

South West England Invaluable Report

Survey data from Shared Lives carers and Shared Lives schemes

2023





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Executive summary

Please note that the data in this report was collected in November 2022.

Fee rates are subject to change in the intervening period.

KEY DATA	There were 10 Shared Lives schemes in the South West in November 2022.
	According to data provided by Shared Lives schemes, care was commissioned by 8 commissioning organisations.
	Shared Lives schemes provided information about 9 different commissioning organisation fee rates.
BANDINGS AND NON-BANDINGS	All 9 commissioning organisation fee rates in the South West are banded.
LOWEST FEE RATES	The <u>smallest</u> lowest live-in fee rate was £65 .
(LIVE-IN ARRANGEMENTS)	The greatest lowest live-in fee rate was £425.00.
	5 out of the 9 (56%) commissioning organisation fee rates in
	the South West were above the regional and English
	banded rates for Shared Lives.
HIGHEST FEE RATES	The <u>smallest</u> highest live-in fee rate was £350.00.
(LIVE-IN ARRANGEMENTS)	The greatest highest live-in fee rate was £765.00.
	6 out of the 9 (67%) commissioning organisation fee rates in
	the South West were above average in comparison to all

	other measures for highest fee rates for live-in arrangements.
BOARD AND LODGINGS	6 out of 9 (67%) commissioning fee rates were below the English national average board and lodgings contributions.
FEE INCREASES	⇒ 6 (67%) of commissioning fee rates were uplifted after April 2022:
	\Rightarrow 3 (33%) were uplifted in the last 1 to 2 years.
CARER SURVEY STATISTICS	Of the 62 Shared Lives carers in the South West who responded to the survey:
	⇒ 73% stated that they were affected by cost of living.
	⇒ 32% have considered leaving Shared Lives due to the cost of living.
	⇒ 24%, said they felt not very or not at all valued, more than the national average of 27%
	⇒ 42% of carers in the South West stated that they felt highly valued, which is less than the national average of 47%
	⇒ Overall, South West carers reported better physical and mental health when compared to carers nationally.
RECOMMENDATIONS	 All commissioning organisations increase the board and lodgings contributions to at or above the regional board and lodgings average of £63.71.
	 Commissioning organisations ensure that they provide a lowest live-in fee rate at or above lowest non-banded fee rate for England: £401.76.

3. Commissioning organisations ensure that they provide a **highest live-in fee rate** at or above the highest banding rate for region: £582.09.

Introduction

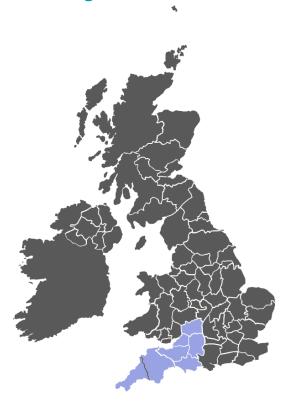
"[We love] sharing our lives and our home with a wonderful young person who came to us a child and had grown into a wonderful and caring adult."

"I can earn more money by not doing Shared Lives, but I have cared for my [supported person] for many years now and I cannot put money before them."

Shared Lives carers, South West England

Shared Lives carers in the South West do amazing work by enriching the lives of the individuals they support, as well as the communities they live in. At Shared Lives Plus, we believe that the dedication of Shared Lives carers should be recognised and reflected in their earnings.

Shared Lives Plus has supported Shared Lives carers and Shared Lives schemes for more than 40 years. During this time, our organisation has primarily been involved in the good management of shared lives schemes, safe delivery of shared lives care, and fair treatment of Shared lives carers.



Although we know it is cost effective, we know that many of our Shared Lives carers are struggling. We also know that the fees and board lodgings contributions provided by commissioning organisations to Shared Lives arrangement are not consistent. The data collected in the Invaluable surveys represents a step change in our understanding of care fees and board and lodgings contributions. It also centres Shared Lives carer voices, reflecting their feelings about fees, the cost of living, and their health and wellbeing.

In this report, you will find specific information about the highest and lowest average care and support fees, and average board and lodgings payments for commissioning organisations in the South West. Please note, for this survey we limited our scope to asking about <u>live-in</u> support, since that is the predominant way in which people are supported. You will also find recommendations for commissioning organisations improving these fees and contributions. We are planning to undertake more collection and analysis of respite and rent data, which is why you will not find that information in this report.

How to use this report

This report has been primarily written for Shared Lives carers and Shared Lives schemes, using the data they provided in the carer and scheme Invaluable surveys. This report may also be of use to others, including commissioners and directors of adult social care.

A note about fees and bandings

Shared Lives is not a homogenous model. The data anomalies in this report reflect the differences between schemes who have evolved over time, and who also cater to the needs of individual supported people.

Shared Lives live-in arrangement fees should consist of three main elements:

- A care and support fee,
- A board and lodgings contribution,
- A rent contribution (not included in this report).

The **care and support fees** reflect the care required of the Shared Lives carer, as specified in a person's support plan.

Some commissioning organisations operate a system of bandings, which sets the rates for care and support fees.

There is no set number of bandings, and this can vary between areas. Some areas also provide an additional or extra fee on top of the banding fees. This can be at the discretion of commissioners and is based on the exceptional needs of an individual.

Several commissioning organisations do not work a banding system <u>or</u> have arrangements which are not within their banding system.

The board and lodgings contributions are not generally banded. In some cases, Shared Lives carers may receive a higher or lower board and lodgings contribution at the discretion of the commissioning organisation. For example:

- where a person has increased electricity usage through double incontinence,
 they may receive a higher contribution.
- Conversely, where a person is under the age of 25 and in receipt of lower benefits, their board and lodgings contributions may need to be lowered to make it affordable.

Lowest and highest fees

To compare data efficiently, this report compares only the highest and lowest live-in care fees reported in the scheme survey. It compares both banded and non-banded data, for a clearer overall picture of fees in this region. See 'Explainer: comparative averages' for more detail on the fee rates averages and benchmarks used in the data tables.

Data report codes

Each commissioning organisation (such as a local authority/council) has been assigned a data report code, e.g., COSW001.

This allows commissioning organisations to remain anonymous, whilst enabling a regional and national comparison of fees.

Shared Lives schemes will be provided with the data reporting code for the relevant commissioning organisations. If you are a Shared Lives scheme or commissioning organisation who does not have the code but would like one, you can contact us: membership@sharedlivesplus.org.uk

Explainer: comparative averages

Shared Lives banded rates for live-in fees

These are the average of commissioning organisation care fee rates which are part of a banding system. Banding systems provide set rates for care fees, based on the needs of the supported person. There are two Shared Lives banded rates in the data table, one for the region, and on for England.

Shared Lives non-banded rates for live-in fees

These are the average of commissioning organisation care fee rates which are not part of a banding system. There are many Shared Lives schemes across England who either do not operate a banding system of set rates, or who have non-banded exceptional rates, (for example where a new Shared Lives scheme has taken over an historic arrangement). There are two Shared Lives non-banded rates in the data table, one for the region, and on for England.

Regional care fee benchmarks

The regional benchmarks are taken from the *Skills for Care's Adult Social Care Workforce Data Set.*¹ These figures cover the period 2021-2022 and are full time equivalents (FTE) based on 37 or more contracted hours a week.

The **average local authority care worker salary** in the South West was £21,400 per annum or £357.20 per week.

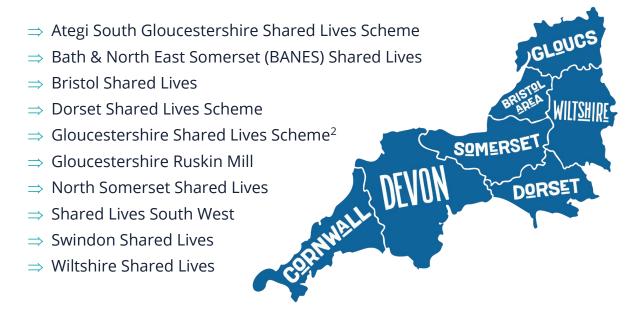
The **average local authority senior care worker salary** in the South West was £25,400 per annum or £409.51 per week.

¹ See: https://www.data.gov.uk/dataset/9cd42409-1a44-4e6c-9696-29d6a760e746/adult-social-care-workforce-data-set-asc-wds

Scheme and carer response rates

Shared Lives schemes

In November 2022, there were **10** Shared Lives schemes covering the South Western counties of Bristol, Cornwall, Dorset, Devon, Gloucestershire, Somerset, and Wiltshire:



7 out of **10** (**70%**) of schemes in the South West provided some data to the Invaluable survey. **No Data was provided by Gloucestershire Ruskin Mil, Swindon, or Wiltshire Shared Lives**.

Shared Lives carers

In November 2022, there were **772** Shared Lives Plus carer members in the South West. Of these, **62** Shared Lives carers responded to the carer survey. **This equated to 8% of the Shared Lives Plus carer members in the South West.**

² Since this data was collected, Gloucestershire Shared Lives has provided contrasting data for lowest and highest live in fees, and board and lodgings contributions. It was not possible to amend these figures in these set of reports.

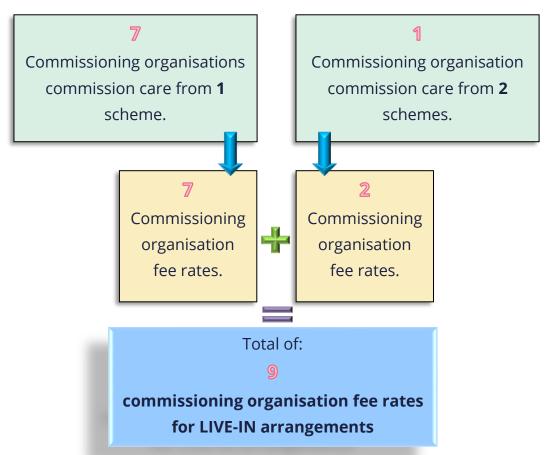
About the commissioning organisations

There were **8** commissioning organisations in the South West according to data provided by **7** Shared Lives schemes in November 2022. These are:

- ⇒ Bath and North East Somerset Council
- ⇒ Bristol City Council
- ⇒ Devon County Council
- ⇒ Dorset Council
- ⇒ Gloucestershire County Council

- ⇒ North Somerset Council
- ⇒ South Gloucestershire Council
- ⇒ Wiltshire Council (commissions care from 2 schemes)

Data reference codes for commissioning organisations

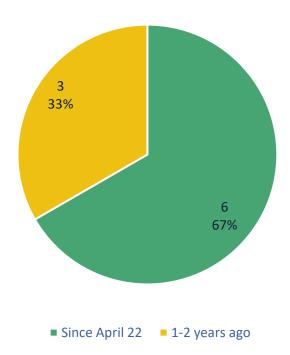


All **9** commissioning organisation fee rates in the South West are banded.

Fee uplifts

Of the **9** commissioning organisation fee rates in the South West:

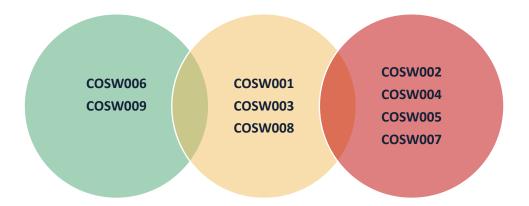
- ⇒ 6 (67%) of commissioning fee rates were uplifted after April 2022:
 - o COSW001
 - o COSW002
 - o COSW003
 - o COSW006
 - o COSW007
 - o COSW009
- ⇒ 3 (33%) of commissioning fee rates were uplifted in the last 1 to 2 years.
 - o COSW004
 - o COSW005
 - o COSW008



Lowest average fee rates for live-in arrangements

Please note that these figures were accurate as of November 2022.

	COSW001	COSW002	COSW003	COSW004	COSW005	COSW006	COSW007	COSW008	COSW009
Lowest Banding Rate	£357.00	£252.00	£327.33	£231.00	£65.00	£418.81	£301.95	£357.00	£425.00
x Lowest Banding Rate (region)					£303.90				
Difference	£53.10	-£51.90	£23.43	-£72.90	-£238.90	£114.91	-£1.95	£53.10	£121.10
x Lowest Banding Rate (England)					£324.57				
Difference	£32.43	-£72.57	£2.76	-£93.57	-£259.57	£94.24	-£22.62	£32.43	£100.43
x Lowest Non-banded Fee (Eng)					£401.48				
Difference	-£44.48	-£149.48	-£74.15	-£170.48	-£336.48	£17.33	-£99.53	-£44.48	£23.52
Average Care Worker					£357.20				
Difference	-£0.20	-£105.20	-£29.87	-£126.20	-£292.20	£61.61	-£55.25	-£0.20	£67.80



2 commissioning organisation fee rates were <u>above average</u> in all 4 regional and national categories for lowest fees.

3 commissioning organisations fee rates were <u>below average</u> in 2 categories, and above in 2.

4 commissioning organisations fee rates were below average in all 4 categories.

This means that **5** out of the **9 (56%)** commissioning organisation fee rates in the South West were **above the regional and English banded rates for Shared Lives.**



COSW009 provided the greatest (lowest) fee of £425.00

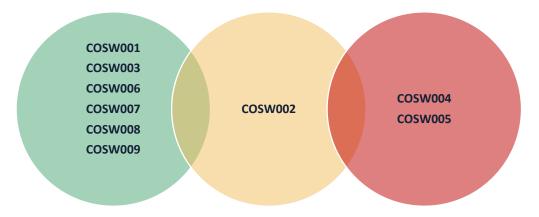


COSW005 provided the *smallest (lowest)* fees of **£65.00**

Highest average fee rates for live-in arrangements

Please note that these figures were accurate as of November 2022.

	COSW001	COSW002	COSW003	COSW004	COSW005	COSW006	COSW007	COSW008	COSW009	
Highest Banding Fee	£765.00	£500.00	£597.00	£378.00	£350.00	£692.65	£606.13	£765.00	£585.00	
x Highest Banding Rate (region)	£582.09									
Difference	£182.91	-£82.09	£14.91	-£204.09	-£232.09	£110.56	£24.04	£182.91	£2.91	
x Highest Banding Rate (England)					£495.12					
Difference	£269.88	£4.88	£101.88	-£117.12	-£145.12	£197.53	£111.01	£269.88	£89.88	
x Highest No-Banded Fee (England)					£431.76					
Difference	£333.24	£68.24	£165.24	-£53.76	-£81.76	£260.89	£174.37	£333.24	£153.24	
Average Senior Care Worker (region)					£409.51					
Difference	£355.49	£90.49	£187.49	-£31.51	-£59.51	£283.14	£196.62	£355.49	£175.49	



6 commissioning organisation fee rates were <u>above average</u> in all 5 average categories for highest fee rates.

1 commissioning organisation fee rates were above average in all but 1 category.

2 commissioning organisations fee rates were <u>below average</u> in all 5 categories.

This means that **6** out of the **9** (**67%**) commissioning organisation fee rates in the South West **were above** average in comparison to all other measures for highest fee rates for live-in arrangements.



COSW001 and **COSW008** provided the joint greatest (highest) fee of £765.00.

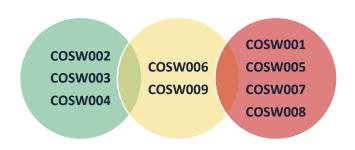


COSW005 provided the *smallest (highest) fees* of **£350.00**.

Board and lodgings contributions

Please note that these figures were accurate as of November 2022.

	COSW001	COSW002	COSW003	COSW004	COSW005	COSW006	COSW007	COSW008	COSW009
Board & Lodgings	£56.00	£76.40	£82.00	£70.00	£47.00	£63.00	£60.00	£56.00	£63.00
x Board & Lodgings (region)					£63.71				
Difference	-£7.71	£12.69	£18.29	£6.29	-£16.71	-£0.71	-£3.71	-£7.71	-£0.71
x Board & Lodgings (England					£62.91				
Difference	-£6.91	£13.49	£19.09	£7.09	-£15.91	£0.09	-£2.91	-£6.91	£0.09



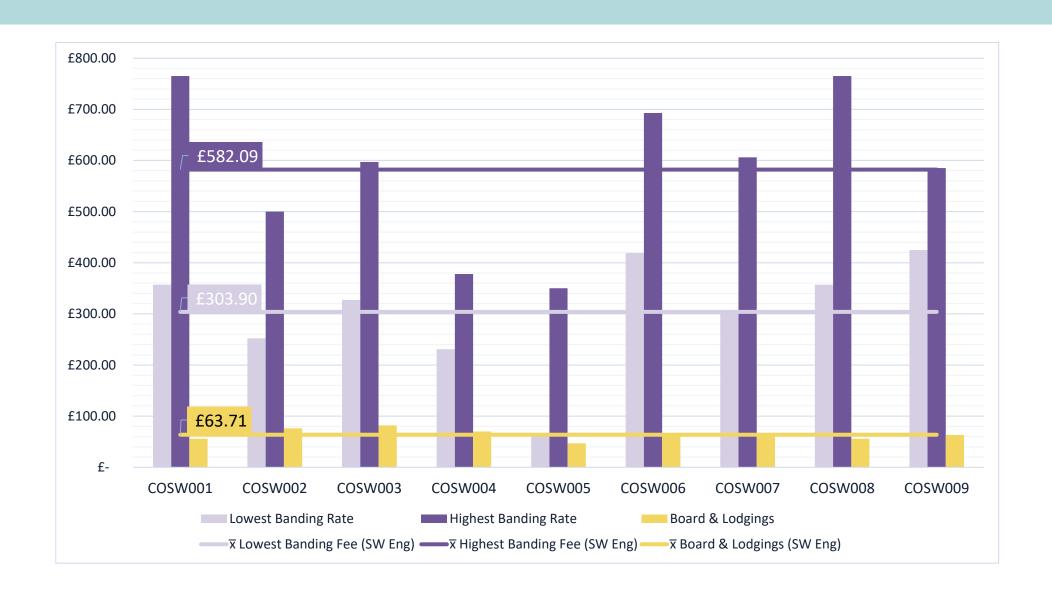
3 commissioning organisation fee rates were above national and regional averages for board and lodgings.

2 commissioning organisation fee rates were below the regional average.

4 commissioning organisation fee rates were below both national and regional averages.

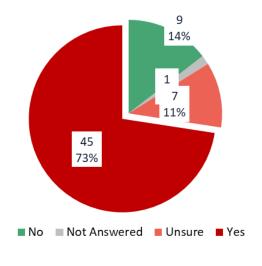
6 out of 9 (67%) commissioning fee rates were below the English national average board and lodgings contributions.

Regional live-in fees and contributions graph



Shared Lives carer survey data

Impact of the cost of living



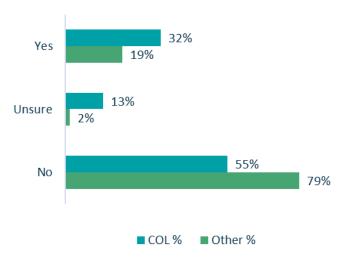
Have you been significantly impacted by cost of living (COL)?

73% of carers who responded to the survey stated that they were affected by cost of living, **just better than the national average** of **77%**:

"The cost of living has risen massively. My two [supported people] have [Play Station 5s), Tv's, iPads which are never off when they are home! As you can imagine we also have a lot of washing within our household."

32% of carers said that they have considered leaving Shared Lives due to the cost of living, which is slightly **more than the national average** of **31%**:

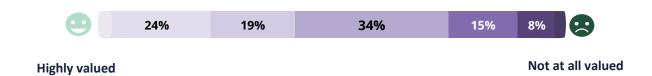
"At the moment I am undecided [as to whether to leave Shared Lives]. I try to save money on electric/heating and ask my ladies to help by turning things off, not wasting water etc., but my ladies really don't understand as [they] have [learning disabilities]. When I asked them to put extra layers on, and one of my ladies said 'why? The radiators are on'."



Have you considered stopping work as a Shared Lives carer due to COL or Other?

How valued do Shared Lives carers feel?

24%, said they felt not very or not at all valued, as seen in the graphic below. This is **more than the national average** of **27%**:



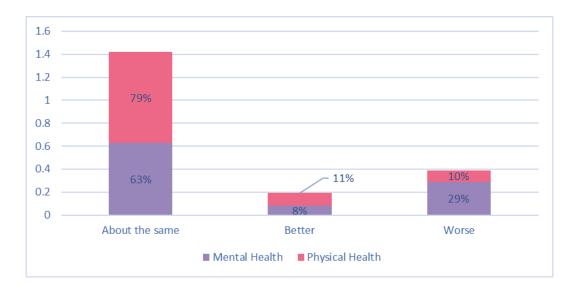
"[There is a] lack of recognition. We feel we are being treated differently from other parts of the care sector."

"I think we are used."

42% of carers in the South West stated that they felt highly valued, which is **less than the national average** of **47%**.

"I love supporting people to be the best they can be. Each milestone makes me proud. What they achieve I achieve more from the joy they have."

Shared Lives carer physical and mental wellbeing



Most Shared Lives carers surveyed in the South West felt that their health was about the same as last year.

Physical health

⇒ 11% of South West carers felt their physical health was better, which was above the national average of 10%. One carer explained that:

"As a household we do yoga once a week together."

- → 79% felt their physical health was the same, which was higher than the national average of 67%.
- ⇒ 10% felt their physical health was worse, which was better than the national average of 22%.

Mental health

- ⇒ 8% of South West carers felt their mental health was better, which was above the national average of 7%.
- ⇒ 63% felt their mental health was the same, which was above the national average of 59%.
- ⇒ 29% felt their mental health was worse, which was also better than the national average of 34%. One carer said of their mental health:

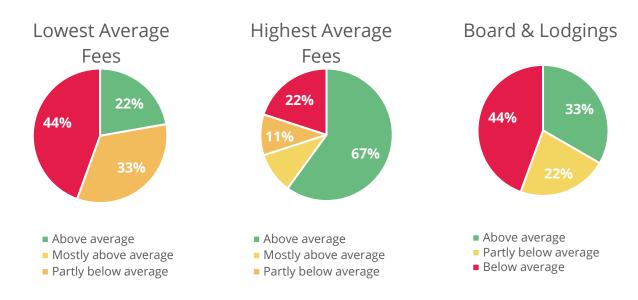
"I was feeling quite tired and felt I didn't have any time for myself or family. I have a son with learning difficulties too, I have now cut back on the hours of [short breaks] I do so that I get every other weekend off as our long-term placement has moved on."

Several carers in the South West identified **financial concerns** as a key cause of mental and physical ill health:

"The stress and worry of trying to do the best you can with your resources for the people you care for but seeing dramatic rises in costs does cause poor mental health at times."

Summary and recommendations

Please note that these figures were accurate as of November 2022.



"The fight for everything I feel we deserve [is difficult]. We need recognition for the actual work that we provide on a daily and sometimes nightly basis. Not necessarily the [Shared Lives] support officers, but the council. I don't believe anyone knows how much love and dedication goes into the role unless you have first-hand experience."

Shared Lives carer, South West

The picture is mixed when it comes to commissioning organisations' provision of live-in fees, and board and lodgings contributions to Shared Lives arrangements in the South West. This is reflected in the similar mix of Shared Lives carer feedback. Many Shared Lives carers expressed how much they enjoyed making a difference to the people they support. Many also told of how financial stress was impacting not only their work, but also their quality of life. See the appendix for more.

We strongly urge commissioning organisations in the South West raise their fees and contributions to meet or exceed the comparative averages outlined in the recommendations section.

Areas of strength

- ⇒ 5 out of the 9 (56%) commissioning organisation fee rates in the South West were above the regional and English <u>banded</u> rates for Shared Lives.
- ⇒ 6 out of the 9 (67%) commissioning organisation fee rates in the South West were above average in comparison to all other measures for highest fee rates for live-in arrangements.

Areas of development

Several commissioning organisations whose rates <u>fall below</u> all comparative averages.

Most notably:

- ⇒ 6 out of 9 (67%) commissioning fee rates were below the English national average board and lodgings contributions.
- ⇒ It is also notable that **43%** of Shared Lives carers in the South West also said they felt **not very or not at all valued**.

Recommendations

Please note: recommendations are based on data collected in November 2022.

All commissioning organisations <u>increase</u> the board and lodgings contributions to at or above the regional board and lodgings average of £63.71.

6 commissioning organisation board and lodging rates fell **below** the English board and lodgings average:

⇒ COSW001
 ⇒ COSW005
 ⇒ COSW008
 ⇒ COSW009

Commissioning organisations ensure that they provide a lowest live-in fee rate at or above lowest non-banded fee rate for England: £401.76

7 commissioning organisations provide lowest fees that **do not meet** the lowest non-banded fee rate for England, which is the highest of the averages. These are:

⇒ COSW001
 ⇒ COSW005
 ⇒ COSW007
 ⇒ COSW003
 ⇒ COSW004

Commissioning organisations ensure that they provide a highest live-in fee rate at or above the highest banding rate for region: £582.09.

3 commissioning organisations provide highest fees that **do not meet** the highest banding rate for region, which is the highest of the averages. These are:

 \Rightarrow COSW002 \Rightarrow COSW005

⇒ COSW004

Appendix: South West Carer voices

Below are anonymised quotes from Shared Lives carers in South West who responded to the Invaluable survey.

What Shared Lives carers like the most about Shared Lives:

Making a difference

- □ I really enjoy supporting and helping shared life's people. I hope that I make a little difference to all that I support, whether it's a smile, laughter or just sitting and listening, I really enjoy all their company and getting to know their different personalities
- Watching progress of individuals, enabling them to learn new skills and try new things. Assisting them to make informed choices and take risks they may not have taken with family. Problem solving. Being creative in assisting people to progress. Watching confidence grow and the sense of achievement people have when they overcome a challenge.
- ▼ I love making a difference to people's lives, helping, and watching them grow in confidence, helping them to improve on daily tasks, building their confidence to move to the next stage of their lives.
- □ I have worked in the care sector with adults with learning disabilities since I was 17 in different residential settings. After 20 years I was fed up with taking people out of activities before they were finished to fit with in staff rotas. My ladies are always the last to leave activities. I like the flexible to meet my ladies' needs.
- ∞ I enjoy the company and enriching the quality of life for the person I support.
- ∞ Watching the people in my care become as self-sufficient as possible.
- ∞ Enjoying the care & support we give our young men, keeping them safe, secure, valued & happy & enjoying the family unit they give us.

- ∞ The satisfaction of helping a vulnerable person in a caring safe environment
- Being able to make a difference to my [supported people] standard of living. Giving them a living family environment. The reward of seeing them blossom into happy humans and treating them as family.
- ∞ "Providing a safe, supportive and enriching environment for our clients.
- Being able to support someone with no time limits. To be able to make a difference in their lives and to see the progress in their abilities. To have them as part of our family.
- ∞ Offering a young person, the opportunity to be independent and live their best life with mine and my partners support and guidance.
- ∞ Helping someone lead a full filling and independent life, we get a good feeling that we provide a good service and a happy home.
- ∞ It has been rewarding to watch young adults learn and thrive enough to move on to independent living.
- I find it very rewarding but challenging no day is ever the same, it's nice when you
 have worked hard with a person and start to see that person grow in independence
 and skills, they are part of our family one person says she has two families one at
 home and one with us.
- Seeing people grow into confident members of society. Getting up each morning knowing I am going to help someone through their struggles of daily life but seeing that smile on a [supported persons] face when they feel that support.
- ∞ I like to think I have been able to support and provide for people with Learning difficulties and other problems over the years, in company with my late wife.
- ™We love making a difference to people's lives helping them achieve and become what
 they want to. Sharing our lives with people and treating them as part of a family.
- we have had to fight for a lot of things for one of our people but know that 2023 is
 going to be the year they are genuinely free for the first time in a long time. I am
 grateful and thankful to have supported them thus far.

 Working one to one with [supported people] without in-house politics getting in the way of supporting [supported people] fully. Promoting independence for [supported people] learning new skills, social skills, life skills & doing things in the community. Enhancing others' lives.

Flexibility and home working

- Works for me to work from home and doing everyday things and helping them grow and learn new skills.
- ∞ No day is the same and I learn new skills each time.
- ∇ I enjoy being at home and no longer being a slave to the corporate world.
- ∞ My quality of life has really improved, while I have been shared lives carer.
- Working from my own home and being able to give help dedication and respect to the person in my care.
- ∞ Able to work from home, whilst providing a safe and comfortable environment for my [supported person] to grow in.

Community and scheme support

- ∞ I can call or visit the office and speak to my Case-Coordinator if I have any concerns.
- They are there always to give us support & advise & have got us through a "few crisis events.
- ∞ [Our Shared Lives support workers] are superb and our young men think that also.
- ∞ Our shared Lives worker is very supportive and she's always quick to respond.
- ∞ My worker is fantastic and very supportive.
- I feel supported by my [scheme workers] and am confident that if I needed more support, I would ask for it.
- They listen to any concerns I may have they try their very best to find answers to any issues concerning me I honestly believe they offer the advice correctly.

- ∞ Great communication between my [scheme worker] and myself. Great bulletins from Shared Lives Plus, and weekly newsletters from [the scheme].
- Our Shared Lives support worker is always available and is always prompt at replying to our queries and keeps us up to date on a regular basis. The whole team are fantastic.
- ∞ They are always there to listen to concerns I may have. They support me in all aspects of my caring role.
- ∞ My [scheme worker] is very supportive and keeps in regular communication. The office staff are always available and friendly and willing to help.
- ∞ Are always there at the end of phone if I need anything at all, even if it's just to talk, which really helps.
- Being a carer has been part of our lives for so long it is how we work as a house hold.
 This has greatly improved since being with Shared Lives as we have such a great team to work alongside.

What Shared Lives carers find most difficult:

Fees

- You could give us [the renumeration] that we are worth. [Compensate] us for training. Don't [renumerate] someone doing day care double to someone looking after the same client 24/7.
- ™ The [fee] is so low and you have to pay for their food, heating etc out of your
 [renumeration] which makes our pay worse. It is so under the nation living wage and
 if you consider how much it would cost if they were in a home, it makes our wages
 look worse.
- ∞ I can earn more money by not doing Shared Lives, but I have cared for my [supported people] for many years now and I cannot put money before them.
- ∞ Feel upset at how little we receive in response to the service we provide.

- ∞ I have found I could go back to working nights and earn a decent living and have my home and life back to normal quite tempting.
- ∞ [Care fees] don't reflect 24/7 care needed.

Cost of living

- with cost of living going up, it's a struggle, a bit more money would help, so I don't
 have to worry about providing a good life for the people I care for.
- Did consider [leaving Shared Lives] but will see how we manage over the next year.
 It's not easy to just give up because of difficulties financially will try to cut back. But energy costs are very worrying.
- If I think it becomes financially unviable to continue in a shared lives role, I will consider returning to paid employment. I enjoy the freedom my current role affords me, but it has to be financially sound.
- ∞ I have been looking for another job, once the bills are paid food fuel heating, nothing left for me.
- ∞ It's been a hard time over the last couple of years or so for me, my family, and the person I care for. I take medication for depression and anxiety.
- Lots of worry about upcoming bills, especially as our mortgage has to be renewed and the mortgage rates are going through the roof.
- ∞ I am ok but with all the rises money is becoming a worry.
- ∞ It is difficult to offer the same opportunities when prices continue to rise and this is one of the few social care roles where no pay award has been implemented.
- Unable to offer support we used to due to cost of living.

Issues with the scheme/other care workers & organisations

∞ "My local staff are lovely, but the CEO was having a coffee morning to meet us and he didn't turn up. Says a lot."

- Was supposed to have a coffee morning with the CEO he never turned up I was not happy waste of a morning driving there and back.
- I have concerns that the overall manager holds two roles within the council. I believe the two roles conflict particular regarding decisions about funding, hence we have not had ANY financial support.
- ∞ There is no support from our scheme. They cannot commission any day services, have no money for training.
- We now have a support worker for our [supported person]. And a support worker for us. To check our paperwork and have a chat. If I try to ask about cost of living or respite. Housing benefit been the same for 7 years, there are no discussions.
- Most of the information and support seems to be directed towards long-term carers and not carers who only provide short breaks.
- Lack of access for individuals to Social Care or a long waiting list for referrals so nowhere to signpost families or individuals to.
- ∞ That Shared lives plus is only guidance, and schemes abuse this.
- ∞ That you as a carer has to do nearly all the chasing and finding out about what out what a supported person is entitled too.
- Feeling judged by "professionals" who just cannot really understand the role without having actually done it.
- ∞ [Shared Lives Plus should] advertise more or lobby government to let them know the work shared lives do I was talking to my local MP where I live, they had no idea what shared lives was.
- Being made to blame for placement breakdown and felt patronised and unsupported.
- ∞ Find social workers are disinterested after someone has been placed with you.
- The [scheme workers] do seem to be off sick quite a lot. I would imagine this is due to stress, and pressure of the job. Could they need more support. This in turn means that [they] aren't there to support us.

- Scheme workers seem to be off sick more than the average. Could this be due to stress of the job? If so does this need to be reviewed.
- ∞ The scheme management also are busy running other parts and day centres within the council. So, I feel they have little time for shared lives carers.
- They could cut some of the red tape, around invoices and getting paid for respite in a timely manner.
- ∞ I am fed up with being asked to go training for nothing using my time and fuel to get there, fed with being asked to print off paper work my ink buying the paper.

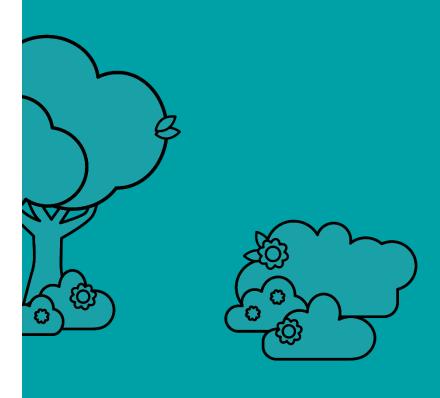
Respite issues and work/life balance

- Not being able to get a break. When he was in foster care with us our adult daughter used to be able to stay with him in our home, but our only current option is for him to go elsewhere which would not work for him. The process to become respite carers seems to be very lengthy given that they have known him for 12 years and have looked after him frequently until he turned 18.
- ∞ Not having enough respite, someone is with this young person all the time.
- ∞ Often being asked by families or individuals to support in areas that are outside my remit because they have no-one else.
- Lack of free time to us and more recently, the squeeze on the household budget whilst the client sees no drop in their own income/lifestyle.
- Not having much respite. I feel I could do my job fair better if I had more respite. It must be remembered that as carers we do not have weekends off, bank holidays/Christmas unless we take the time off as respite.
- ∞ Only having two weeks off a year and if it wasn't for my family, I wouldn't have a holiday.
- ∞ Only 10 days paid leave. Not being able to have time off for illness, serious family illness and bereavement.
- Not being paid for sickness or holidays and getting enough work as my husband is a shared lives carer too so it's our only income. Two weeks paid respite is not enough.

- ∞ 24/7 Care. Being on call at all times. Full responsibility is daunting at times. No privacy.
- Iron out discrepancies in short break funding for late cancellations and ensure effective communication regarding decisions around funding to ensure there aren't mixed messages.
- ∞ Respite with a shared lives Carer costs more than what we get paid.
- ∞ The lack of day care and placements now mean [supported people] are at home most of the time.
- It's really hard not getting much respite and having to take unpaid respite after only two weeks.

Challenges with supported people

- ∞ My life has to revolve around the people in my care at all times, behaviours can be quite challenging at time.
- Being unable to prevent my charge making poor choices that can lead to her being taken advantage of by her family. Little structure to their life. No work or volunteering as she finds it too difficult. I feel she is drifting and not making the most of her opportunities.
- Life restrictions. The person that lives with us finds lots of situations difficult making it hard for us to access some of the things we like to do. We need to plan all activities thoroughly.
- Being expected to not cross the line between being a "family" Carer and a professional one, very difficult when you have lived with and supported someone for many years.





Report by:

Dr Rebecca Viney-Wood, Support and Engagement Manager **Liz Collings,** Data and Support Officer

With support from:

Lynne Harrison, Head of MembershipLydia Bates, Digital Communications Officer

Shared Lives Plus

Eleanor Rathbone House Connect Business Village 24 Derby Road Liverpool L5 9PR 0151 227 3499

Reg Charity number (England and Wales) 1095562 Company number 4511426 Reg Charity No (Scotland) SC)42743