Shared Lives Plus

Key Messages

• The Shared Lives sector has continued to grow over the past year by 580 people (5%). Since the first national survey in 2012/13 the number of people using Shared Lives has increased by 2780 (30%)

• The number of Shared Lives carers has also increased in the last year by 290 (4%), an increase of 1660 (23%) since the first national survey in 2012/13.

• The number of Shared Lives scheme staff has increased in the past year by 30 (4%), and increased by 110 scheme staff (15%) since 2012/13

• There has been a significant increase in the number of people with a mental health issue accessing Shared Lives within the last year (170 people or 23% increase)

• Live in Shared Lives arrangements increased by 380 people (6%), Shared Lives day support arrangements increased by 260 people (11%), Shared Lives short breaks decreased by 90 people (-3%). Rising eligibility thresholds and councils extending charging appear in at least some areas to account for the drop in people accessing short breaks. We know that these factors are reducing the number of people accessing social care overall.

• Lancashire, Southampton and West Sussex support 10% of their learning disability populations known to adult social care in Shared Lives arrangements. If all areas caught up with this level an additional 4997 people with learning disabilities would be using Shared Lives with savings of around £70,148,000 a year.

• Croydon supports 6.5% of the mental health population known to adult social care in Shared Lives arrangements. If all areas caught up with this, an additional 4754 people with mental ill health would be supported in Shared Lives with savings of around £16,608,000.

• Cheshire West supports 2.6% of older people (over 65years) in Shared Lives. If all areas caught up with this, an additional 14,221 older people would be using Shared Lives.

• If all areas caught up with the best performing around 34,942 people would be supported in Shared Lives arrangements with actual total annual savings of £227,390,000 in addition to cost avoidance with reduced trips to A&E, GPs, hospital admissions and reduced reliance on community health services.

• Shared Lives outperforms other models of regulated care services with 95% rated good or outstanding by CQC and none rated inadequate.

• Shared Lives carer recruitment is a key challenge for schemes that must be supported in order to sustain and grow the number of people using Shared Lives.

• The North West, South West and London all experienced significant growth, whilst the South East, Yorkshire and the East of England all saw a reduction in the number of people using Shared Lives. This has resulted in a slow-down in the overall growth of Shared Lives in England over the past year

• The North West experienced a significant 280 (25%) people using Shared Lives day support

2 Based on average 54% long term arrangements at £26,000 annual savings.

3 Based on average 54% long term arrangements at £8,000 annual savings.
Shared Lives Statistics

In England in 2015/16
- 11880 people were being supported in Shared Lives arrangements
- Over 6350 (53%) people were living in live in Shared Lives arrangements
- Over 3100 (26%) people were enjoying Shared Lives short breaks
- Over 2430 (20%) people were accessing Shared Lives day support

The main primary support needs of people using Shared Lives:
- 8490 (71%) have a learning disability
- 910 (8%) have a mental health issue
- 580 (5%) are on the autism spectrum
- 530 (4%) have a support need associated with older age
- 510 (4%) have a physical impairment

Age groups of people using Shared Lives:
- 40 (<1%) are young adults (aged 16-17)
- 1900 (16%) are young adults in transition (aged 18-24)
- 7960 (67%) are working age adults (aged 25-64)
- 2000* (17%) are older people

In England in 2015/16 there were 8770 Shared Lives carers:
- 6020 (69%) provide live in Shared Lives arrangements
- 2750 (32%) provide short breaks and day support

*Estimates based on data received from 73% of Shared Lives schemes in England
Acknowledgements

This report demonstrates that Shared Lives is already a significant and highly effective part of the social care system.
Introduction

There are an estimated 11,880 people supported in Shared Lives in England and around 13,450 across the UK. They are primarily adults with learning disabilities, mental ill health, autism and dementia, but also come from every type of adult social care client group.

In Shared Lives, a Shared Lives carer shares their home and family life with an adult who needs care or support to help them live well. Local Shared Lives schemes, which are regulated by the Care Quality Commission, individually match trained and approved Shared Lives carers with people who need their support. In Shared Lives, the goal is an ordinary family life, where everyone gets to contribute, have meaningful relationships and are able to be active, valued citizens.

People using Shared Lives are supported by their Shared Lives carer to develop or maintain independent living skills, friendships and live as part of their local community; giving them a sense of wellbeing in a safe and supportive environment. They also enjoy other activities and support during the day to help them live their own independent and fulfilling life. Many people moving into Shared Lives arrangements from more institutional services are able to do things for the first time in their lives – to learn to cook, volunteer, work, make new friends and go on their first holiday.

The Care Quality Commission (CQC) consistently rate Shared Lives as one of the safest and most effective forms of care and support and this continues to remain the case under their new inspection regime. As of 20th December 2016, 86 Shared Lives schemes had published inspections, with 78 (91%) being rated as good, 4 (4.5%) outstanding and 4 (4.5%) being rated in need of improvement. The table below shows how Shared Lives compares to the other adult social care services, based on published inspections by CQC, for the same period.

<table>
<thead>
<tr>
<th>Type of service</th>
<th>Rating</th>
<th>No. inspections per sector</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Outstanding</td>
<td>Good</td>
</tr>
<tr>
<td>Residential</td>
<td>134 (1%)</td>
<td>9,622 (77%)</td>
</tr>
<tr>
<td>Community</td>
<td>2 (1%)</td>
<td>144 (74%)</td>
</tr>
<tr>
<td>Shared Lives</td>
<td>4 (4.5%)</td>
<td>78 (91%)</td>
</tr>
</tbody>
</table>

Our ambition is for more people to benefit from Shared Lives and in this report we aim to set out how this ambition can become reality. A growing evidence base places Shared Lives Plus in a better position than ever before to describe the key success factors to expansion of Shared Lives and how recent growth has met the needs of a greater range of people. Sharing learning and spreading best practice is a priority and this report ends with key learning from the past year and looks at future priorities, expansion potential and outlines how Shared Lives Plus can support local areas and organisations to harness Shared Lives making it a key element of the health and social care landscape.
Methodology for the report

For 2015/16, the State of Shared Lives in England survey provided returns from 101 Shared Lives schemes (75%) which has provided the most accurate picture of Shared Lives to date.

Shared Lives Plus used the returned data from 75% of Shared Lives schemes to create a baseline data set of the national state of Shared Lives in England. We have used this data to provide a detailed estimation of the overall size and diversity of the Shared Lives sector and this information is presented in the tables and graphs throughout the report. Shared Lives Plus has continued to work with schemes to ensure the accuracy of submitted data and to ensure that social care activity that is similar to, but not technically classed as Shared Lives, is recorded separately.

National statistics have been taken from Community Care Statistics, Social Services Activity England 2015-16. In previous reports, similar statistics were taken from the Rap and ASC-car collections which have been replaced by the SALT (Short and Long Term Services) collection. This tracks the number of journeys through the social care system, unlike RAP which was designed to track the number of clients. Another key change to the way data is recorded is that Primary Client Type has been replaced by Primary Support Reason. This means that there cannot not be a direct comparison between the data used in this report and that used in previous State of Shared Lives reports. More details are available at: http://content.digital.nhs.uk/media/20388/Meth-Changes-Community-Care-Statistics-England-2014-15-11032016/pdf/MethChange11032016SALT.pdf

The figures quoted represent the total number of long terms clients receiving services during the period 1st April to 31st March. Long term support is defined as that provided or commissioned by social services or an NHS health partner under Section 75 Agreements and must be part of a care / support plan following an assessment of need. Not included in Long Term Support are aids and adaptations, short term residential (not respite), professional support e.g counselling.

The people who are using Shared Lives

Shared Lives schemes provided data on the primary adult social care client group of people using Shared Lives. Survey responses show that Shared Lives is still primarily a service for people with a learning disability. Over the past year there has been a small decrease in the number of people with learning disabilities accessing Shared Lives, due to Shared Lives schemes focusing on increased diversification of their schemes. The way the state of the sector data has been collected makes it difficult to determine whether these decreases have been occurring in live-in, short break or day support Shared Lives arrangements. From discussions with Shared Lives schemes, Shared Lives Plus understands that decreases are likely to relate to a reduction in the number of people using Shard Lives short breaks.
People from all adult social care client groups are also increasingly accessing Shared Lives. This year’s survey captured data about the number of people on the autism spectrum, people with a dual diagnosis (mental health and a learning disability) and people with HIV/AIDS for the first time.

### Primary adult social care client group

<table>
<thead>
<tr>
<th>Primary adult social care client group</th>
<th>Rounded figures (nearest 10)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning disability</td>
<td>8480</td>
<td>71%</td>
</tr>
<tr>
<td>Mental ill health</td>
<td>910</td>
<td>8%</td>
</tr>
<tr>
<td>Autism/ Asperger’s Syndrome</td>
<td>580</td>
<td>5%</td>
</tr>
<tr>
<td>Support need associated with older age (not including dementia)</td>
<td>540</td>
<td>5%</td>
</tr>
<tr>
<td>Physical impairment</td>
<td>510</td>
<td>4%</td>
</tr>
<tr>
<td>Dementia</td>
<td>330</td>
<td>3%</td>
</tr>
<tr>
<td>Dual diagnosis (mental health and a learning disability)</td>
<td>140</td>
<td>1%</td>
</tr>
<tr>
<td>Sensory impairment/ Deaf</td>
<td>70</td>
<td>1%</td>
</tr>
<tr>
<td>Substance misuse (Drug/ Alcohol)</td>
<td>30</td>
<td>0%</td>
</tr>
<tr>
<td>HIV/ AIDS</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Other</td>
<td>300</td>
<td>3%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>11890</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

71% of people using Shared Lives have a learning disability as a primary social care support.
Case Study – Rose

In April 2016, a lady called Rose began to use Shared Lives services after 20 years of living in a residential placement. Rose has a complex and profound learning disability, she is very limited in verbal communication and in some ways, a very vulnerable young woman. Before she came to Shared Lives she was labelled ‘challenging’ and it was clear she would need several Shared Lives carers.

Rose now lives with her Shared Lives carer, Maxine. She also has four other Shared Lives carers who provide day support and some overnight breaks for Maxine. It was a 6 month process of introductions, which included afternoons spent with Maxine, then a full day and finally, she stayed with Maxine two days a week. Towards the end of the 6 month period Rose had an overnight stay at Maxine’s which went really well, that along with training, countless meetings with all Rose’s Shared Lives carers and her mum. After a few difficulties in their initial meeting, both Maxine and Rose built a positive relationship, and Maxine earned Rose’s trust.

Since joining Shared Lives Rose does regular activities that include horse riding, swimming, going for coffee, socialising with friends and going to church has been big feature in her life. Maxine has included Rose in every aspect of her life, Rose is now able to share her everyday life and activities with Maxine which was unimaginable two years ago. Rose has now been at Maxine’s for one year. There have been ‘incidents’ and challenges, but everyone involved in Rose’s life agrees that this has been a real success. Rose is leading a ‘normal’ life in her community, with people in her life who care and take an active interest in her life, expand, develop and create fresh experience and opportunities. Rose’s social circle has grown significantly and will continue to do so.

need, 8% have mental ill health, 5% have a support need associated with old age and 4% have a physical impairment. Several primary adult social care support need groups experienced a decrease in use this year which included: substance misuse (drug/alcohol), intermediate care, and a support need associated with older age. Despite the reduction in people primarily with a support need associated with older age, the overall number of older people accessing Shared Lives has continued to grow. This is due to older people increasingly having a wider range of primary support needs for accessing Shared Lives, rather than simply being an older person.

The range of people using Shared Lives continues to expand every year. There has been positive growth across several client groups between 2012/13 and 2015/16: Learning disability (860 people or 11%); physical impairment (250 people or 96%), mental ill health (260 people or 40%).
Case Study – Becky

Becky is a twenty year old who uses Shared Lives day support services. She has unstable personality disorder and Asperger’s. Becky moved into her own flat 14 months ago but has found it difficult to live independently due to being admitted to hospital several times. This meant her tenancy was at risk, after being referred to Shared Lives she was introduced to a Shared Lives carer whilst 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 carer 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.

Annual comparison of people using Shared Lives by primary social care support need: main social care groups

<table>
<thead>
<tr>
<th>Year</th>
<th>Mental Health</th>
<th>Autism</th>
<th>A support need associated with old age</th>
<th>Physical Impairment</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012/13</td>
<td>650</td>
<td></td>
<td></td>
<td>260</td>
<td>270</td>
</tr>
<tr>
<td>2013/14</td>
<td>660</td>
<td></td>
<td></td>
<td>730</td>
<td>380</td>
</tr>
<tr>
<td>2014/15</td>
<td>740</td>
<td></td>
<td></td>
<td>710</td>
<td>390</td>
</tr>
<tr>
<td>2015/16</td>
<td>910</td>
<td>580</td>
<td></td>
<td>530</td>
<td>330</td>
</tr>
<tr>
<td>% of people using Shared Lives</td>
<td>8%</td>
<td>5%</td>
<td>4%</td>
<td>4%</td>
<td>3%</td>
</tr>
<tr>
<td>No. Diff between 2012/13 and 2015/16</td>
<td>260</td>
<td>250</td>
<td>60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Diff between 2012/13 and 2015/16</td>
<td>40%</td>
<td>96%</td>
<td>22%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In the table (left) the specific data for ‘Support need associated with old age’ was not collected in the first national survey, but has been in the subsequent national surveys. This means that Shared Lives Plus is unable to provide the number and % change of people with a support need associated with old age, accessing Shared Lives between the first and current national survey. Data on the number of people with autism using Shared Lives was collected for the first time in the 2015/16 survey, so there is no annual comparison available for people from this client group.

Shared Lives is also being used by an emerging number of people who include: people with substance misuse support needs; people with a sensory impairment/ Deaf; HIV/ AIDS; Dual diagnosis (mental health and a learning disability). The use of Shared Lives from these client groups is relatively small at less than 1% per group.

The table below shows the breakdown of Shared Lives arrangement type:

<table>
<thead>
<tr>
<th>Type of Shared Lives arrangement</th>
<th>Estimated number of people</th>
<th>% of each type of Shared Lives arrangement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live-in</td>
<td>6350</td>
<td>54%</td>
</tr>
<tr>
<td>Short break</td>
<td>3100</td>
<td>26%</td>
</tr>
<tr>
<td>Day support</td>
<td>2430</td>
<td>20%</td>
</tr>
<tr>
<td>Total</td>
<td>11880</td>
<td>100%</td>
</tr>
</tbody>
</table>

**Types of Shared Lives arrangements**

There are three different types of Shared Lives arrangement that people access:

- Live-in Shared Lives: where an individual with support needs lives with a Shared Lives carer and their family – (this is sometimes referred to as “long term”).
- Short breaks: an individual stays with their chosen Shared Lives carer on a regular basis, from one night to several weeks.
- Day support: an individual receives support from their Shared Lives carer during the day. The Shared Lives carer’s home is used as a base for community activities.

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**Case study**

James and Andy are in a Shared Lives arrangement. Andy is James’s Shared Lives carer – they have lived together for 7 years. James came to Shared Lives in December 2010, he was diagnosed with epilepsy when he was 6 years old and also has a learning disability, until the age of 40 he was in specialised care. James feels that he did not learn new things before he used Shared Lives services.

In December 2012 epileptic seizures clustered and in the next two months James had 12 hospital admissions for varying lengths of time. All local hospitals and one in North London tried to treat James. Each time more medication was prescribed that had significant impact on James without decreasing the seizures. James was put in an induced coma and spent 3 weeks in Critical Care.

Since being with Shared Lives, James’ life has completely changed for the better. He gives a training session to new carers about epilepsy once a month, has helped lead a workshop on Community Connecting at the Shared Lives Plus conference and is part of a team that supports health checks for Shared Lives schemes. He is in a place he feels safe and comfortable and this helped him get better.

He believes other people would feel the same. The frequency of epileptic seizures has significantly decreased to the extent that he did not have a seizure for 21 months and had what Andy describes as a small ‘blip’ in January 2017 when James had some seizures, which he recovered well from and was back to his normal self soon after.

James health has vastly improved since he has been with Shared Lives and dramatically improved over the last three years.
The number of live-in and day support Shared Lives arrangements has continued to grow in the past year.

- Live in Shared Lives arrangements have increased by 380 people (6%). Compared to 2012/13 there are now an additional 1540 people (32%) living in live-in Shared Lives arrangements.
- Short breaks usage has decreased by -80 people (-3%). Compared to 2012/13 there are now an additional 260 people (9%) using Shared Lives short breaks.
- Day support has increased by 260 people or 11%.
- Compared to 2012/13 there are now an additional 970 people (66%) using Shared Lives for day support.

### Case Study – James & Andy

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People using Shared Lives by age, gender, ethnicity and sexuality

Shared Lives schemes were asked to provide any demographic information that they collect about the age, gender, ethnicity and sexuality of people using their Shared Lives scheme.

Gender of people using Shared Lives

Gender

The people using Shared Lives are a near equal mix of men and women.

Age of people using Shared Lives

Younger people using Shared Lives are 16 or 17 years old and represent the smallest age category of Shared Lives usage (40 people). Younger people using Shared Lives have often grown up in state care including fostering. Some access Shared Lives for a short break. Living in a Shared Lives arrangement can enable the young person to decide whether they wish to live independently and also develop the skills to do so. It can lead to them living in a longer term Shared Lives arrangement, or exploring other forms of supported living. This year saw a decrease in the number of younger people aged 16-17 using Shared Lives. The main reason for this decrease was that Shared Lives schemes were increasingly having to wait until adult social care funding was in place for the individual, to set up a Shared Lives arrangement (usually on the person’s 19th birthday). Over the past year an increasing number of Shared Lives schemes have changed their CQC registration status to enable them to support 16-17 year olds, but unless funding
for 16-17 year olds can be released, the number of people using Shared Lives from this age range will not be able to grow.

For Shared Lives Plus to have a better understanding of the number of people using Shared Lives who are in transition to adult services (defined as people aged 18-24), an additional age category was added to this year’s data collection. The data collected shows there is a significant number of people using Shared Lives in this age group (1890 people or 16% of all people using Shared Lives. The addition of this age group category has meant this report has not included an annual comparison of each age group.

Shared Lives carer, Khalid supports Victor, a man in his 50’s through Shared Lives services. He was living independently until he began having problems with his illness. He was very depressed and began to self-harm. Victor also stopped taking his medication and his flat was in bad condition. It was decided that he should move to a group home where he could be monitored and supported with the idea that he would eventually live independently, once again. Since then he has been involved with Shared Lives. Once Victor became a part of the scheme he was helped to get through his relapse, and his medication was monitored daily. He initially isolated himself from his housemates and others but after a few months he began to be more sociable, and his trust in his Shared Lives carer grew. He had previously enjoyed playing tennis but there were barriers stopping him from using certain facilities due to previous behaviour. However, considerable efforts were made by his Shared Lives carer, Khalid to join a local club. He’s a lot more confident and is proactively trying to be more independent. He’s looking forward to the future and is excited about getting his own place. As well as playing tennis he is also taking driving lessons and having guitar lessons. Challenging himself in these ways will help him to adapt to independence. He definitely appreciates the help he’s received and sees how important Shared Lives has been to his progress.

Working age people (aged 25-64 years) using Shared Lives has continued to be the largest group of people using Shared Lives (7960 people or 67%).

Older people, aged 65+, using Shared Lives are the second largest age group of people using Shared Lives from the four age categories (2000 people or 17%). An additional 350 older people or 21% accessed Shared Lives in the past year, this continues a trend since the State of the Sector surveys have been completed by Shared Lives Plus.

The number of older people using Shared Lives between 2012/13 and 2015/16 has increased by 570 people (40%). Shared Lives is increasingly seen as an effective form of care and support for older people, and as local authorities and NHS trusts continue to explore how the care and support needs of an ageing population can be met, we expect to see continued growth in the number of older people using Shared Lives.

People using Shared Lives are still predominately white (76%), but also include people from a wide range of ethnicities. For just under 17% of people using Shared Lives ethnicity information was either not recorded by Shared Lives schemes or they did not know the ethnicity of people using Shared Lives (12%). The past year has seen an improvement in Shared Lives schemes recording of equalities data compared to last year, and we expect this to continue to improve.
Regional variation

Shared Lives is provided by schemes across nine regions of England which comprise: North East; North West; Yorkshire; East Midlands; West Midlands; South East; South West; London; East of England. This section of the report highlights the key differences amongst the regions by:

- Type of Shared Lives arrangements being accessed: live in, short breaks and day support.
- Age ranges of people using Shared Lives, split into younger people (16-17), Young adults in transition (18-24), working age (25-64), older people (65+).
- Social care need – looking at the regions with the highest and lowest levels of access for specific support needs e.g. learning disability, mental health, or dementia.
- Shared Lives carers by type of Shared Lives arrangement provided.

Ethnicity

Ethnicity of people using Shared Lives

- White/ White English /Irish traveller/ Welsh / Scottish / Northern Irish / British
- Mixed/ multiple ethnicity groups
- Asian/Asian British
- Black / African / Caribbean / Black British
- Other ethnicity groups
- Don’t know / didn’t say
- Don’t collect this information

Regional adult social care population

People using Shared Lives as a proportion of regional adult social care population
Total Shared Lives users by region

There is significant variation across the regions in terms of the number and size of Shared Lives schemes; the number of Shared Lives carers and people using Shared Lives. The table below shows the return rate of surveys for each of the regions:

<table>
<thead>
<tr>
<th>Region</th>
<th>No. responses received</th>
<th>No. Shared Lives schemes in the region</th>
<th>Response rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td>7</td>
<td>8</td>
<td>88%</td>
</tr>
<tr>
<td>North West</td>
<td>19</td>
<td>28</td>
<td>68%</td>
</tr>
<tr>
<td>Yorkshire</td>
<td>14</td>
<td>14</td>
<td>100%</td>
</tr>
<tr>
<td>East Midlands</td>
<td>7</td>
<td>8</td>
<td>88%</td>
</tr>
<tr>
<td>West Midlands</td>
<td>6</td>
<td>11</td>
<td>55%</td>
</tr>
<tr>
<td>South East</td>
<td>15</td>
<td>15</td>
<td>100%</td>
</tr>
<tr>
<td>South West</td>
<td>10</td>
<td>13</td>
<td>77%</td>
</tr>
<tr>
<td>London</td>
<td>15</td>
<td>27</td>
<td>56%</td>
</tr>
<tr>
<td>East of England</td>
<td>8</td>
<td>11</td>
<td>73%</td>
</tr>
</tbody>
</table>

Annual comparison of growth per region

The past year has seen variable growth across each region of England. The North West, the South West and London all experienced significant growth, whilst the South East, Yorkshire and the East of England all saw a reduction in the number of people using Shared Lives.
Regional breakdown of support categories
The use of live-in, short break and day support Shared Lives arrangements varies across the regions. This section of the report analyses those variations and annual trends for each type of Shared Lives arrangement. In the North West, London, South West, East Midlands and the North East schemes have experienced growth in all types of Shared Lives arrangements. Other regions have mixed growth across the three types of Shared Lives arrangements. This is explored in more detail in the sections which follow.

Live in
Live in Shared Lives arrangements are where a person with a support need lives with a Shared Lives carer and their family and receives care and support from them. A key part of any live in Shared Lives arrangement is the person using Shared Lives being an extended part of the Shared Lives carer's family and getting to take part in family life, whilst having their support needs met.

Regional Annual Comparison Live In Shared Lives arrangements

London experienced the biggest growth in live-in Shared Lives arrangements (250 people or 30% increase). The other highest growth rates with live-in Shared Lives arrangements were: South West (180 people or 23%), North West (170 people or 15%) London has the highest regional proportion of live-in Shared Lives arrangements (82% of all Shared Lives arrangements in the region. The other highest regional proportions were: South East (74%); West Midlands (73%); South West (55%).

A couple of regions experienced a decrease in the number of people using Shared Lives for live in arrangements: South East had a reduction of -190 people or -16%; Yorkshire and Humberside - 60 people or -11%; North East -10 people or -2%.
The North West has the highest number of people using Shared Lives for live in support (1250 or 19% of all Shared Lives live-in arrangements), followed by the South East (1020 people or 17%), London (1090 people or 17%) and the South West (990 people or 16%)

Most of the regions have experienced significant growth in the number of live in Shared Lives arrangements between 2012/13 and 2014/15: London has an additional 420 people or 63%; South West has an additional 330 people or 50%; North West has an additional 290 people or 30%; South East has an additional 150 people or 17%; Yorkshire has an additional 200 people or 61%.

Short Breaks

Short break Shared Lives arrangements are where a person stays with a Shared Lives carer from one night to several weeks. Short breaks are usually accessed by people using live in Shared Lives arrangements, to have a break from staying with their main Shared Lives carer. They are also being increasingly used by people who live with a family carer, as an alternative to traditional respite.

The data used for calculating the number of short break Shared Lives arrangements disregards those people who are also accessing live in Shared Lives arrangements, to avoid any double counting and to avoid an inaccurate calculation for the total number of people using Shared Lives.

There is a significant variation in the use and growth of the number of people using Shared Lives short breaks across the nine regions. The two regions which had the highest growth in short breaks were Yorkshire and the North West: Yorkshire increased its short breaks by 60 people (13% increase), Lancashire also increased short breaks by 60 people (11% growth). The East Midlands saw a reduction in the number of people using short breaks (-80 people or -20%) and the South East saw a reduction in short breaks of -70 people (-22%).

The South West has the highest number of people using Shared Lives short breaks (22% of all people...
using Shared Lives short breaks), followed by the North West (20%); Yorkshire (17%); East Midlands (10%); South East (8%).

The East Midlands area has the highest regional proportion of overall people using Shared Lives short breaks (40% of all people using Shared Lives in the region). The other regions with the highest regional proportions were: South West (38%); East Midlands (37%); North East 33%; Yorkshire 33%

The regions which have seen the largest growth since 2012/13 are: South West (230 people); Yorkshire and Humber (150 people); East Midlands (80 people) London (60 people). During this time period several regions experienced a drop in the number of short breaks being accessed: South East (-160 people); East of England (-50 people); North East (-40 people); West Midlands (-40 people)

Despite this mixed picture of Shared Lives short break usage overall there has been an increase of 290 people (10%) in the number of people using Shared Lives short breaks between 2012/13 and 2015/16.

Day support

In Shared Lives day support arrangements a person receives support from their Shared Lives carer during the day. The Shared Lives carer’s home is used as a base for community activities.

Annual regional comparison of Shared Lives day support arrangements

Over the last year the North West had the highest use of Shared Lives day support (1380 people), followed by Yorkshire (370 people); and East Midlands (170 people). The region which had the biggest increase in people using Shared Lives day support was the North West (280 people or 25%). The North East also experienced growth in the number of day support arrangements (70 people)

Several regions experienced a reduction in the amount of Shared Lives day support being provided: East of England -130 people, Yorkshire (-20 people)

Between 2012/13 and 2014/15 there has been a significant 970 people or 66% increase in the number of Shared Lives day support arrangements. The regions with the highest levels of growth during this time are: North West (970 people); East of England (60 people)
Shared Lives carers

Shared Lives carers share their home and family life with adults who need care and support. They are recruited, trained, approved and supported by local Shared Lives schemes to ensure the provision of safe and effective care and support to people with a wide range of needs. By opening their homes and sharing their lives with an individual who they treat as ‘one of the family’ Shared Lives carers provide much more than paid support: people are supported to develop and maintain their independence, build meaningful relationships and play an active part in their local communities. Shared Lives carers will often support the person to look at what they can do, rather than what they can’t. In exchange for the support they provide, Shared Lives carers are paid, receive rent and also receive a contribution towards the running of the household.

Shared Lives carers come from a variety of backgrounds and are passionate and dedicated about the support they provide. Not everyone can be a Shared Lives carer: it takes a special kind of person with the right values, who will open up their home to others and who is able to give the time and encouragement to provide a stable and supportive environment. Being a Shared Lives carer is much more than just a job and is a way of life.

Shared Lives carers by numbers

In England there are an estimated 8770 Shared Lives carers, providing live in, and short break and day support Shared Lives arrangements. A total of 101 Shared Lives schemes provided data about their Shared Lives carers which is categorised by the support they provided as: live in or providing short breaks and day support. For the purposes of the survey Shared Lives carers who provide both live in, short breaks and day support are only recorded once, according to the main type of Shared Lives they provide as detailed below:

- There are 8770 Shared Lives carers, an increase of 310 (4% increase)
- 6020 (69%) are providing live-in Shared Lives arrangements.
- 2750 (31%) are providing short breaks or day support Shared Lives arrangements
- 99% of schemes offer live in support in Shared Lives
- 96% of schemes have Shared Lives carers offering short breaks or day support

Since the State of the sector surveys started there are an additional 1660 Shared Lives carers. This growth in the number of Shared Lives carers has been required to sustain the existing Shared Lives sector and to also enable the ongoing growth of Shared Lives in England. For the past couple of years there has been a decrease in the rate of Shared Lives carer growth, with Shared Lives schemes focusing on maintaining their existing Shared Lives carer numbers. Shared Lives Plus would like to see a national recruitment campaign of Shared Lives carers, backed by the government, to help raise the profile of Shared Lives and to ensure the ongoing sustainability and growth of the Shared Lives sector.

Characteristics of Shared Lives carers

Every year the state of the sector survey asks Shared Lives schemes to provide demographic and equalities data about the age, gender, ethnicity and sexuality of their Shared Lives carers. This section of the report details the responses from schemes.

Age

Shared Lives carers are classified into two age categories: working age (18-64) and older people (65+). The results of the survey demonstrate that the majority of Shared Lives carers are of working age (7020 Shared Lives carers or 79%), whilst 1920 (or 21%) of Shared Lives carers are older people. Shared Lives is increasingly being viewed by retirees as an interesting alternative to retirement, which enables them to continue to use their knowledge, experience and skills to support people using Shared Lives. Shared Lives schemes are increasingly recognising the value of recruiting older Shared Lives carers.

<table>
<thead>
<tr>
<th>Year</th>
<th>No. Shared Lives carers</th>
<th>Annual no. difference</th>
<th>Annual % change</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012/13</td>
<td>7110</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2013/14</td>
<td>7830</td>
<td>720</td>
<td>10%</td>
</tr>
<tr>
<td>2014/15</td>
<td>8480</td>
<td>650</td>
<td>8%</td>
</tr>
<tr>
<td>2015/16</td>
<td>8770</td>
<td>290</td>
<td>3%</td>
</tr>
<tr>
<td>No change 2012/13 - 2015/16</td>
<td>1660</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% change 2012/13 - 2015/16</td>
<td>23%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Since the State of the sector surveys started there are an additional 1660 Shared Lives carers. This growth in the number of Shared Lives carers has been required to sustain the existing Shared Lives sector and to also enable the ongoing growth of Shared Lives in England. For the past couple of years there has been a decrease in the rate of Shared Lives carer growth, with Shared Lives schemes focusing on maintaining their existing Shared Lives carer numbers. Shared Lives Plus would like to see a national recruitment campaign of Shared Lives carers, backed by the government, to help raise the profile of Shared Lives and to ensure the ongoing sustainability and growth of the Shared Lives sector.

Characteristics of Shared Lives carers

Every year the state of the sector survey asks Shared Lives schemes to provide demographic and equalities data about the age, gender, ethnicity and sexuality of their Shared Lives carers. This section of the report details the responses from schemes.

Age

Shared Lives carers are classified into two age categories: working age (18-64) and older people (65+). The results of the survey demonstrate that the majority of Shared Lives carers are of working age (6890 Shared Lives carers or 79%), whilst 1880 (or 21%) of Shared Lives carers are older people. Shared Lives is increasingly being viewed by retirees as an interesting alternative to retirement, which enables them to continue to use their knowledge, experience and skills to support people using Shared Lives. Shared Lives schemes are increasingly recognising the value of recruiting older Shared Lives carers.

<table>
<thead>
<tr>
<th>Age of Shared Lives carer</th>
<th>No. Shared Lives carers</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-64</td>
<td>6890</td>
<td>79%</td>
</tr>
<tr>
<td>65+</td>
<td>1880</td>
<td>21%</td>
</tr>
<tr>
<td>Total</td>
<td>8770</td>
<td>100%</td>
</tr>
</tbody>
</table>

Demographic and equalities characteristics about Shared Lives carers

Gender

1740 are male, 7030 are female and 0 are transgender.

Ethnicity

The way that Shared Lives schemes record ethnicity data varies significantly, so for the purposes of the survey ethnicity was categorised as: White; Black; Mixed ethnicity; Asian; other ethnicity; don’t know; don’t collect this information.

76% of Shared Lives carers are white, 16% of all Shared Lives carers are black, Asian, of mixed ethnicity or from another ethnicity group. 11% of survey data was recorded as don’t know/ don’t collect this information.
Number of Shared Lives carers by type of Shared Lives arrangement provided

Total Shared Lives carers

The graph below show the regional breakdown of Shared Lives carers for each type of Shared Lives arrangement provided. The growth figures in the table below are for changes between 2012/13 and 2015/16.

Annual regional comparison of Shared Lives carers

Most regions have experienced an increase in the overall number of Shared Lives carers, with an overall growth of 290 Shared Lives carers (3%) since 2014/15. Since Shared Lives Plus started gathering national data on the Shared Lives sector the number of Shared Lives carers in England has increased by 1660 Shared Lives carers (23%).

The area of highest percentage growth is London with an additional 280 Shared Lives carers. Other regions with high levels of Shared Lives carer growth included the North West (130 Shared Lives carers); East Midlands (130 Shared Lives carers); South West (70 Shared Lives carers). The South East, Yorkshire and the East of England all experienced a reduction in the number of Shared Lives carers. The reasons for this included the retirement of Shared Lives carers due to old age or ill health.

Overall the figures for the continued growth in the number of Shared Lives carers is positive and will enable Shared Lives schemes to continue to grow and develop.

Live-in Shared Lives carers

Shared Lives carers provide live-in Shared Lives arrangements to adults with a care or support need. Overall, there has been a slight decrease in the number of live-in Shared Lives carers over the past year. Several regions saw significant increases in the number of live-in Shared Lives carers. The regions with the highest increases were: London (260 Shared
Lives carers); North West (150 Shared Lives carers); East Midlands (140 Shared Lives carers); East of England (70 Shared Lives carers). Several regions experienced a decrease in the number of live-in Shared Lives carers: South West (-280 Shared Lives carers); South East (-210 Shared Lives carers); North East (-40 Shared Lives carers).

### Live in Shared Lives carers

<table>
<thead>
<tr>
<th>Region</th>
<th>2012/13</th>
<th>2013/14</th>
<th>2014/15</th>
<th>2015/16</th>
<th>No. change</th>
<th>% change</th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td>190</td>
<td>230</td>
<td>310</td>
<td>270</td>
<td>-40</td>
<td>-13%</td>
</tr>
<tr>
<td>North West</td>
<td>840</td>
<td>930</td>
<td>1110</td>
<td>1260</td>
<td>150</td>
<td>14%</td>
</tr>
<tr>
<td>Yorkshire &amp; Humber</td>
<td>590</td>
<td>610</td>
<td>680</td>
<td>540</td>
<td>140</td>
<td>8%</td>
</tr>
<tr>
<td>East Midlands</td>
<td>330</td>
<td>270</td>
<td>210</td>
<td>350</td>
<td>140</td>
<td>66%</td>
</tr>
<tr>
<td>West Midlands</td>
<td>510</td>
<td>510</td>
<td>550</td>
<td>550</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>South East</td>
<td>1010</td>
<td>1180</td>
<td>1070</td>
<td>860</td>
<td>-210</td>
<td>-20%</td>
</tr>
<tr>
<td>South West</td>
<td>610</td>
<td>680</td>
<td>1080</td>
<td>800</td>
<td>-280</td>
<td>-26%</td>
</tr>
<tr>
<td>London</td>
<td>570</td>
<td>510</td>
<td>620</td>
<td>880</td>
<td>260</td>
<td>41%</td>
</tr>
<tr>
<td>East of England</td>
<td>240</td>
<td>400</td>
<td>430</td>
<td>500</td>
<td>70</td>
<td>16%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>4890</td>
<td>5320</td>
<td>6060</td>
<td>5970</td>
<td>-90</td>
<td>-2%</td>
</tr>
</tbody>
</table>

### Short Breaks Shared Lives

Shared Lives carers providing short breaks have decreased by -40 people or 1% across the regions. The South West (30 Shared Lives carers), the South East (40 Shared Lives carers) and the North East (40 Shared Lives carers). Most of the other regions demonstrated growth, with the exception of the East of England (-130 Shared Lives carers); North West (-20 Shared Lives carers) and the East Midlands (-10 Shared Lives carers)

### Short breaks and day support Shared Lives carers

<table>
<thead>
<tr>
<th>Region</th>
<th>2012/13</th>
<th>2013/14</th>
<th>2014/15</th>
<th>2015/16</th>
<th>No. change</th>
<th>% change</th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td>120</td>
<td>90</td>
<td>90</td>
<td>130</td>
<td>40</td>
<td>44%</td>
</tr>
<tr>
<td>North West</td>
<td>450</td>
<td>770</td>
<td>840</td>
<td>820</td>
<td>-20</td>
<td>-2%</td>
</tr>
<tr>
<td>Yorkshire &amp; Humber</td>
<td>460</td>
<td>460</td>
<td>440</td>
<td>450</td>
<td>10</td>
<td>2%</td>
</tr>
<tr>
<td>East Midlands</td>
<td>240</td>
<td>280</td>
<td>250</td>
<td>240</td>
<td>-10</td>
<td>-4%</td>
</tr>
<tr>
<td>West Midlands</td>
<td>140</td>
<td>340</td>
<td>160</td>
<td>190</td>
<td>30</td>
<td>13%</td>
</tr>
<tr>
<td>South East</td>
<td>310</td>
<td>150</td>
<td>300</td>
<td>340</td>
<td>40</td>
<td>13%</td>
</tr>
<tr>
<td>South West</td>
<td>220</td>
<td>210</td>
<td>280</td>
<td>250</td>
<td>30</td>
<td>-11%</td>
</tr>
<tr>
<td>London</td>
<td>140</td>
<td>80</td>
<td>170</td>
<td>190</td>
<td>20</td>
<td>12%</td>
</tr>
<tr>
<td>East of England</td>
<td>140</td>
<td>130</td>
<td>270</td>
<td>140</td>
<td>-130</td>
<td>-93%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>2220</td>
<td>2510</td>
<td>2800</td>
<td>2760</td>
<td>50</td>
<td>-1%</td>
</tr>
</tbody>
</table>
Shared Lives schemes workforce

Shared Lives schemes are responsible for the recruitment, training, approval and ongoing support of Shared Lives carers. They are also responsible for matching people who wish to use Shared Lives to approved Shared Lives carers, and establishing and monitoring all Shared Lives arrangements they set up. Shared Lives schemes in England are regulated by the Care Quality Commission, who have found that Shared Lives in one of the safest and most effective forms of care and support.

There are 122 Shared Lives schemes in England, operating across nine regions and providing Shared Lives to the majority of local authority areas with a responsibility for adult social care. The map below shows where Shared Lives is available across the country.
Staffing

The staffing of Shared Lives schemes varies significantly from schemes having one worker who also manages the scheme, to large schemes which have scheme managers, Shared Lives workers and admin support.

- The smallest Shared Lives scheme has one worker, who is also the registered manager of the scheme.
- The largest Shared Lives scheme has 38 scheme staff, which operates across several local authorities. This scheme comprises of one registered manager, 19 Shared Lives workers and 18 dedicated admin workers.
- 59% of Shared Lives schemes have a dedicated admin worker. This is a 12% decrease in the number of schemes who have a dedicated admin worker compared to 2014/15). Shared Lives schemes greatly benefit from specialised admin workers who understand how the scheme works and how to ensure that Shared Lives carers receive the correct payment for the care and support they provide, on time. General admin workers within local authorities do not generally have this level of understanding, which can result in Shared Lives workers having to spend an increasing amount of their working day dealing with admin tasks and decreasing the overall efficiency and effectiveness of the Shared Lives scheme.

Shared Lives schemes vary in size from one person managing and delivering the scheme, to large Shared Lives schemes which have several managers, lots of Shared Lives workers and some admin support workers.

The national Shared Lives scheme workforce has increased by 30 scheme staff (4% increase in staffing figures). Since 2012/13 there has been an overall increase of 110 scheme staff or a 15% increase in staffing levels in Shared Lives schemes. This staffing increase has been required to keep up with the overall growth in the number of people using Shared Lives. This staffing growth is positive and required if Shared Lives schemes are to continue to develop, be cost effective and offer high quality Shared Lives.

### Annual comparison of Shared Lives work

<table>
<thead>
<tr>
<th></th>
<th>Shared Lives scheme manager</th>
<th>Shared Lives worker/officer</th>
<th>Dedicated admin</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared Lives manager</td>
<td>150</td>
<td>150</td>
<td>150</td>
<td>140</td>
</tr>
<tr>
<td>Shared Lives worker/officer</td>
<td>460</td>
<td>480</td>
<td>500</td>
<td>540</td>
</tr>
<tr>
<td>Dedicated admin</td>
<td>120</td>
<td>140</td>
<td>140</td>
<td>150</td>
</tr>
<tr>
<td>Total</td>
<td>720</td>
<td>770</td>
<td>800</td>
<td>830</td>
</tr>
<tr>
<td>No. change 2012/13 to 2015/16</td>
<td>-10</td>
<td>80</td>
<td>30</td>
<td>110</td>
</tr>
<tr>
<td>% change 2012/13 to 2015/16</td>
<td>-7%</td>
<td>17%</td>
<td>25%</td>
<td>15%</td>
</tr>
</tbody>
</table>
Demographics and equality characteristics of Shared Lives scheme staffing

Shared Lives schemes provided data about the age, gender, ethnicity and sexuality of their scheme staff. The data provided by schemes on the sexuality of their workers shows that whilst 380 (46%) are heterosexual, 430 (52%) of survey responses were recorded as don’t know.

**Age**

690 (83%) scheme workers are of working age (18-64), whilst 140 (17%) are 65 or over. Shared Lives schemes demonstrate by employing such a high level of over 65’s that they value the knowledge, skills and experience that these workers bring to their roles.

**Gender**

680 women (82%) and 150 men (18%) make up the Shared Lives workforce. Despite Shared Lives schemes predominately employing women as scheme workers, the proportion of men is in line with the rest of adult social care.

**Ethnicity**

The majority of Shared Lives scheme staff are from a ‘white background’ (90%). Whilst schemes have improved their recording of ethnicity data compared to last year for their staff, 3% of Shared Lives schemes are still not recording ethnicity data for their scheme staff.

**Ethnicity of Shared Lives scheme staff**

- White/White English/Irish Traveller/ Welsh
- Scottish/Northern Irish/British
- Mixed/multiple ethnicity groups
- Asian/Asian British
- Black/African/Caribbean/Black British
- Other ethnicity groups
- Don’t know/didn’t say

**Age of Shared Lives scheme staff**

- 690 (18-64)
- 140 (65+)

**Gender of Shared Lives scheme staff**

- Male
- Female
- Transgender
Development and Expansion of Shared Lives –
What works, where expansion is needed and who should be reached?

Shared Lives has grown significantly over the past three years and much has been learnt about what helps schemes to expand and what barriers they face. We believe that Shared Lives has the potential to help many more people live an ordinary family life and experience the health and social benefits that come with a sense of belonging, continuity of care from familiar people and being respected as a valued citizen. To help continue this level of growth we aim to set out what has worked well and how these lessons can be spread more widely, consider what expansion could look like should local areas meet or exceed national benchmarks, and show priority themes Shared Lives Plus will focus on through a range of strategic programmes.

The vast majority of Shared Lives schemes have continued to grow and develop despite the ongoing cuts to adult social care. The graph below shows the Shared Lives schemes which have had the highest (Shared Lives schemes 1-4) and lowest levels of growth (Shared Lives schemes 5-7), since Shared Lives Plus has been conducting the state of Shared Lives survey. So why do some schemes grow strongly and others maintain or decline?

Comparision of highest and lowest growth of Shared Lives schemes

<table>
<thead>
<tr>
<th>Scheme</th>
<th>2013/14</th>
<th>2014/15</th>
<th>2015/16</th>
</tr>
</thead>
<tbody>
<tr>
<td>scheme 1</td>
<td>112</td>
<td>135</td>
<td>167</td>
</tr>
<tr>
<td>scheme 2</td>
<td>155</td>
<td>156</td>
<td>210</td>
</tr>
<tr>
<td>scheme 3</td>
<td>170</td>
<td>242</td>
<td>252</td>
</tr>
<tr>
<td>scheme 4</td>
<td>133</td>
<td>196</td>
<td>209</td>
</tr>
<tr>
<td>scheme 5</td>
<td>22</td>
<td>23</td>
<td>19</td>
</tr>
<tr>
<td>scheme 6</td>
<td>13</td>
<td>19</td>
<td>13</td>
</tr>
<tr>
<td>scheme 7</td>
<td>27</td>
<td>27</td>
<td>22</td>
</tr>
</tbody>
</table>
Successful expansion: key factors and barriers

Independent evaluation\(^4\) of a Cabinet Office funded project to extend Shared Lives into mental health services considered the key factors to successful expansion. It recognised that Shared Lives schemes vary in size, scale and geography, and operate in local contexts with different challenges and priorities, however there are a number of key factors which proved critical to successful expansion. This evidence reflects what Shared Lives Plus’s wider membership says is important to strong and sustainable growth for Shared Lives schemes.

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.

\(^4\) Cabinet Office Evaluation of the Shared Lives Mental Health Project, NDTI, December 2016
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 carers** – the Shared Lives carer is key to making a Shared Lives arrangement work. Good support for carers through recruitment, assessment, induction and ongoing support through placements ensure they can fulfil their roles.

**Barriers to successful expansion**

Where Shared Lives growth is slow or static, there are common themes on barriers faced.

1. **Only for people with low to moderate level learning disability** – despite a large number of Shared Lives schemes diversifying to work with a wider range of people using adult social care services (29% of those using Shared Lives have a primary support need other than learning disability), there remains a perception that Shared Lives is predominantly only for people with low to moderate level learning disability. This perception pigeon-holes Shared Lives schemes and limits potential impact.

2. **Not integral to the adult social care services landscape** – Shared Lives is an option within a wider menu of social care services, however, in areas of limited growth, local schemes report having little involvement in or influence on care pathways, placement panels, or with brokerage teams. Strategic planning, including assessing local need and provision via market position statements, also limits or omits Shared Lives as an option. Where there is little or no senior leadership buy-in or champion to ensure Shared Lives is represented at a strategic level, Shared Lives schemes plateau or decline.

3. **Lack of genuine commitment to personalised community-based lives** - Shared Lives is different to other forms of care, it requires a fundamental belief in and commitment to people being part of a family and thriving as a result. Where schemes operate in this cultural context, they are considered an integral part of achieving local plans on personalisation, where local priorities speak to but do not act on meaningful personalisation, Shared Lives is not utilised as a vehicle for change.

4. **Changes to eligibility criteria for short breaks and day support** – short breaks and day support represent 46% of Shared Lives provision across England. Local schemes report that changes to eligibility criteria resulting in fewer people being provided with these types of support has limited their ability to expand these elements of the Shared Lives scheme.
5. **Emergency response versus planned provision** – as health and social care systems come under greater pressure, responding to immediate presenting need is required in favour of longer-term, more stable arrangements. “Good matching” is fundamental to the success of Shared Lives arrangements however schemes report two key challenges in balancing quality arrangements in ‘emergency’ situations –

- speeding up the matching process can result in placement breakdown and Shared Lives carers losing trust in the scheme
- building Shared Lives carer capacity to meet emergency placements can result in disengagement of Shared Lives carers when referrals are not made

6. **Same old recruitment channels** – ‘word of mouth’ recruitment consistently produces better results than mainstream methods. Where traditional advertising and promotion channels are relied upon, carer recruitment does not keep pace to sustain expansion ambitions.

7. **Invest to yield return** – schemes which have experienced limited expansion report having no staffing capacity with which to grow the service.

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**Where expansion is needed: what expansion could look like against national benchmarks**

Interest in the expansion of Shared Lives is growing. Those leading and commissioning health and social care tell us they want to better understand how they can support the growth of Shared Lives in their local area or region, what level of growth is realistic and where effort and investment is best targeted. Some regions are taking a collaborative approach to development and expansion, seeking economies of scale and more cross-border approaches; whilst others are looking to expand the provider market so the commissioning of Shared Lives can benefit from the expertise and capacity of new providers.

Some NHS health commissioners are already aware of Shared Lives and spot purchase individual arrangements or work closely with some Shared Lives schemes who are already set up to receive referrals from health, though funding for Shared Lives arrangements mostly still comes from social care. There is therefore an opportunity for Shared Lives to respond. Health outcomes for people in Shared Lives are already well documented; over 200 Shared Lives carers responded to a 2015 survey⁶, which asked about how the health of the people they supported had been improved by being part of a Shared Lives household. The survey discovered that 73% had received positive feedback from an NHS colleague about the difference their support was making to an individual’s health.

Shared Lives continues to have significant untapped potential with some areas having no scheme, and a number of regions not utilising Shared Lives to the same extent as others – from the East of England supporting just 0.5% of its adult social care population through Shared Lives to the North West achieving 2.2%.

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⁵ SCIE, Future of Care, Number 1, November 2016

⁶ A Shared Life is a Healthy Life: How the Shared Lives model of care can improve health outcomes and support the NHS.
But the potential is clear - national frontrunners include Lancashire, Southampton and West Sussex who each support 10% of their learning disability populations known to adult social care in Shared Lives arrangements; Croydon out performs other areas by supporting 6.5% of its mental health population in Shared Lives arrangements; and 2.6% of older people (over 65 years) benefit from Shared Lives in Cheshire West. These national benchmarks show what is possible from both a commissioning perspective but also as market development opportunities for value-based providers of health and social care services.

Who should be reached?

There is increasing movement away from Shared Lives operating predominantly for people with learning disabilities (84% in 2013/14 compared to 71% in 2015/16) to reaching other groups using health and adult social care. Shared Lives Plus, along with partners, has led a number of national development programmes supporting schemes to diversify the types of services they provide and widen the range of people who use them, whilst also gathering a strong evidence base of positive outcomes achieved.

Our strategic programmes continue to promote Shared Lives as a model integral to meeting the challenges faced by the health and social care system and which is appropriate for people with a diverse range of needs.

As such, future priorities and growth will focus on:

- Intermediate Care / Re-ablement / Short term Rehabilitation
- Transforming Care (As an alternative to long term stays in Assessment Treatment Units) and for those people placed out of area coming back home
- Short breaks
- Funding through Integrated Budgets (e.g. Integrated Personal Commissioning)
- Social Prescribing (As an option for high intensity users of healthcare)
- People with a forensic history or those who are at risk of offending
- People inappropriately placed or those who are at risk of (e.g. people inappropriately placed in residential care / supported accommodation / in hospital settings due to lack of local options)
- Mental health, complex needs and dual diagnosis (Learning Disabilities and/or autism/mental health and substance abuse/mental health)
- Young people in transition from children’s services to adult’s services
- Dementia
Reaching these priority groups and developing additional areas of practice will be delivered through a number of channels including an NHS England funded programme (£1.75m) in pilot partner areas Barnsley; Bolton; South Tees; Southern Derbyshire and Portsmouth. Two ‘accelerator regions’ are receiving additional support to grow and scale up at pace. This “Scaling up Shared Lives in health” programme is set to run for five years and aspirations are that by 2021, 2000 people will have their health needs met with support from a Shared Lives carer.

A focus on Intermediate Care is supported by Dunhill Medical Trust and Department of Health Innovation, Excellence and Strategic Development Fund. The project aims to help Shared Lives schemes offer an intermediate care service for people leaving hospital or to avoid hospital admission through offering short term Shared Lives arrangements; pilot areas are Sefton, Shropshire, Rotherham, Birmingham, Wolverhampton and Staffordshire (PSS Midlands), Bournemouth, Dorset and Poole (Tricuro), Shared Lives South West and Wigan. These pilot areas will explore the system changes necessary to enable more people to benefit from reablement care in a family setting. Each participating scheme will receive support to develop services and trial new innovative ways of working. Practical outcomes will include developing new assessment tools, creating a new referral pathway, matching process and developing training to support Shared Lives carers in this new area of work. Aspirations are that 40% of Shared Lives schemes in England will be offering intermediate care services within 5 years of the project ending.

Reaching more people experiencing mental ill health will continue to be a focus for Shared Lives Plus. Independent evaluation of a Cabinet Office funded pilot conducted by NDTI found 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 and crisis/emergency response. The people supported through the project had a range of diagnosed mental health conditions including bipolar disorder, schizophrenia, obsessive-compulsive disorder, personality disorder, depression and anxiety, with Shared Lives carers enabling their needs to be met in the community. Pilot areas Bradford, Derby, East Sussex, Lincolnshire, North Somerset, Rochdale and Telford and Wrekin exceeded project targets to support 106 people with mental illness to be supported in family homes and increased Shared Lives carer capacity by an additional 112. We hope learning from the programme will enable greater take up in other areas of the country.

A further strand to our development work will see the creation of more family-based options for young people with additional needs who are leaving care. The two year project is funded by the Department for Education’s Children’s Social Care Innovation Programme, and will support eight schemes explore new approaches to help prepare young people for the transition to adulthood.

Growth in work with older people and people living with dementia has slowed down in the past year, primarily as a reflection of the support being provided to this cohort through adult social care. There has been a £160 million cut in total spend in real terms on older people’s social care in the five years to 2015/16 (Age UK Briefing 2017), meaning fewer older people are being offered support. There is also an increasing culture of older people’s services being provided by block contract, squeezing smaller providers out of the market. To ensure older people don’t miss out on the benefits of Shared Lives, particularly day support and short breaks, our development work will be looking at stronger pathway for those wishing to self-fund.

https://www.ndti.org.uk/resources/publications/evaluation-of-the-shared-lives-mental-health-project
Shared Lives Plus – our offer to support expansion

Shared Lives Plus has developed a range of support to help organisations explore expansion of Shared Lives and turn theory in to reality on the ground. We work alongside those leading or commissioning Shared Lives, providing step by step support to start, review, grow or diversify services on a local or regional basis. Our expertise combined with coproduction enables us to advise on all aspects of development including levels of local provision versus national benchmarks and expansion options modelling rooted in national best practice. We undertake full activity reviews of Shared Lives scheme’s practices, productivity and use of resources and underpin this with cost-benefit analysis which gives an accurate picture of unit costs and any savings to be achieved by using Shared Lives in place of other approaches.

We draw on our links with government, regulators, academics and independent research organisations to bring together the most up to date policy and thinking to each project we deliver, and our partnership with Social Finance provides social investment opportunities to stimulate growth.

Market development is key to Shared Lives Plus’s expansion support offer. Our consultancy work assists commissioners in key aspects of procurement activity including coproduction, advice on service design and specification, quality assurance and contract monitoring. We also facilitate provider engagement activity and can offer support programmes to organisations interested in providing Shared Lives as an addition to their regulated care portfolio.

Shared Lives – the next 12 months

As Surrey County Council draws back from a referendum on increasing Council Tax for local residents to fund the shortfall in adult social care budgets, and the BBC reports one patient waiting 449 days before suitable discharge from hospital, there is no doubt that the acute challenges being experienced by social care and health are not diminishing.

In an overly-complex system where solutions seem to be escaping even the most passionate of people, it feels right to turn to something simple, to turn to family, relationships and to love. Shared Lives offers those basics of humanity that a system has somehow lost sight of. It challenges prevailing assumptions about what good quality care and support looks like and where the best place is for it to be provided. Social Care Institute for Excellence’s (SCIE) “Future of Care” shows how local areas can move away from types of care that can provide poor outcomes and value for money to models which provide opportunities for people to care for one another in meaningful, safe, supportive arrangements, arrangements which continue to outperform other models of regulated care services and which are more cost effective for the taxpayer.

Our ambition to develop a more integrated approach between social care and health is being realised through the announcement of five pilot areas which will receive part of a £1.75m grant from NHS England to scale up Shared Lives in health and foster new routes for people back in to real homes and family life. This is the first large-scale programme of its type bringing together, Clinical Commissioning Groups, local Shared Lives schemes and other partners which will
focus on building community capacity to manage chronic and long-term conditions in family environments.

We will continue to build a strong evidence base of the positive outcomes experienced by people involved in Shared Lives – that the reciprocal nature of the model brings benefits to all involved. Our work with independent research organisations and through our own evaluation tool “My Shared Life” strengthens our belief that Shared Lives is an effective, personalised approach, and this developing evidence base can offer confidence to those commissioning for better outcomes.

At the heart of Shared Lives is a silent army of Shared Lives carers who quietly provide stable, supportive and consistent family life and go beyond that which is detailed in any commissioning specification. We are committed to raising awareness of what Shared Lives carers do and encourage more people to think about sharing their life and home with someone who needs support.

This report illustrates that ambitious expansion of Shared Lives is possible when key success factors are in place. 2017 will see our strategic programmes, development and consultancy work create these conditions in more areas of England.