationship with an individual in a relevant team or position. For those that don't have these links it is a bigger challenge to start from scratch. In terms of gaining access to mental health teams, local authority schemes appear to have an advantage over independent schemes. This was most strongly the case in areas where there were greater levels of integration between health and social care, for example where mental health teams are located in the same building as the Shared Lives scheme, or where they share communication systems.

Building awareness through these approaches is often a slow process and in a short-term project the schemes may not have yet had the time to see the fruits of their efforts. While some of them felt they had made a lot of effort for limited results, one scheme where the lead described talking to anyone who would listen, feels this approach has been key:

> *"Getting relationships established is vital. Once people understand what it's about it opens things up"* Shared Lives Lead

Despite some of the frustrations voiced by schemes that they had not got as far as they would have liked in increasing levels of awareness among mental health professionals and practitioners, interviews across the schemes demonstrated that they have all made progress in this area. Where mental health professionals have become aware of what Shared Lives can offer, it was often met with significant enthusiasm:

> *"Shared Lives is a wonderful, wonderful idea… Institutions deskill and dehumanise. They keep people safe but no other aspect of their lives is considered, the person doesn't have a life… Shared Lives is a great way of achieving positive outcomes away from institutions..."* Service Manager, Mental Health team

> *"I think it's an ideal way to support people… it's so much better than other respite options."* Community Mental Health Matron

> *"In some respects Shared Lives is an ideal solution for a lot of people… The case I've had has opened me up to it as an option."* Mental Health Specialist Accommodation team

This last statement is key – having seen what Shared Lives can offer, this mental health professional was "converted" to the concept of Shared Lives. In the very vast majority of cases it was as a result of seeing a case that convinced people that Shared Lives is a good option for people with mental ill health, rather than as a result of the networking and

promotional activity that the schemes had attempted. A health professional at a hospital where a patient had moved on to a long-term Shared Lives placement, had never heard of Shared Lives before. Having observed the application process and seeing how the patient had settled in with his Shared Lives carer, she commented:

> *"What an absolutely marvellous thing. One of the best things I've ever seen!"* Health professional

For these professionals, it has been seeing the positive impact it has on their patients or clients that has convinced them. These enthusiastic people have become 'champions' for Shared Lives, telling colleagues about it and recommending Shared Lives as an option. This demonstrates how important it is for people to "see" how Shared Lives can work for people rather than just hear about it. It is not simply a matter of getting mental health professionals to be aware of it as an option, but to consider it.

> *"For social workers the idea of living in someone's home is a strange concept – they're not thinking about it, it's not on their radar. Professionals need to build their confidence in it."* Manager, Mental Health Trust

Interviews with mental health professionals who have experience of referring to Shared Lives reveal that Shared Lives schemes are well regarded and there are high levels of trust. However, this trust and confidence needs to be built through experience and this will take time.

Although it may feel to schemes that progress is slow in this area, there are definite signs that awareness of Shared Lives for people with mental ill health is expanding. Schemes looking to develop Shared Lives as an option for people with mental health should acknowledge that this is not going to happen overnight and that the best way of spreading the word is through providing really good support and getting this known about.

Recommendation for Shared Lives schemes: Make the best out of existing links - identify existing links that people within the Shared Lives team have with mental health teams or people in strategic roles and start with these.

Recommendation for Shared Lives Plus: Develop guidance or provide support to help Shared Lives schemes understand the structure of mental health services and who to liaise with or target.

Recommendation for Shared Lives schemes: Identify Shared Lives champions - harness the enthusiasm of mental health professionals who have seen the outcomes of Shared Lives and encourage them to be an ambassador or champion for Shared Lives within their teams and organisations.

Recommendation for Shared Lives schemes: Make use of case studies – when you have a good story, tell it! Stories help people to visualise what Shared Lives can offer better than a description of the model. Think about different ways of sharing stories – for example on your website or through short films.

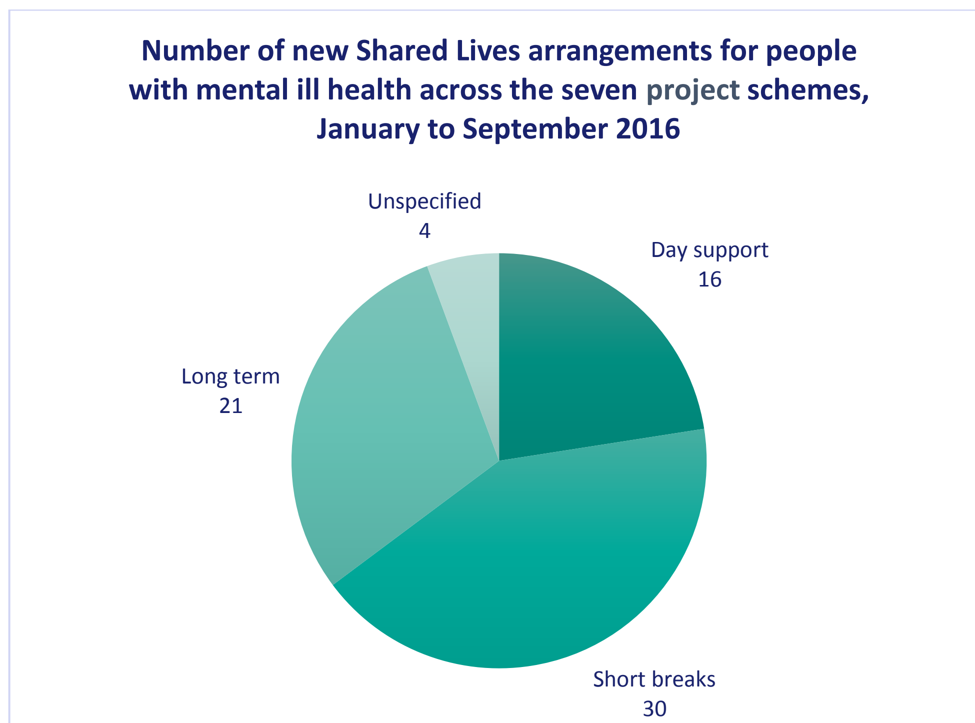
Recommendation for Shared Lives Plus: Develop a section of the Shared Lives Plus website dedicated to mental health – tell stories through case studies or short films.

OUTCOME: Increased capacity within the Shared Lives sector to support people with mental ill health

c) More people with mental ill health in Shared Lives arrangements

The target for the project was that the schemes would grow their mental health support by 100 arrangements across the seven schemes, which will be a combination of day, short break and long-term arrangements. Project monitoring data provided in monthly reports to Shared Lives Plus shows that by the end of September (Quarter 3) there were a total of 71 new arrangements across the seven schemes - 16 day arrangements, 30 short breaks, 21 long term and 4 that were not specified (likely to be a combination of support). Given that momentum appears to be increasing as the project has progressed it seems likely that the target will be met by the end of December 2016.

Figure 2: Number of new Shared Lives arrangements



While all schemes have made progress towards increasing the number of people in Shared Lives arrangements, in terms of generating new referrals, the experience of the Shared Lives schemes was varied. In some schemes referrals have been higher than anticipated, and in

two cases the steady flow of regular referrals has led to the recent or imminent recruitment of a new team member in order to manage demand.

Where volume of referrals has exceeded expectations, there have been a number of factors. The schemes that have generated more referrals than they had initially anticipated are those who, either through design or opportunity, are in a position where Shared Lives can routinely be put forward as an option when support packages are considered. For example, in two schemes a member of the Shared Lives scheme staff attends weekly or fortnightly mental health panel meetings where support packages for individuals are discussed. Having this presence means that the Shared Lives staff member is able to identify where Shared Lives would be an appropriate option for an individual. This is working well both in generating new referrals and raising the profile of Shared Lives among mental health teams. In another scheme there is an integrated brokerage process that all social care packages go through whether they are learning disabilities or mental health, and in this area the local authority has directed that Shared Lives should be considered for all options. Becoming part of the process in these ways creates regular opportunities for Shared Lives to be considered. It seems that local authority schemes are more likely to have these opportunities to become integrated into processes than independent schemes.

Another factor is where schemes have been able to seize opportunities (or respond to demand) as a result of local gaps in services or provision. In one scheme, where Shared Lives is being used primarily for long-term arrangements, an increase in referrals has been part of a drive to move people with mental ill health out of residential care. In two of the schemes, use of Shared Lives for short breaks is progressing well as a result of there being limited alternative options for respite.

As a personalised form of support, Shared Lives seems to be growing more quickly in areas that place high priority on person-centred approaches:

> *"We're very focused on the personalised care agenda… you would have to have a very good reason for someone to go into residential care… We're trying to develop a continuum of services with things like local area co-ordination and Shared Lives"* Head of Service for Mental Health teams

It seems that Shared Lives is more likely to flourish in areas where there is a strong ethos of personalisation.

While all of the schemes have generated new referrals, some have reported difficulties with reaching the targets specified for the project. A number of particular challenges have been identified.

For schemes that have not had the opportunity to become integrated into the process of agreeing support packages such as attending panel meetings, there is a sense of having to work hard for each referral by putting a great deal of work into increasing the knowledge of individual mental health professionals and promoting Shared Lives as described above. One scheme has worked hard on promoting Shared Lives through trying to meet with mental health teams and mental health organisations but found that referrals were slow. Having now had the opportunity to meet with the head of commissioning for mental health who is considering commissioning Shared Lives specifically for enablement, the Shared lives staff have recognised the importance of this:

> *"Until we get commissioners on board, there's nowhere we can go. If this doesn't happen, we'll just be chipping away at it slowly."* Shared Lives staff

For Shared Lives to expand more than one case at a time, there needs to be 'buy-in' from those with strategic or commissioning responsibilities. However, the experience of one scheme shows that this on its own is not enough. In this area, although interest in developing Shared Lives for people with mental ill health was initiated by the Mental Health Trust and preceded the project, referrals were slow:

> *"the [Service Manager] is behind it, the Mental Health Trust is behind it, the problem is translating this into actual referrals."* Mental Health Trust

This scheme had found that despite 'buy-in' from the right people within the Mental Health Trust, work still needed to be done with social workers and mental health practitioners to generate referrals.

Another set of challenges are those arising from local authority and/or health processes (or the interface between the two). One scheme reported the challenge of a backlog in the referral system as their social work team is short of capacity to undertake the necessary assessments. The system ensures that people referred to Shared Lives are eligible for social care and hence will receive adequate funds, but can also create significant delays in beginning the matching process. In another scheme, where the team are able to handle direct referrals from any source, staff also described difficulties around delays in funding allocation, and referenced past experiences where Shared Lives arrangements have fallen through where adequate funds had not been allocated. In one local authority scheme, for the mental health team to make a referral to Shared Lives, a mental health professional has to go through the general public council telephone number, often with long waits of up to 20 minutes. This has the result of deterring referrals from busy professionals. In some cases incompatible IT systems make referrals more complicated than needed.

Funding mechanisms in theory can offer an opportunity, but were more often a barrier. As described above, there are a range of ways that Shared Lives arrangements can be and are

funded. Whether the funding mechanism is an enabler or a barrier depends on a number of variables, including whether the scheme is in-house local authority or independent, and the extent to which personal budgets and direct payments are used in the area. One scheme attributed the recent increase in the use of day support to the growth of personal budgets for people with mental ill-health. Recognising this as an opportunity, they had actively sought to increase this type of referral, yet this requires good working knowledge of personal budgets and brokerage services and the local systems of administration. Some local authority schemes are under a block contract with social care, some specifically for learning disabilities, and receiving other forms of funding is either not possible or is difficult. There were varied experiences across the seven areas in terms of how the local authority has implemented the use of personal budgets - with some being predominantly council managed and one area having high use of direct payments. The local authority schemes were not able to accept direct payments or self-funding. While schemes that are part of the local authority may enjoy benefits of easier access to becoming part of the process, independent schemes tend to be more flexible in the kind of funding they can receive.

> *"The funding is not straightforward – it would be more straightforward if we were independent".* Shared Lives lead

The generation of referrals depends on the right combination of type of organisation and type of funding mechanism - the funding mechanism needs to fit with the structure and processes of the scheme.

These insights demonstrate that there is no straightforward one-size-fits-all route to successfully generating new referrals. There is a huge variety of factors even across just seven areas: whether the scheme is council or independent; the level of integration between health and social care; the structures and processes used to decide on support packages; the extent of the use of personal budgets and direct payments; all have an impact on generating referrals and all have the potential to enable or be barrier.

Recommendation for Shared Lives schemes: Become part of the process – understand your local commissioning procedures, identify the key mechanisms (e.g. panel, brokerage, preferred provider lists) and focus on ensuring that the scheme fits with the process.

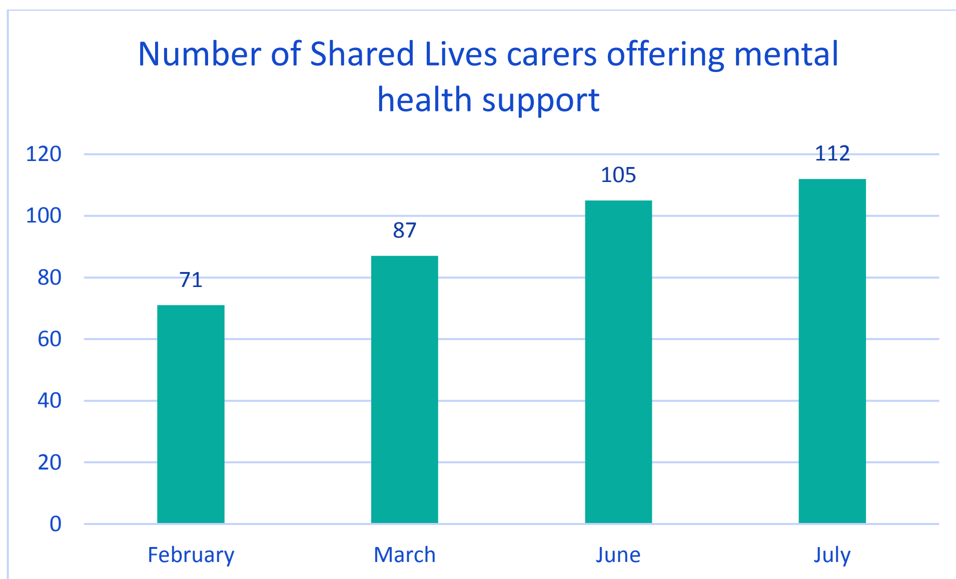
Recommendation for Shared Lives schemes: Identify decision makers – if referrals have to come through a care manager, focus attention on promoting Shared Lives to social workers and mental health teams; in areas of high levels of use of direct payments, focus attention on promoting Shared Lives to individuals and their families.

Recommendation for Shared Lives Plus: Develop guidance or provide support for Shared Lives schemes to better understand commissioning and funding processes.

d) More Shared Lives carers

The target for the project was to increase the number of Shared Lives carers offering mental health support by 31 across the seven project schemes. At the first reporting month for the project (February 2016) the schemes reported 71 Shared Lives carers offering mental health support. This steadily increased to 87 at the end of Quarter 1, 105 at the end of Quarter 2 and 112 carers at the end of Quarter 3. The project has therefore met its target in terms of increasing the numbers of Shared Lives carers offering mental health support.

Figure 3: Number of Shared Lives carers offering mental health support



All schemes reported that the increase came from both existing Shared Lives carers who had been supporting people with other primary support needs, and from new Shared Lives carers recruited specifically to support people with mental ill health. Most of the schemes let their existing Shared Lives carers know about the project, and some targeted those who they knew had a background or some experience of working with people with mental ill health. New Shared Lives carers going through the usual recruitment processes are given the option to say whether they would support people with mental ill health, learning disabilities, people with dementia etc. (depending on what each scheme offered).

The evaluation identified a variety of methods employed by schemes to recruit new Shared Lives carers, including traditional marketing methods such as leaflets and newspaper adverts to reach potential new Shared Lives carers in the local community. One of the schemes specifically targeted a recruitment advert at attracting people to provide support to people with mental ill health but found this attracted very few enquiries relative to the cost of advertising. Some methods were dependent on the location of the team. For example, one scheme was able to place advertisements for Shared Lives in the payslips of care staff employed by the Council, which was thought to provide a useful and cost-effective means of reaching a highly relevant audience. One scheme mentioned that this would be an

effective approach but they do not have access to it since they are located outside of the local authority. Schemes also commented that most new Shared Lives carers come to learn of the scheme through word of mouth. This is perhaps unsurprising given the significance of an endorsement from a well-known and trusted source, who can share detailed insights of their personal experience.

The schemes had attracted a number of new or existing Shared Lives carers with significant past experience of working in mental health. These included someone with experience of working in a psychiatric ward, a mental health nurse, a mental health lecturer and people with related experience such a nursing and foster care. There were mixed views about whether experience of mental ill health, either through past employment or through personal experience was needed to offer support for people with mental ill health.

> *"We don't get people who are just a bit depressed – they won't be eligible. It's more acute, people are likely to have been hospitalised, have a label of schizophrenia, bipolar, early onset dementia – I think carers need to have had some experience of mental ill health to be able to deal with this."* Shared Lives staff

On the other hand, a new Shared Lives carer whose first long term arrangement was someone with depression, anxiety and autism who had no experience with either mental health or learning disabilities felt that the training she received as part of the application and induction process prepared her well, and the placement had gone smoothly.

Another area which attracted mixed views around Shared Lives carer recruitment was the extent to which the stigma surrounding mental health deters carers from supporting people with mental ill health.

> *"I would have said no this isn't an issue until our recent recruitment drive… when we mention mental health people are wary… people's perceptions are definitely a barrier. More people want to support people with learning disabilities"* Shared Lives lead

As part of the fieldwork in one scheme we had the opportunity to meet around 20 existing Shared Lives carers as part of their quarterly meeting, most of whom had been Shared Lives carers for some time with people whose primary support needs were learning disabilities. They were asked about general feelings towards supporting someone with mental ill health. There was a general sense of caution. Some who had grandchildren at their homes said they would be more wary of supporting someone with mental ill heath in their home than someone with learning disabilities. The scheme lead later told us that several of these same Shared Lives carers currently support people who have quite significant mental health problems alongside a learning disability:

"The carers say "we wouldn't touch mental health" – but they're already doing it! Lots of the people with learning disabilities that they support also have mental health issues. They see the person they care for as individuals, they don't see their mental health problems." Shared Lives lead

It seems that while the label might deter Shared Lives carers, faced with an individual with a set of needs, they are more likely to see beyond the diagnosis.

"People are carers because they care, they need to see the individual not the label" Shared Lives scheme lead

Recommendation for Shared Lives schemes: Support Shared Lives carers to see people as individuals rather than the mental health diagnosis they may have - provide them with sufficient information about the individual so they can see past the label to the person.

Recommendation for Shared Lives schemes: Continue to raise awareness about mental health through educating and training Shared Lives carers. Make use of the Shared Lives Plus training pack for Shared Lives carers.

Recommendation for Shared Lives Plus: Promote and distribute the Shared Lives Plus training pack for Shared Lives carers.

e) Well supported Shared Lives carers

The assessment, training and induction of Shared Lives carers follows similar structures in each scheme, including a series of checks, references and visits, training sessions over a number of weeks and approval via an independent panel. All of the Shared Lives carers interviewed spoke positively about the process, understanding the need for the detailed assessment and feeling prepared for the role.

One issue raised by some new Shared Lives carers was the wait between being approved and getting their first 'match'. One person had left her job to become a Shared Lives carer and initially felt frustrated that there wasn't someone ready waiting for her. As one Shared Lives staff member described it:

"It's a bit chicken and egg with recruiting Shared Lives carers with mental health experience – if we have a Shared Lives carer and then can't place someone for a while they get frustrated." Shared Lives staff

This is an almost inevitable challenge for a model which places so much emphasis on getting the match right. This is not unique to mental ill health, and is identified as a challenge for the Shared Lives model in general.

Shared Lives carers were happy with the level of ongoing training and support. They talked of training, some of it optional, some that all Shared Lives carers were expected to attend, including on subjects such as deprivation of liberty safeguards, mental capacity, safeguarding, medication and first aid. The schemes all had regular carers meetings, some had additional get-togethers without Shared Lives staff, and some schemes put on social events for Shared Lives carers to attend with the people they were caring for.

Shared Lives carers usually have an identified support officer or similar who supports them. The Shared Lives carers interviewed spoke highly of the support they received from Shared Lives staff:

> *"The Shared Lives team are absolutely fantastic – if they weren't it would be different. It's a good service and it's well run."* Shared Lives carer

In particular, they spoke of there being support for them when they needed it:

> *"Support from [the scheme] has been brilliant. If my support officer is not there someone else will help."* Shared Lives carer

> *"I'm very happy with the process, and [name of Shared Lives staff] is an absolutely tremendous support for me. If I've got any queries I know that she will follow that up."* Shared Lives carer

> *"[the scheme] are open to any communication from us. If we think there's an issue we just get in contact. If there's something we think needs addressing, if they can deal with it they do, if they need to go higher up the chain then they do."* Shared Lives carer

> *"I think that because the communication is so good with Shared Lives, you don't feel as though you're on your own. I know for a fact that I can ring this office, and there will be someone to help straight away. I don't know of any other service that I could compare it with."* Shared Lives carer

> *"I think they've got it right. I don't need more calls, I know if I need help I can call them".* Shared Lives carer

An area where this could be challenged is if the impact of continued funding pressure means a reduction in size of the Shared Lives staff team. In one scheme, as a direct result of having to reduce the staff team, meetings with Shared Lives carers were reduced from once a month to once every two months and there were some early signs that this was being felt by Shared Lives carers. Although this only came up in one scheme, with the ongoing funding pressures there is the possibility that this could be experienced more widely.

The main issue that the Shared Lives carers identified as problematic was when they did not receive sufficient information about the person placed with them:

"One of my young men is very complex, he can refuse to leave the house even though it was agreed he'd be out of the house every day, his needs are much greater than the social worker told us…. the information from the social worker was lacking so the package I was offered is not what I've got." Shared Lives carer

Similar issues were raised a number of times by Shared Lives carers, though in all cases they recognised it was because the mental health professionals had not shared important information, rather than the Shared Lives staff. It was not clear whether mental health professionals felt Shared Lives carers and staff didn't need to know, or whether there was an element of deliberate withholding in order to secure a placement for their client. The importance of Shared Lives carers receiving full information should not be underestimated – this was the single biggest criticism identified by Shared Lives carers across the schemes.

In terms of the impact that being a Shared Lives carer has on their own lives, overall there was great enthusiasm about their roles.

"It's enhanced my life, they're part of my family, it's an absolute pleasure." Shared Lives carer

Several Shared Lives carers stressed the impact it has on their own wellbeing and happiness. Two Shared Lives carers emphasise how happy the role makes them compared to other jobs they've had:

"I'm happier… At my last job I used to dread going home from holidays. Now I look forward to seeing [people she supports] again." Shared Lives carer

"It's been good for me too. It gives me a balance. I won't work full time for [company name] again… I have fun with these [people she cares for], they know I like a laugh and a joke." Shared Lives carer

Another Shared Lives carer talked of the freedom she feels she has compared to a conventional job being able to have the freedom to do her own thing and pursue hobbies when the people she cares for are out during the day.

Shared Lives carers are paid an allowance but it is not the equivalent of a wage. Interestingly low "pay" was primarily raised as an issue by the staff rather than the Shared Lives carers we spoke to. As one Shared Lives carer highlighted, although the amount she got for providing day support was low, she used to do a similar activity voluntarily. Shared Lives carers tended to stress that it's not about the money:

"People close to us think we must get paid a lot to do this. But we don't, cleaners are paid more. But we don't do it for that." Shared Lives carer

"I do it for the love, not the money" Shared Lives carer

Rather than the money, Shared Lives carers are motivated by the reward they get from seeing improvements in the lives of the people they care for:

> *"When we know them, we know when they are doing well and that is priceless. We look at how he is now, and how he was at the start and that is the main reward for us."* Shared Lives carer

> *"I look and I think, that's the fruit of my hard work, the progress that they make."* Shared Lives carer

> *"What you put in you get out… Me supporting [person's name] and him having a good life is great. It's rewarding."* Shared Lives carer

This enjoyment and reward that Shared Lives carers experience frequently leads them to recommending it to friends and family – an important source of recruitment as highlighted above.

> *"I'm a poster girl for Shared Lives! It's a great job."* Shared Lives carer

Recommendation for Shared Lives schemes: Ensure adequate support is provided to Shared Lives carers – where resources (financial and staffing) are stretched, explore different ways of providing support e.g. conference calls, webinar training/support, online support.

OUTCOME: Individuals with mental ill health have better choice and control over their lives and their support, and improved mental health and wellbeing

The underlying rationale for this project and for aiming to extend Shared Lives for people with mental ill health is that it is a form of support that will deliver better outcomes for the individuals supported. This outcome, therefore is particularly important.

a) Individuals have better choice and control over their lives and their support

Choice and control can be considered in a number of areas; choice and control over the support option, choice and control over elements of the support, and choice and control over activities and day to day living enabled through being in a Shared Lives arrangement.

A number of examples emphasise the choice that individuals had in deciding whether Shared Lives was the right option for the support they needed. One particularly vulnerable man was not able to return to his family home after a spell in hospital and a long-term Shared Lives arrangement was suggested to him as an option. A healthcare professional working at the hospital described the level of care the Shared Lives staff took to ensure he understood the option and that he knew he had a choice. He was visited by a Shared Lives staff member who described Shared Lives and gave him time to think about it to see if felt right for him. He was then visited in hospital by the Shared Lives carer they had identified

for him and again given time to think about it. This was followed by a visit to the Shared Lives carer's house for tea. Although the individual was clearly enthusiastic about both the thought of Shared Lives and the carer he was introduced to, the healthcare professional described how impressed she was at how they made it clear at each stage that it was his decision.

In another case, Shared Lives was being considered for respite for a woman as an alternative to a residential respite which she hadn't liked. The mother of the woman describes how they both met the Shared Lives family to see what her daughter thought of the idea. After meeting the family her daughter was happy about the arrangement.

> *"I just felt it would be alright. I knew that she wouldn't say she wanted to go if she doesn't want to."* Mother of person in Shared Lives arrangement

This choice at the stage of agreeing a placement seems to be well embedded within the Shared Lives model.

Although there was a choice of whether to be in the arrangement or to choose another support option, there was limited evidence of individuals having a choice over the Shared Lives carer or placement. The careful matching process conducted by Shared Lives teams, takes into account the individual needs and preferences of the person, including geographical location, but we only came across one example of individuals being able to choose their carer. One of the schemes highlighted that they would like to do this but it simply wasn't possible with the number of Shared Lives carers they have available – sometimes it can be difficult to find a suitable match, let alone to be able to offer a choice of Shared Lives carers. Although this is something some schemes may aspire to, in reality it is very difficult for schemes to be in the position of having enough Shared Lives carers with vacancies to be able to offer this.

Part of the rationale behind why Shared Lives is seen as a positive alternative to more traditional forms of care and support is that people are living in communities, among families and that this gives them the opportunity to pursue their own interests in a way that they may not have the opportunity to do in more traditional settings. There were many examples of this. One young woman who receives day support started to write some music in response to a bereavement she had experienced. As the Shared Lives carer's son produces music as a hobby, they are working together to make her music into a CD. Another Shared Lives carer works part time in their local pub so has introduced the two men she cares for to the locals in the pub who they now play pool with. Others who enjoy gardening or baking have been matched with Shared Lives carers who like to do similar things. One man in a long term arrangement talked about his bedroom which is full of Star Wars paraphernalia – something he had not been able to do where he previously lived. People have been able to share family holidays with their Shared Lives carers. One Shared Lives

carer who has been supporting two men with mental ill health in long-term arrangements which pre-date this project told us about a trip the three of them had taken to take aid to the refugee camp in Calais. One man told us about how the thing he had wanted most when he came to live in his Shared Lives arrangement was to own a motorcycle. His Shared Lives carer supported him to save up for one, he has now bought it and this has given him the freedom to be more independent and to visit his family and improve relationships with them.

The individual's right to choice and control does not always work perfectly from the point of view of Shared Lives carers – one described how she was looking forward to sharing her hobbies of camping, sailing and walking with the young man she cares for but all he is interested in is watching TV. On one hand, this was his choice and it is important that he is able to make it. On the other hand, this example demonstrates that there needs to be careful balance between choice for the individual and the key principle of Shared Lives that the supported person is fully involved in the life of the Shared Lives carer and their family, which can include providing motivation for the person to pursue activities.

One scheme actively engages advocates to work with individuals when they need to make important decisions including where they may conflict with the interests of Shared Lives carers – for example for one person who felt it was time to move on and wanted to leave the arrangement, and for another person who was unsure whether to continue attending a day centre.

One area where an individual's choice may be constrained is the expectation in some long-term placements that the person is out of the house during week days. One young man who went to college felt unhappy that during the college holidays the Shared Lives scheme had made it clear he was expected to stay out of the house. Although he was extremely positive about his placement and his Shared Lives carer, this aspect made it felt less like it was his home. It is our understanding that this is in the interest of carers as they are not expected to provide care and support for 24 hours a day, but can have the result of restricting people in their choices of what to do during the day.

Recommendation for Shared Lives Schemes: Where possible and appropriate provide people entering into Shared Lives arrangements a choice over their Shared Lives carer.

Recommendation for Shared Lives Schemes: Ensure that Shared Lives carers and staff are aware of all the local options available to people with mental health needs e.g. peer support groups, recovery colleges, drop-in centres etc., as well as other non-mental health activities to ensure people in Shared Lives arrangements have full choice.

Recommendation for Shared Lives Schemes: Encourage the use of independent advocacy to support choice around important decisions.

Recommendations for Shared Lives Plus: Promote the use of independent advocacy to Shared Lives schemes.

Individuals with mental ill health have improved mental health and wellbeing

It was initially envisaged that the My Shared Lives outcome tool would provide the primary source of data to measure this outcome. As the evaluation has progressed it has become clear that it is the qualitative accounts – the observations of Shared Lives carers and mental health practitioners, the stories of people in Shared Lives arrangements, and the case studies provided by schemes - which provide a rich insight into the impact that Shared Lives can have on the lives of people with mental ill health.

In terms of the impact on general wellbeing, Shared Lives carers are in a good position to observe changes in the person they care for and there were consistent observations about the improvements:

> *"He has put on weight, he's wearing new clean clothes, he's in a good routine. He used to just watch TV, now he's out doing something every day"* Shared Lives carer

> *"She is doing well, she is very careful with her money. She controls her finance. She does her own shopping. She eats well. She wasn't eating much before, when she was staying with her family."* Shared Lives carer

> *"He seems more relaxed, looks healthy, has been eating healthier with us and has lost some weight."* Shared Lives carer

Individual stories are the best illustration of the impact that Shared Lives can have on people's mental health and wellbeing. Through the evaluation we heard many examples and stories. The examples selected here show a range of different ways that Shared Lives arrangements have benefited the lives of individuals.

Ryan's case shows how a long-term live-in arrangement provided him with the stable and supportive environment to focus on his college work and prepare him for independent living.

Ryan, 20, has depression, anxiety and Asperger's. Earlier this year his relationship with his family broke down and he found himself in a homeless hostel.

Ryan was told about Shared Lives while he was in the hostel *"There were other options but I was too nervous to do those. I wasn't ready to live on my own, at that time I wanted more support, I had depression, I didn't want to be on my own".*

He liked the idea of Shared Lives and was matched with a couple, Alison and Terry. He visited them for tea, then stayed a night and moved in 3 days later. He was initially

apprehensive as he had moved a lot, and people he'd trusted had turned their back on him, but he very quickly felt he could trust Alison and Terry.

Ryan feels very at home and settled with Alison and Terry. He has meals with them and spends time with their extended family who come round. He thinks of Alison and Terry a bit like adoptive parents and likes the fact that they're there for him, checking he's eating well and taking his medication *"I quite like having someone looking out for me… there's someone there if I need it".*

Ryan goes to college and works part-time. Having the stability of living with Alison and Terry has meant he can focus on these instead of worrying about his situation *"A lot of worries have gone away, I could get back to thinking about college instead of worrying."*

Having lived with Alison and Terry for 6 months he is now starting to think about living independently *"Six months living with a family has prepared me for the real world, I wasn't ready to live on my own six months ago, I'd have ended up in debt, homeless, mental health breakdown. It's a good stepping stone."*

He thinks he will miss Alison and Terry and they'll miss him but he knows they will keep in touch.

Elizabeth's case provides an example of how a planned short break arrangement has prevented a mental health crisis and hospital stay.

Elizabeth, 58, has a mild learning disability and long history of mental ill health with a diagnosis of personality disorder. Elizabeth lives on her own with a substantial support package to help her to live in the community. She has a long history of verbal and physical aggression towards professionals and support workers and had recently physically assaulted the manager of one of the teams who supports her, resulting in that provider withdrawing.

Elizabeth usually goes into crisis a couple of days before the anniversary of the deaths of significant people in her life – her family members and best friend – and is usually hospitalised for up to four weeks at a time. Elizabeth was referred to Shared Lives by her care co-ordinator who felt she would benefit from respite around the time of these difficult anniversaries.

Elizabeth was able to be matched with two carers who knew her from having supported her in residential services when she was younger. The plan was for Elizabeth to go and stay with the carers two days before a significant anniversary to try and avoid a crisis and significant deterioration in her mental health.

Shared Lives collected the relevant information together ensuring care plans, assessments and crisis plans were all in place. After discussions with Elizabeth to ensure she was happy to go ahead with the placement, she had a tea visit and a day visit before her first three-night break before the anniversary of her friend's death. The carers ensured that they spent lots of time with Elizabeth, listened to her advice about when she needed to be on her own and talked with her about her friend when she wanted to. Although it was an intense few days, the visit was very successful from the points of view of all parties. The care co-ordinator said that this was the first time in five years that Elizabeth was not admitted to hospital around the time of this particular anniversary. Elizabeth said she had felt safe at the carers house and that she knew there was someone there who cared about her. The next visit is currently being planned.

Becky's story illustrates how Shared Lives day support is supporting her to maintain independent living and prevent hospitalisation.

Becky, 20, has been diagnosed with unstable personality disorder and Asperger's. She has a history of self-harming and has attempted suicide in the past. She has been supported by the mental health team for some time and has had several admissions to hospital.

Becky moved into her own flat around 14 months ago but has spent very little time living independently due to being readmitted to hospital several times. This put her tenancy at risk. Becky was referred for Shared Lives day support and was introduced to a Shared Lives carer while she was still in hospital with a view to her having support when back at home. Becky was initially hesitant but when she realised the carer had similar interests, such as a love of dogs and being outdoors, she began to engage.

Annie, the Shared Lives carer, has been supporting Becky for two days per week for a few weeks now. The support has encouraged Becky to engage in other support being provided by housing. Becky is a very quiet and shy individual but, due to the Shared Lives Annie's sensitive approach, she has opened up to her and they are developing a supportive relationship.

This has been the longest Becky has lived independently without being readmitted to hospital. She is feeling positive about the future at present and is exploring further education and voluntary work with the support of Annie.

Due to the short timescale of the project the people who have entered arrangements as part of the project have had relatively short periods in Shared Lives arrangements. The case studies below – Jeremy and Tamsin – are examples from some of the schemes who had

supported a number of people with mental ill health before the project. Jeremy’s story shows how Shared Lives support has been able to change from supporting him in a long-term arrangement to supporting him through respite to support him living independently. Tamsin’s case shows how support in long-term arrangement has given her stability and significantly reduced the support she needs from the mental health team.

Jeremy, 48 years old, has been supported by Shared Lives since 2013. He had previously been married, owed his own home and had a full time job. Following the break-up of his marriage he was admitted to hospital under the Mental Health Act and was re-admitted several times over a number of years. Following his last hospital admission, he was discharged to supported accommodation for a fixed period of 2 years. During this time, he experienced fluctuations in his mental health, leading to dependency on alcohol, and did not find the support from the scheme consistent.

As the supported accommodation period came to an end, the mental health team approached Shared Lives to look at the possibility of accommodation and he was placed in a live-in arrangement with Tony. After meeting with two carers and their families, Jeremy decided that he would prefer to live in Tony’s household, feeling that he had more in common with him.

A period of adjustment followed, with initial difficulties throughout the first six months. Tony was already supporting two other people through Shared Lives, and Jeremy found it difficult to form a relationship with one of them and tensions would rise. Over time, the two men have developed a strong friendship.

Jeremy has found that support has been there when he has needed it. He has been able to talk to Tony about his anxieties and has slowly worked on reducing his alcohol intake. Tony has worked alongside Jeremy to alleviate anxieties around going out in the community and has helped him to become more confident. They have also worked on Jeremy’s self-care, slowly developing a routine of regular showering and changing his clothes. The support has also enabled Jeremy to re-build relationships with his parents, who have expressed their pride in the progress that he has made.

Jeremy now has his own tenancy, although he continues to stay with Tony on a respite basis when needed. He is no longer heavily involved with the mental health team. Jeremy has become involved in social events and taken part in new activities that he would previously have avoided due to his anxieties and fear of crowded places. He recently attended a charity fish and chip supper with over 100 people. He has also accompanied Tony on a trip to the jungle in Calais to deliver a caravan and supplies for refugees, which he says he feels honoured to have been involved in.

Tamsin, aged 26, had experienced severe bullying whilst training to be a medic with the Navy. She was subsequently diagnosed with severe depression, OCD and post-traumatic stress. Following her diagnosis, Tamsin was allocated a support worker who arranged a placement in a supported living scheme, where her mental health continued to deteriorate: *"I wasn't well, I was basically put into the house and left. I ended up taking a massive overdose and then ended up being sectioned."*

After being discharged from hospital, social workers introduced Tamsin to Rachel and Colin, who have supported her in a long-term live-in arrangement since 2013. The Shared Lives supervisor who arranged the placement for Tamsin, felt Rachel would have the listening skills to support Tamsin through this period of her life. Thinking back to the start of the placement, Tamsin describes the first weeks as: *"amazing – the family were so welcoming; it was amazing to be part of the family, I settled in really quickly, I didn't feel like I was treading on eggshells, there was no pressure. I felt I could approach the carer and they would be non- judgemental."*

Tamsin describes the ways that Rachel has helped her to manage her OCD in particular: *"I stroke the light switches, its better to laugh about it if I can, I check the doors all the time, Rachel tells me to leave it and she will check it, this really helps, otherwise I would sit by the door all night."* She also describes the overall impact that living in the arrangement has had on her confidence: *"I've got a strength I've never had, I've had lots of encouragement, I've talked for hours with the carers, there is no such word as can't."*

In the time that she has been in the placement, Tamsin has been able to come off her medication, and her mental health has stabilised, even in the absence of support from the mental health team: *"Rachel has been my mental health team...I've not had a dip since I've been here and I've learnt to listen to my body."* Tamsin describes feeling a part of the family, and its ongoing importance for her: *"things like Christmas are amazing we get so many gifts, I never expected it. We all eat dinner together its important as I can chat, considering it's their house it's amazing they are always there for me."* The support has also enabled her to re-establish contact with her mother, who had previously found it difficult to come to terms with her illness.

Since starting the placement, Tamsin has completed a Level 2 NVQ and now works part-time. Reflecting on how she has changed throughout the placement she describes a transformation of her experience: *"At the very start of my journey I didn't want to be in the world - but since coming into this placement it's been great…There is hope no matter how unhopeful you feel. I've never looked back its been brilliant."*

The examples above show how day support, short breaks and long-term arrangements can all work to support an improvement in people's mental health. They have shown how Shared Lives can work as planned crisis prevention, as a step towards independence and to maintain stability. Someone with lived experience of mental ill health who has experienced inpatient stays described how he thinks it has a role in facilitation of hospital discharge:

> *"When I came out of hospital everything seemed too fast. You either make it or you don't and I didn't. Going back to living on your own can be too hard. Shared Lives could be a stepping stone."* Person with lived experience of mental ill health

The evidence from interviews, change stories and tentative indications from the outcome measurement tool data (as discussed in section 6) suggests that Shared Lives can indeed deliver some very positive outcomes for people with mental ill health in terms of the mental health and wellbeing.

An important question is what it is about Shared Lives as an intervention that is key to making this difference. The consistent message, which will come as no surprise to Shared Lives Plus or the Shared Lives schemes, is that it is the opportunity of being part of a family or family home that makes the difference.

> *"It's better than these respite places, its one person, it's still a home, still a house. Mum wouldn't have gone to a respite place, she prefers one to one. Also we get to know [carer] and her family, you wouldn't get that in respite, there would be different staff. She's more of a friend than a carer."* Daughter of woman in short break arrangement

> "*I was welcomed as a family member, their parents come round, I'm mates with their nephew, I take the dog out for a walk. It's more of a home than a lodging".* Person in long-term Shared Lives arrangement

> *"Shared Lives is a family home, individuals get attention, I can see the benefits of that… Shared Lives provides that more personal service, a home, a family, support that's more tailored"* Mental Health team staff

One mental health team Service Manager described how Shared Lives had been able to help in a difficult situation with a young person with schizophrenia and possible learning disabilities. The young person's family had not allowed services in so the mental health team had not been able to support her. She was placed in a Shared Lives arrangement as an emergency situation when her mother's own health broke down. The family started to see the Shared Lives carer as part of the family and as part of their support network:

> *"They would keep nurses and social workers at arm's length and didn't want them involved, but the way they took to the Shared Lives carer almost like she was part of the family and brought her into their circle rather than seeing her as external. They*

now have that as an ongoing support because that respite, with the Shared Lives carer will continue when she is discharged." Mental health team service manager

One final additional aspect to note in this section on wellbeing, though not one of the outcomes initially identified, was the impact that Shared Lives has on the wellbeing of family carers. A 23 year old who cares full-time for her mother who has schizophrenia, had had long periods of being unable to leave her mother alone and was unable to see friends or do anything for herself to the extent that her own mental health was at risk. Eventually after coming close to crisis, support kicked in and her mother now has short breaks with a Shared Lives carer, giving the daughter a much needed break:

"I'm happy we've got the help we need after fighting for so long, it was tiring, I wanted to run away and not come back, I was getting stressed out. Everything is more stable now." Daughter of person getting Shared Lives short breaks

This section has illustrated the very positive impact being in a Shared Lives arrangement can have for some people with mental ill health. It is not an option that will be right for everyone and we heard of a small number of cases which had not worked out, with the individual moving on to other forms of accommodation or support. But it is clear that for some people, at the right point in their mental health recovery, Shared Lives is form of support that can deliver positive outcomes in terms of mental health and wellbeing.

Recommendation for Shared Lives schemes: Support Shared Lives carers to understand the principles of recovery so that they continue to offer flexible support to help keep people well and avoid crisis.

OUTCOME: Shared Lives is part of local mental health promotion and prevention services/support

This outcome reflects the long-term vision that Shared Lives will become part of the landscape of mental health services or provision in the local areas. We have seen in examples described throughout this report that Shared Lives has a potential role to play in all of the ways described in Section 4:

- Planned prevention
- Facilitated discharge from hospital
- Step towards independent living
- Maintenance
- Crisis/emergency

While the project has demonstrated that Shared Lives *can* be part of the landscape of mental health support, and this has started in all of the seven areas, it is not there yet. This is unsurprising in a short project, but caused frustration to some:

> *"It's slow, it's hard to keep the momentum and enthusiasm going. I want it to be part of what is normally considered."* Mental Health Trust staff

There is some way to go in all of the areas, but as the number of people experiencing positive outcomes through being in Shared Lives arrangements increases, as champions of Shared Lives within mental health teams continue to spread the word, and as health and social care processes change to incorporate consideration of Shared Lives as an option as routine, it seems likely that this will start to change.

One concern which was voiced by Shared Lives staff does pose a potential barrier to this growth. Recognising that some people had improved quite considerably and their mental health had stabilised, there was concern about whether they would stop being eligible for funding and lose the Shared Lives support that was so key to their stability. This scenario had not come about in the period of this project but it is a potential issue that is less likely to arise with support for people with a learning disability whose support needs may be more stable over time. This of course is an issue for preventative services in general – despite emphasis on prevention in the Five Year Forward View for Mental Health[8], the difficulty of balancing statutory obligations with prevention work in local authorities is acknowledged[9].

Recommendation for Shared Lives schemes: Change takes time - be prepared for change to happen slowly, and be patient.

Recommendation for Shared Lives Plus: Continue to promote Shared Lives as an option for people with mental ill health beyond the project period at national and regional levels to Shared Lives schemes and in the mental health sector.

OUTCOME: Increased skills, knowledge and contributions of people accessing, experiencing and delivering Shared Lives

This final outcome cuts across all of the other areas and recognises the broader outcomes generated through this project – not only for those who are directly receiving support through Shared Lives but also those delivering Shared Lives as carers, as staff or as volunteers.

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[8] The Mental Health Taskforce (2016), The five year forward view for mental health, London: The Mental Health Taskforce

[9] Local Government Association (2016), Adult social care funding: 2016 state of the nation report, London: Local Government Association

In terms of skills and knowledge there has been an increase in knowledge about mental health both by Shared Lives staff – some of whom have backgrounds or experience in mental health, but many for whom their experience has been primarily in learning disabilities – and Shared Lives carers. Most of the schemes now include sections on mental health in their general Shared Lives carer induction and training processes and schemes are starting to make use of the mental health training pack for carers developed alongside this project. Knowledge about mental health extends beyond the staff and Shared Lives carers however; being supported in families and in the community helps to break down the stigma of mental health. One Shared Lives carer commented how she thinks it's been good for her own sons who also live with her to understand more about the needs of different people. As a mental health professional comments:

> *"It doesn't just benefit the person – there are benefits to the carer, to society, to community."* Service Manager, Mental Health team

> *"In residential people are taken around in herds. In Shared Lives they're living in normal communities – this is helping to address stigma."* Social Worker

In terms of encouraging contributions, project monitoring for the project has recorded a total of 356[10] social action opportunities. Social action is described as "people coming together to help improve their lives and solve problems that are important in their communities". Within this project examples have included re-establishing contact with the church, taking a GCSE, joining a gym, visiting Blackpool illuminations and reconnecting with family.

A total of 45 volunteering opportunities were created as part of this project. This includes people volunteering to support Shared Lives – for example through promotion, events, recruitment of carers and being on Shared Lives panels – as well as people in Shared Lives arrangements volunteering. In one case someone who had spent 18 months in hospital after being sectioned under the Mental Health Act left hospital to live in a long-term Shared Lives arrangement. She started volunteering for a charity shop within a matter of weeks of being in the arrangement.

A particularly positive example of volunteering has been where people with lived experience of mental ill health have participated on Shared Lives panels to recruit new Shared Lives carers.

[10] Note that social action opportunities are counted every month and this is the total until the end of September – as some action are recurring this number reflects the number of times people were involved in social action not necessarily new opportunities

"I love doing the interviews, I really feel a part of it. We did interviews with six people at a time, now who'd have thought [own name] would have done that?... We had a good day that day, it was really nice and I was glad to be a part of it. I've never done anything like that." Person with lived experience of mental ill health in a Shared Lives arrangement

One man, who has not been part of a Shared Lives arrangement himself but was invited to be part of the Shared Lives panel for this project because of his lived experience of mental ill health, describes the very significant impact the opportunity to use his own experiences to benefit others has had on him:

"I have turned a corner. Someone's took a chance on me. I'm not just a mental illness… It's the best thing what's ever happened to me. I treat it like it's my job… What I've felt ashamed of before is now helping me and helping others, my experiences are useful and being used." "I'm loving it, somebody wants my experience, they want to know what I think, I've got something out of the 38 years of having a mental health problem… It's given me more confidence, more friends, I feel more independent."
Person with lived experience volunteering as Shared Lives panel member

Having found that his experience is an asset and that his contributions on the panel are valued has given this man a confidence he has never had before and he is now thinking about applying for jobs, something he has not done for years.

Involvement in this project or actions taken as a result of the project has both increased general awareness of mental ill health and supported people to contribute more widely; the project has a wider impact than the impact it has directly on the lives of those receiving support.

Recommendation for Shared Lives schemes: Look for ways of increasing opportunities for people with lived experience of mental ill health to be involved in Shared Lives.

Recommendation for Shared Lives Plus: Provide some support or guidance around setting up volunteering opportunities for people with lived experience of mental ill health.

6. My Shared Lives Outcomes Measurement Tool

Shared Lives Plus has commissioned the development of a tool to provide a quantitative assessment of the key impacts of Shared Lives support for individuals. Developed by the Personal Social Services Research Unit at the University of Kent, the tool has been designed in consultation with Shared Lives carers, users and schemes. The questions and key outcome areas have been defined in accordance with the impacts of Shared Lives arrangements as reported by users. The tool has been designed to be completed as part of current process, and follows a 'before-after' approach where outcomes are captured at baseline (i.e. at the start of the intervention) and then at later points in time.

It was initially anticipated that one of the key methods for measuring the outcome of improved wellbeing was the data generated through the My Shared Lives outcome tool. For reasons described in this section the data from this in terms of the impact on individuals has been more limited and difficult to interpret than anticipated. In this section we describe the response to the tool, the limitations and reflect on what the data available indicates bearing in mind the limitations described.

Response rates

A total of 28 individuals with mental ill health have been recorded on the My Shared Life dataset, with baseline data recorded for each. The counts from each scheme are shown in figure 4 below.

Figure 4: Counts from the Shared Lives Schemes

Shared Lives Scheme	Respondents with baseline data (n)	Respondents with follow-up data (n)
Bradford	1	1
Derby	2	1
East Sussex	2	1
Lincolnshire	15	10
North Somerset	2	0
Rochdale	3	3
Telford & Wrekin	3	2
Total	28	18

Responses reflect the experiences of people in the 3 different types of Shared Lives arrangements, as shown in figure 5.

Figure 5: Counts from the Types of Shared Lives Schemes

Type of arrangement	Respondents with baseline data (n)	Respondents with follow-up data (n)
Long Term	11	5
Short Break	7	4
Day Support	6	5
Unknown	4	4
Total	28	18

Data limitations

The limitations to the data collected through the tool should be noted. Project monitoring figures indicate that there have been a total of 71 new Shared Lives arrangements as a result of the project, but survey responses have been collated for 28 people, and just over half of these are from a single scheme. Some variation is to be expected, since the numbers of people reached by each scheme will inevitably vary. However, gaps in completion means that the findings will be less reliable and skewed towards the scheme that has returned a higher number. In addition, the tool is designed to measure the change occurring over time for people supported by Shared Lives, with measures repeated on a quarterly basis. In order to accurately reflect the difference that the support makes to people, this approach relies on completion of initial questionnaires at the outset to ensure a 'true' baseline, yet the data indicates that some baseline questionnaires have been completed retrospectively and in some cases more than one year after placements started. Follow-up data is available for 18 individuals, which offers a low base from which to make judgements about the impact of Shared Lives. It is important to note that this is in part due to the relatively short amount of time that has elapsed since the start of the project; individuals who entered Shared Lives arrangements after August 2016 will not yet have been supported for three months (as of end October 2016). As a result of these limitations any findings based on the data collected through the tool should be taken as tentative indications only.

My Shared Lives findings

As part of the My Shared Lives outcome tool people were asked how they feel about different aspects of their lives and their well-being at baseline and the same questions are repeated at follow-up, after support has been ongoing for some months. Each question has 4 response options, ranging from the worst to the best possible scenario, as illustrated in the example below:

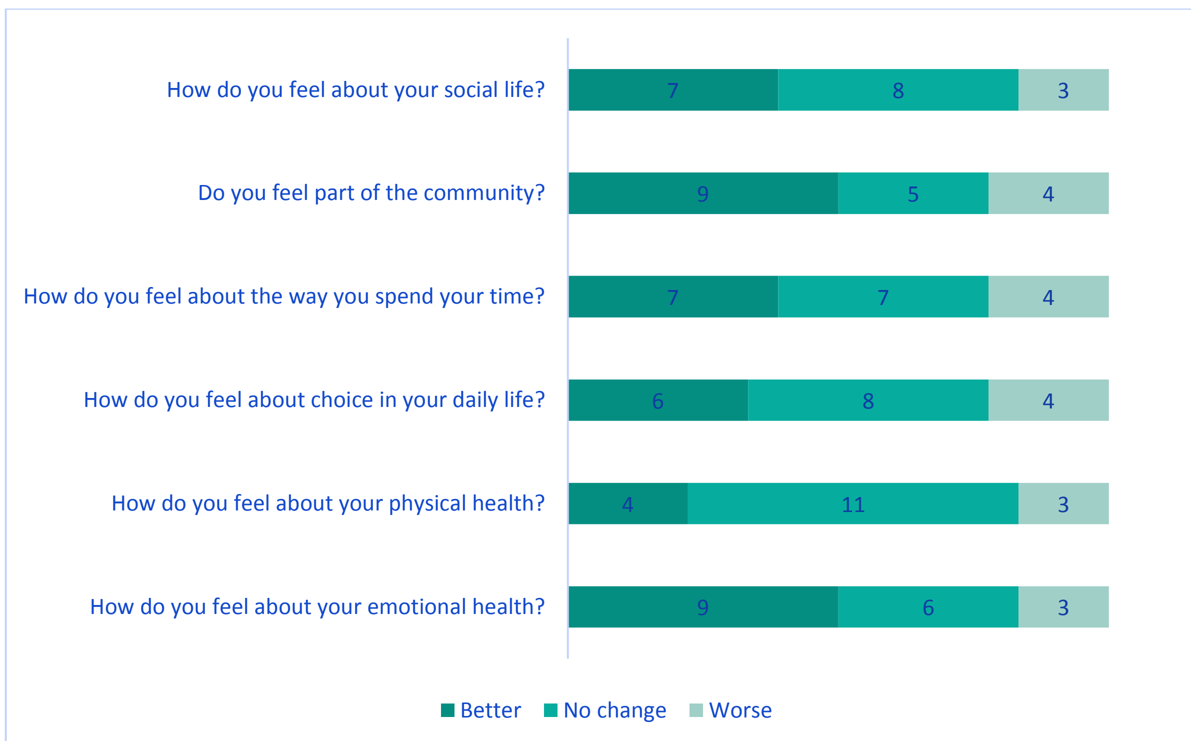
Figure 6: example of question format from My Shared Life tool

How do you feel about choice in your daily life?

I have no choice. It is bad.
I have some choice. But I would like more.
I have enough choice. It's ok.
I have as much choice as I want. It is great.

The graph below shows how many people at follow-up indicated that each aspect has improved, stayed the same, or worsened. This is based on a simple count of the number of people whose response was more positive, less positive, or the same, and does not reflect the extent of that change. The follow-up data presented here draw on responses to the first follow-up questionnaires recorded and are therefore indicative of the initial impacts of Shared Lives support for people with mental ill health. Some individuals who have been supported for longer have completed further questionnaires, but these have not been analysed since they are few in number (n=4). As more are completed, they will be an important indicator of whether (and which) impacts are sustained over the longer-term.

Figure 7 Change in respondent feelings in relation to Shared Lives outcome areas

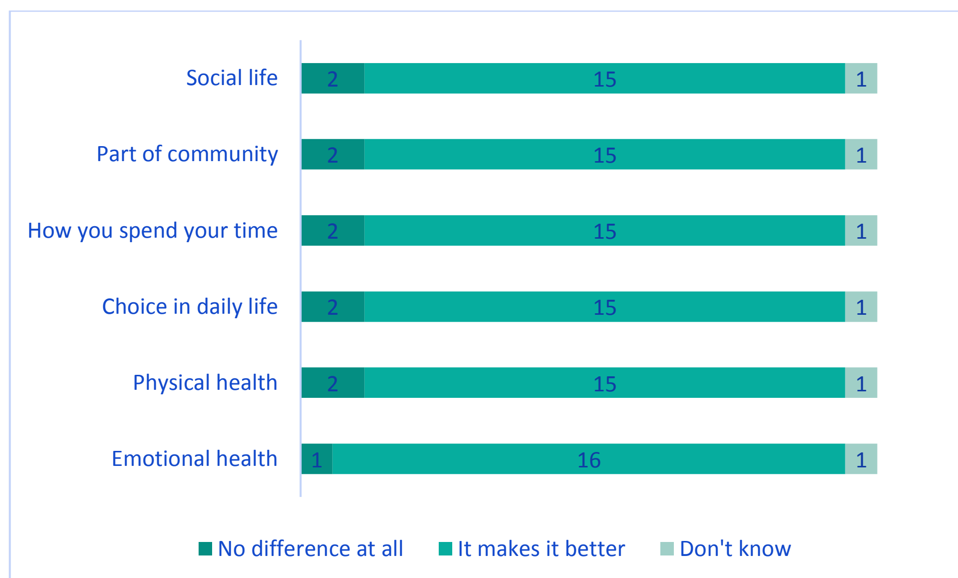


Base: n=18 respondents who completed baseline and follow-up questionnaires

Scope for detailed interpretation of these responses and analysis of the extent of the change is limited due to the low number of responses. Based on these responses, the broad implication is that Shared Lives support can impact positively in all of these areas. In particular, it is interesting to note that 9 out of the 18 reported better emotional wellbeing at follow up. However, it is important to note that within the responses, there were people who gave the most positive response at baseline and have declined somewhat since then. In some responses, Shared Lives staff have detailed events that have affected the person's response on that particular day. It is therefore difficult to judge whether changes in responses captured by the outcome measurement tool genuinely reflect the effects of the support provided, and whether there is any room for improvement, particularly as fluctuation in responses can in part reflect the instability of a person's mental health and their response to their situation at that given time. Furthermore, as one of the Shared Lives leads highlighted when she voiced concerns about how the tool would reflect people with mental ill health – for some people with acute mental ill health, maintaining the same level of emotional wellbeing (i.e. preventing deterioration) can be an extremely positive outcome. Given the limitations to the My Shared Lives data described above, the findings should be taken as an early indication of the impact that Shared Lives can have for people with mental ill health, rather than an assessment of the impact of the project. As further data is captured this will allow a greater degree of confidence in the results.

The outcomes tool also measures to what extent people feel their Shared Lives carer makes a difference to their lives in each of the outcome areas. These responses are shown in the graph below.

Figure 8 Difference that Shared Lives carers make in relation to Shared Lives outcome areas

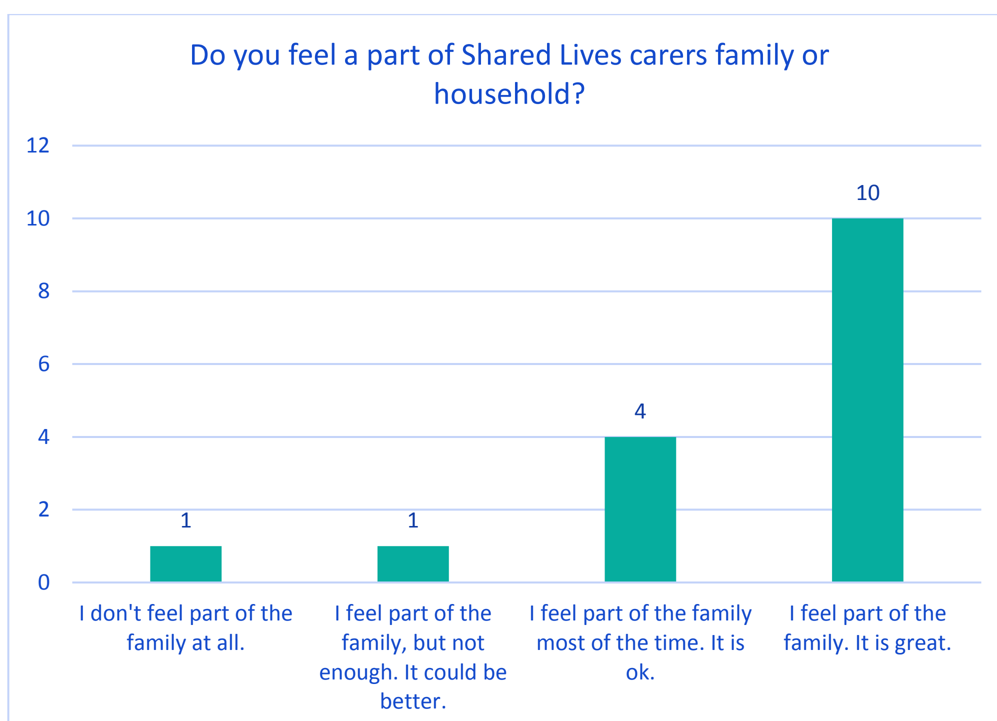


Base: n=18 respondents who completed baseline and follow-up questionnaires

In all six areas almost all respondents reported that Shared Lives carers made things better. Importantly, the responses demonstrate that people report that the support does make a difference even when the response to a particular question is negative – i.e. they may report poor emotional wellbeing *but* the carer makes things better in this area. No individual reported that support from Shared Lives carer makes things worse in relation to any aspect.

At follow-up, the outcomes tool also asks people in Shared Lives arrangements whether they feel a part of the family or household (figure 9). The responses were broadly positive, with 10 people reporting 'I feel part of the family. It is great.' and 4 people reporting 'I feel part of the family most of the time. It is 'ok.' One person said they did not feel part of the family at all, while one other said they felt part of the family, but not enough.

Figure 9: Whether respondents feel part of the family or not



Base: n=16 respondents who completed baseline and follow-up questionnaires (2 respondents did not answer this question)

These findings broadly indicate some positive outcomes, in terms of impact on wellbeing, the difference the Shared Lives carer makes and the extent to which people feel part of the family. However, at this stage, until a greater volume of data is generated, the rich qualitative findings reported above provide us with greater insight in all of these areas.

Recommendation for Shared Lives schemes: Support Shared Lives Plus to produce high quality data about the outcomes of Shared Lives through consistent use of My Shared Lives outcome tool. Having high quality data is crucial for individual schemes, as well as Shared Lives Plus in order to demonstrate impact to local commissioners.

Recommendation for Shared Lives Plus: Support schemes to understand the importance of, and increase use of the My Shared Lives tool to ensure it is a reliable measure of outcomes for people supported though Shared Lives. This evidence of outcomes is crucial to share with commissioners.

Recommendation for Shared Lives Plus: Continue to monitor the data generated by My Shared Lives to assess whether it is suited to people with mental ill health.

7. The costs of Shared Lives

It was not part of the evaluation brief to conduct a cost-effectiveness or cost benefit analysis, but in the current climate of increasing pressure on both health and social care, it is important to acknowledge the importance of support costs when considering Shared Lives as an option for people with mental ill health.

A number of research studies have found that Shared Lives can be lower cost than residential care[11]. However, it should also be noted that a recent attempt to look at the costs of Shared Lives for older people highlighted that the range of costs across schemes, the lack of consistent cost information and the difficulty in collecting cost data make it difficult to estimate true costs[12]. When the subject of costs came up with the schemes it broadly reflected these findings. There were examples of Shared Lives being considerably lower cost than alternative options, for example in one case where a young woman who had been living in specialist residential care moved into a long-term Shared Lives arrangement at a weekly saving of £700. However, in the same scheme it was also highlighted that Shared Lives was higher cost than supported accommodation in the local area. The schemes reported examples of Shared Lives being lower cost, comparable cost and higher cost than other options, but as this wasn't a focus of the evaluation we did not gather enough information to come to any overall conclusions. Importantly, there was recognition from mental health professionals that whether higher or lower cost, it was the better outcomes that it delivers that are important:

> *"It's not only one of the cheaper solutions, it's one of the best solutions"* Community Matron, Mental Health Team

> *"If a service is worth commissioning it's better to go with that – it will prevent spending in the future. We have cheaper respite but its rubbish."* Team Manager, Mental Health Trust

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[11] Dickinson, J. (2011) 'Shared Lives – model for care and support' in Curtis, L. Unit costs of Health & Social care 2011, Canterbury: PSSRU; Roe, D. (2011), Illustrative cost models in learning disabilities social care provision, London: Lang & Buisson; Social Finance (2013), Investing in Shared Lives, London: Social Finance

[12] Brookes, N. and Callaghan, L., (2014), 'Shared Lives - improving understanding of the costs of family-based support' in Curtis, L. Unit costs of Health & Social care 2014, Canterbury: PSSRU

Recommendation for Shared Lives schemes: Consider undertaking a local cost benefit or cost effectiveness analysis to compare the cost of Shared Lives to other options in your local area.

Recommendation for Shared Lives Plus: Consider undertaking a national cost benefit or cost effectiveness analysis for Shared Lives for people with mental ill health.

8. Summary: Developing Shared Lives for people with mental ill health – What works?

We have seen through this report that there is great variation in how Shared Lives has been delivered to support people with mental ill health across schemes, and there are many factors which have both challenged and enabled the development of the support for people with mental ill health. There is variation in: type of arrangement offered by schemes; the scheme itself (whether independent or local authority); health and social care systems; funding mechanisms; and the support needs of individuals. As a result of such variation, there is no one single recommended model of delivery. Instead eight key factors for supporting the development of Shared Lives as a form of support for people with mental ill health have been identified as illustrated in the diagram below:

Figure 10: Developing Shared Lives for people with mental ill health – what works?

1. **Getting a "way-in"** – finding a "way in" to mental health teams in order to promote Shared Lives to potential referring practitioners is crucial. This could be through making the most of existing contacts or links, sustained attempts to secure e.g. invitations to mental health team meetings, or going to the 'top' and making contact with those with more strategic responsibility.

2. **Becoming part of the process** – although this can be a challenge, especially for independent providers, becoming integrated into the process where decisions are made about support packages (whether this is through being part of panel meetings, brokerage or being on a preferred provider list) is key to growth happening at any pace.

3. **Having ambassadors or champions** – having enthusiastic ambassadors or champions *within* mental health teams can be very effective at promoting Shared Lives.

4. **Seizing opportunities, filling gaps** – making the most of local opportunities such as gaps in certain types of provision or drives to move away from traditional forms of support – i.e. fulfilling demand - can lead to growth at a faster rate.

5. **Flexibility** – being flexible about the type of arrangement that can be offered, to whom, and being flexible about the role of Shared Lives (e.g. as planned prevention, facilitated discharge or maintenance) at least at the early stages of development can open schemes up to a greater number of opportunities.

6. **Compatible funding mechanisms** – although this is not always within control of Shared Lives schemes, especially in-house local authority schemes, to maximise opportunities, schemes need to ensure the local funding mechanisms (block contracts, personal budgets etc.) fit with the schemes processes. Ultimately, being able to accept all forms of funding through whatever route or mechanism will maximise opportunities.

7. **Good matching** – a fundamental element of the Shared Lives model for people with all support needs is the importance of good matching between Shared Lives carer the person being supported, and this is no different for people with mental ill health. Good matching leads to positive outcomes and referrals follow good outcomes.

8. **Well supported Shared Lives carers** – the Shared Lives carer is key to making a Shared Lives arrangement work. Good support for Shared Lives carers through recruitment, assessment, induction and ongoing support through placements ensure they can fulfil their roles.

9. Conclusion and recommendations

This evaluation has found evidence of the positive impact that having support through a Shared Lives arrangement – whether it is day support, short breaks or long-term arrangements – can have on the lives of people with mental ill health. We have seen examples of improvements in general wellbeing and increased participation in community life, as well as specific examples where people's mental health has stabilised and hospital stays have been prevented. The impact goes beyond those in Shared Lives arrangements to family members of those being supported, Shared Lives carers and their families and communities that people are supported in. Shared Lives will not be right for everyone, but for the right person, at the right point in their mental health recovery, Shared Lives can offer an individualised, person-centred form of support at the heart of the community. As such, it has the potential to play an important role as one option, among other types of accommodation, short breaks and day support on offer to people with mental ill health.

Although some of the seven project schemes experienced challenges and frustrations and in some cases growth was slow, all saw increases in the number of new arrangements for people with mental ill health and all saw increases in the number of Shared Lives carers offering mental health support. Some useful lessons have been learnt along the way that other Shared Lives schemes looking to develop their support for people with mental ill health can learn from.

To summarise, the recommendations identified in this report are:

For Shared Lives schemes

Recommendation for Shared Lives schemes: Be prepared to be flexible. Offering flexibility in the ways that Shared Lives can be delivered (by arrangement type, referral route and funding accepted) will both maximise the opportunities for Shared Lives as an option and offer more personal individualised support.

Recommendation for Shared Lives schemes: Make the best out of existing links - identify existing links that people within the Shared Lives team have with mental health teams or people in strategic roles and start with these.

Recommendation for Shared Lives schemes: Identify Shared Lives champions - harness the enthusiasm of mental health professionals who have seen the outcomes of Shared Lives and

encourage them to be an ambassador or champion for Shared Lives within their teams and organisations.

Recommendation for Shared Lives schemes: Make use of case studies – when you have a good story, tell it! Stories help people to visualise what Shared Lives can offer better than a description of the model. Think about different ways of sharing stories – for example on your website or through short films.

Recommendation for Shared Lives schemes: Become part of the process – understand your local commissioning procedures, identify the key mechanisms (e.g. panel, brokerage, preferred provider lists) and focus on ensuring that the scheme fits with the process.

Recommendation for Shared Lives schemes: Identify decision makers – if referrals have to come through a care manager, focus attention on promoting Shared Lives to social workers and mental health teams; in areas of high levels of use of direct payments, focus attention on promoting Shared Lives to individuals and their families.

Recommendation for Shared Lives schemes: Support Shared Lives carers to see people as individuals rather than the mental health diagnosis they may have - provide them with sufficient information about the individual so they can see past the label to the person.

Recommendation for Shared Lives schemes: Continue to raise awareness about mental health through educating and training Shared Lives carers. Make use of the Shared Lives Plus training pack for Shared Lives carers.

Recommendation for Shared Lives schemes: Ensure adequate support is provided to carers – where resources (financial and staffing) are stretched, explore different ways of providing support e.g. conference calls, webinar training/support, online support.

Recommendation for Shared Lives schemes: Where possible and appropriate provide people entering into Shared Lives arrangements a choice over their Shared Lives carer.

Recommendation for Shared Lives schemes: Ensure that Shared Lives staff and carers are aware of all the local options available to people with mental health needs e.g. peer support groups, recovery colleges, drop-in centres etc., as well as other non-mental health activities to ensure people in Shared Lives arrangements have full choice.

Recommendation for Shared Lives schemes: Encourage the use of independent advocacy to support choice around important decisions.

Recommendation for Shared Lives schemes: Support Shared Lives carers to understand the principles of recovery so that they continue to offer flexible support to help keep people well and avoid crisis.

Recommendation for Shared Lives schemes: Change takes time - be prepared for change to happen slowly, and be patient.

Recommendation for Shared Lives schemes: Look for ways of increasing opportunities for people with lived experience of mental ill health to be involved in Shared Lives.

Recommendation for Shared Lives schemes: Support Shared Lives Plus to develop high quality methods of capturing the outcomes of Shared Lives. Having high quality data is crucial for individual schemes, as well as Shared Lives Plus in order to demonstrate impact to local commissioners.

Recommendation for Shared Lives schemes: Consider undertaking a local cost benefit or cost effectiveness analysis to compare the cost of Shared Lives to other options in your local area.

For Shared Lives Plus

Recommendation for Shared Lives Plus: Develop guidance or provide support to help Shared Lives schemes understand the structure of mental health services and who to liaise with or target.

Recommendation for Shared Lives Plus: Develop a section of the Shared Lives Plus website dedicated to mental health – tell stories through case studies or short films.

Recommendation for Shared Lives Plus: Develop guidance or provide support for Shared Lives schemes to better understand commissioning and funding processes.

Recommendation for Shared Lives Plus: Promote and distribute the Shared Lives Plus training pack for Shared Lives carers.

Recommendations for Shared Lives Plus: Promote the use of independent advocacy to Shared Lives schemes.

Recommendation for Shared Lives Plus: Continue to promote Shared Lives as an option for people with mental ill health beyond the project period at national and regional levels to Shared Lives schemes and in the mental health sector.

Recommendation for Shared Lives Plus: Provide some support or guidance around setting up volunteering opportunities for people with lived experience of mental ill health.

Recommendation for Shared Lives Plus: Support schemes to understand the importance of, and increase use of the My Shared Lives tool to ensure it is a reliable measure of outcomes for people supported though Shared Lives. This evidence of outcomes is crucial to share with commissioners.

Recommendation for Shared Lives Plus: Continue to monitor the data generated by My Shared Lives to assess whether it is suited to people with mental ill health.

Recommendation for Shared Lives Plus: Consider undertaking a national cost benefit or cost effectiveness analysis for Shared Lives for people with mental ill health.

Appendix- Cabinet Office Shared Lives Plus Mental Health Project - Theory of Change March 2016

The issue: Shared Lives (SL) is not currently well recognised or used as an option for people with mental ill health (MIH)

Context

SL is well established for people with other support needs
Evidence shows SL has positive outcomes and can be lower cost than alternatives
MH policy emphasis on prevention
High pressure on MH services including funding pressure

Assumptions and project rationale

People with MIH should have choice and control over where they live
SL is a positive and financially viable alternative to other housing and support options for people with MIH
Being supported through SL will have a positive impact on wellbeing and MH

Shared Lives Mental Health Project – January to December 2016

Mechanisms/activity

Recruitment and support of more SL carers
Enable existing SL carers to support people with MIH
Promotion of SL for people with MIH
Engaging with the MH sector

Driving/supporting the change

Cabinet Office funding
Support from SL Plus
Peer support and shared learning between schemes

Outcomes

1. Increased capacity within the SL sector to support people with MIH including:
   a. More people with MIH in SLs arrangements
   b. More and well supported carers
2. Individuals with MIH using SL have:
   a. Better choice and control over their lives and their support
   b. Improved MH and wellbeing
3. Increased understanding of SL as a viable option for people with MIH in the MH sector including:
   a. Greater awareness and understanding of SL among people and organisations working with people with MIH
   b. Better partnerships/relationships with people and organisations working with people with MIH
4. SL is part of local MH promotion and prevention services/support
5. Increased skills, knowledge and contributions of people accessing, experiencing and delivering SL

Longer-term impact

SL is seen, used and established as an option for people with MIH
A change in attitude and mindset around support and housing options for people with MIH
Reduced stigma for people with MIH