

State of the Nation Report 2016: Shared Lives Cymru



Key Messages for Shared Lives Cymru

- There has been significant growth in the number of people using Shared Lives since it started in Wales, with a total of 970 people now using the service.
- Caerphilly currently supports 14% of people with learning disabilities using services in Shared Lives. If all areas in Wales caught up with this, an additional 994 people with learning disabilities could be using Shared Lives with new savings of around £16,796,000 (based on 65% average long term arrangements in Wales).
- Offering substantially lower costs per person than traditional forms of care, whilst providing quality outcomes, Shared Lives fits well within the Welsh Assembly's vision for a future of health and social care which is flexible, innovative, value for money, and outcomes focused.
- Over half of the people using Shared Lives in Wales enjoy flexible, personalised short breaks and day support with a Shared Lives carer, indicating the effectiveness and affordability of Shared Lives as an alternative to traditional models.
- Schemes in Wales are developing and diversifying into offering services to people from all social care client groups. 12% of people using Shared Lives are older people or people living with dementia.
- Wales is the first of the four UK nations to have a Shared Lives scheme covering every Local Authority area.
- Nine schemes operate across the 22 Local Authority areas of which two are delivered by voluntary sector organisations, with the others run by the public sector.
- In three areas in Wales, local authorities have formed partnership arrangements to jointly provide or commission Shared Lives schemes and have been able to achieve a level of coverage and scaling up of services which has the potential to be replicated.
- Where Shared Lives is the "default option" for support for adults i.e. try this before any other option, the take-up is significantly higher.

Future Challenges for Shared Lives Cymru

- Shared Lives needs to be diversified to support many more groups of people who could benefit from being supported as part of families in the community, not just those with a learning disability.
- Schemes with fewer than 20 Shared Lives carers are likely to be at risk of becoming unsustainable and not making good use of resources. For these schemes Shared Lives Plus suggests an urgent need to develop and grow to enable them to become fully sustainable and maximise their potential.
- The ground breaking Social Services and Well-being (Wales) Act 2014 will be implemented from April 2016, and commissioning services will need to reflect the new ethos.
- The new Shared Lives Plus project beginning in April 2016, with its focus on older people and people with dementia, should be able to benefit from Welsh Government's efforts to bring together NHS provision and social welfare services.
- The 16–18 year old cohort of young people are not currently covered by Welsh regulations, as they are in England, thus rendering them ineligible to benefit from Shared Lives in Wales. Shared Lives Cymru

will have an opportunity to influence the new regulations coming in to force over the coming years on this issue.

- There are as yet no Homeshare schemes in Wales.
- Shared Lives Plus will need to work effectively with other Third Sector organisations in Wales, given the financial challenges facing public service provision as well as putting in place strong data gathering mechanisms for future reports.

Foreword by Mark Drakeford AM, Minister for Health and Social Services

I am delighted to introduce this first state-of-the-nation report about Shared Lives in Wales.

It shows how far the Shared Lives concept has been embraced in Wales over the past decade. We can be proud of the fact that Wales is the first of the UK nations to have Shared Lives schemes in all of our local authority areas.

When the adult placement schemes regulations were made in 2004, Shared Lives was mainly used for adults with learning disabilities who needed a supportive placement in a family home in order to live fulfilled lives within their local communities. Since then we have seen the development of many innovative and pioneering schemes across Wales, which have extended these placements to a wide range of vulnerable adults at various stages of their lives, including adults with dementia, frail older people, vulnerable adults released from prison after serving their sentence and people discharged from hospital. For some, Shared Lives offers a long-term home; for others a short-term placement as they prepare for more independent living. The advantage of the Shared Lives approach is that it is flexible enough to respond to a variety of individual needs and circumstances and no Shared Lives arrangement is exactly the same. It offers the sort of person-centred, preventative and supportive approach to social care we want to promote in Wales.

Shared Lives would not work without the willingness of householders to offer themselves as Shared Lives providers and without their commitment and dedication to the Shared Lives approach. I would like to thank all those who work so hard to make Shared Lives arrangements work for those whose care and support needs are best met in this way.

For the past four years the Welsh Government has supported the development work undertaken by Shared Lives Cymru with grant funding. Shared Lives Cymru has been successful in applying for a grant under our new Sustainable Social Services scheme for three years from April 2016. This will be focused on developing Shared Lives approaches for an increasing number of older people in Wales and supports the transformation of public services delivery that will take place when the Social Services and Well-being (Wales) Act 2014 comes into force in April.

I look forward to reading in future reports the difference Welsh Government funding has made and the exciting and innovative ways in which Shared Lives develops in Wales in the future.

Key Statistics

In Wales in 2014/15 there were:

- **970** people supported in Shared Lives arrangements
- **49%** in live in Shared Lives arrangements
- **32%** of people enjoying short breaks and respite
- **19%** of people are receiving day support

The main primary support need of people using Shared Lives:

- **710 (73%)** have a learning disability
- **90 (9%)** have dementia
- **80 (8%)** have a mental health issue
- **30 (3%)** have a support need associated with old age
- **20 (2%)** have a physical impairment

Age groups of people using Shared Lives:

- **770 (79%)** are working age people (16-64)
- **200 (21%)** are older people (65+)

In Wales in 2014/15 there were 670 Shared Lives carers:

- **470 (60%)** provide live in Shared Lives arrangements
- **200 (40%)** provide short breaks and day support



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Shared Lives Plus

Shared Lives Plus is the UK network for shared living approaches to care and support for disabled or older people. Our members include 5,000 Shared Lives carers, 150 local Shared Lives schemes and 13 Homeshare organisations, right across the UK.

Our aim is to see Shared Lives and Homeshare become the go-to options for care, support and inclusion. Shared Lives is growing rapidly as it is recognised as an alternative form of care, health and wellbeing service, which helps people who may have complex support needs, to live good lives in ordinary family homes and as valued parts of their communities.

Shared Lives Plus helps our members to work together to survive and thrive, influencing local and national policy makers and providing support, training, events, resources, research programmes and access to insurance.

The Shared Lives model of care

In Shared Lives, an adult who needs support and/or accommodation moves in with or regularly visits an approved Shared Lives carer, after they have been matched for compatibility. Together, they share family and community life. Half of the 13,000 people using Shared Lives across the UK are living with their Shared Lives carer as part of a supportive household; half visit their Shared Lives carer for day support or overnight breaks. The figures for Wales in some circumstances are slightly different from UK average numbers, and where relevant this is shown within this report.

Shared Lives is also used as a stepping stone for someone to get their own place. The outcomes can be startling, with people reporting feeling settled, valued, and as if they belong for the first time in their lives. They make friends and get involved in clubs, activities and volunteering.

Shared Lives is used by people with learning disabilities, people with mental health problems, older people, care leavers, young disabled adults, parents with learning disabilities and their children, people who misuse substances and offenders. It is being developed as a home from hospital service, an acute mental health service and a form of short breaks for family carers. There are over eight thousand Shared Lives carers in the UK, recruited, trained and approved by over one hundred and fifty local schemes, which are regulated by each UK home nation's care inspectors.



- [1] Blaenau Gwent
- [2] Bridgend
- [3] Caerphilly
- [4] Cardiff
- [5] Carmarthenshire
- [6] Ceredigion
- [7] Conwy
- [8] Denbighshire
- [9] Flintshire
- [10] Gwynedd
- [11] Isle of Anglesey
- [12] Merthyr Tydfil
- [13] Monmouthshire
- [14] Neath Port Talbot
- [15] Newport
- [16] Pembrokeshire
- [17] Powys
- [18] Rhondda Cynon Taff
- [19] Swansea
- [20] Torfaen
- [21] Vale of Glamorgan
- [22] Wrexham

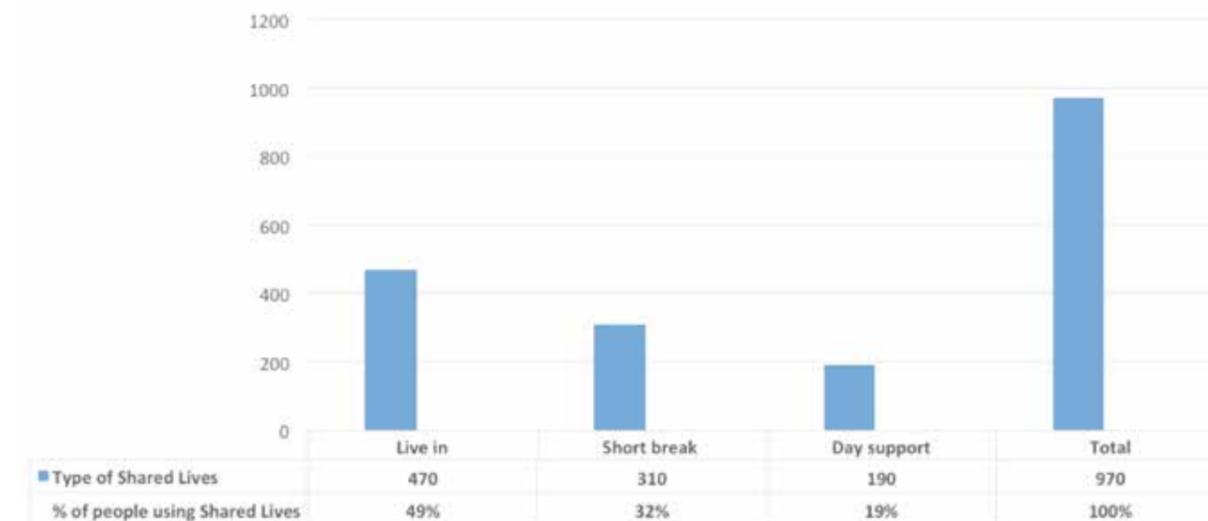
People who use Shared Lives

Traditionally, Shared Lives has been mainly used by people with learning disabilities. While this is still the largest group of people using Shared Lives, schemes are beginning to develop and diversify their services to work with new groups of people and offering a range of live in, short breaks and day support as the following information shows.

Types of Shared Lives arrangements

Type of Shared Lives arrangement	Estimated number of people	% each type of Shared Lives arrangement
Live in	470	49%
Short Breaks	310	32%
Day support	190	19%
Total	970	100%

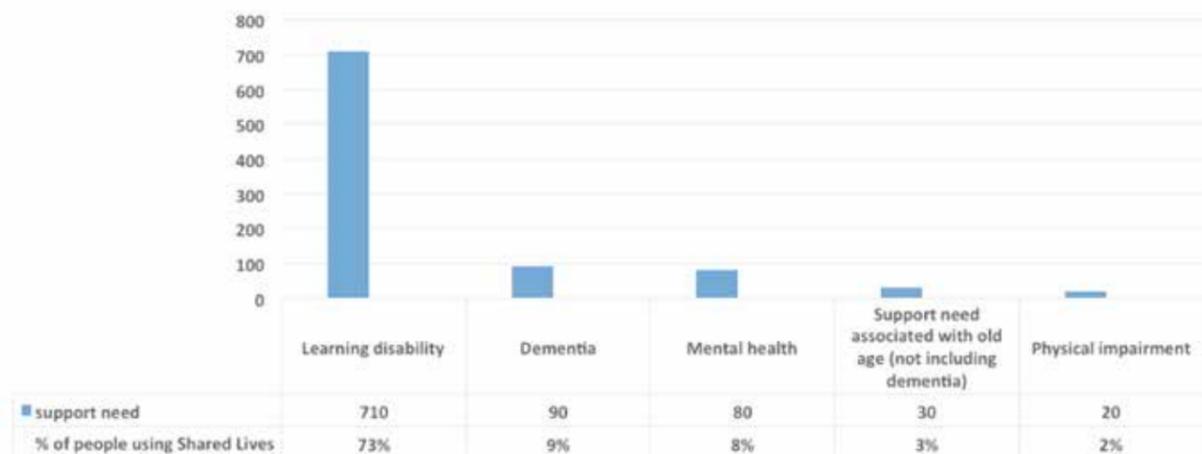
People using Shared Lives by type of Shared Lives arrangement



Seven Shared Lives schemes provided information on the main support need for people using Shared Lives in Wales, estimates are based on these figures. 73% of people using Shared Lives are primarily using it as a learning disability service, 9% are people living with dementia and 8% use Shared Lives as a mental health service. The table below shows the 'primary' support needs of people supported in Shared Lives arrangements only, as judged by scheme managers and secondary conditions are not captured here.

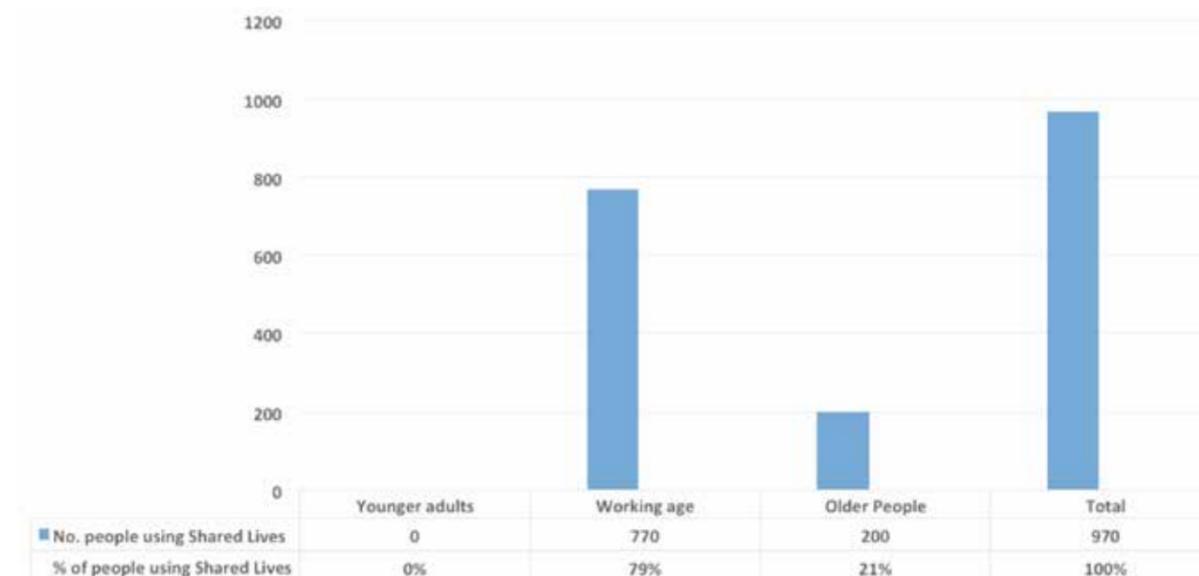
Main support need	%
Learning disability	73%
Dementia	9%
Mental health	8%
Support need associated with old age (not including dementia)	3%
Other	2%
Physical impairment	2%
Drug/ Alcohol	1%
Transition/ non-disabled care leaver	1%
Parent with child	<1%
Intermediate care/ reablement	<1%
Offenders	<1%
Transition/ disabled children	0%
Total	100%

People using Shared Lives by primary social care support need: main social care groups



People using Shared Lives by age, gender and ethnicity

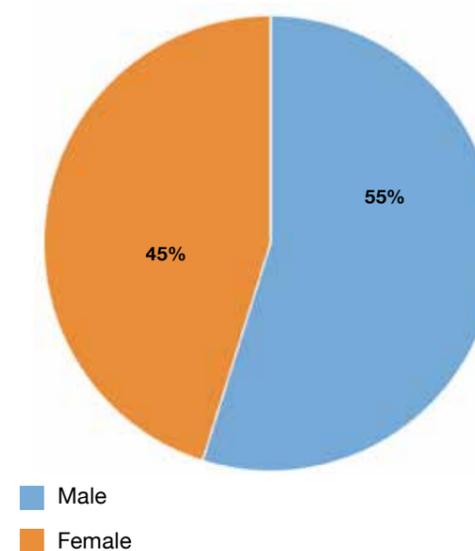
Age of people using Shared Lives



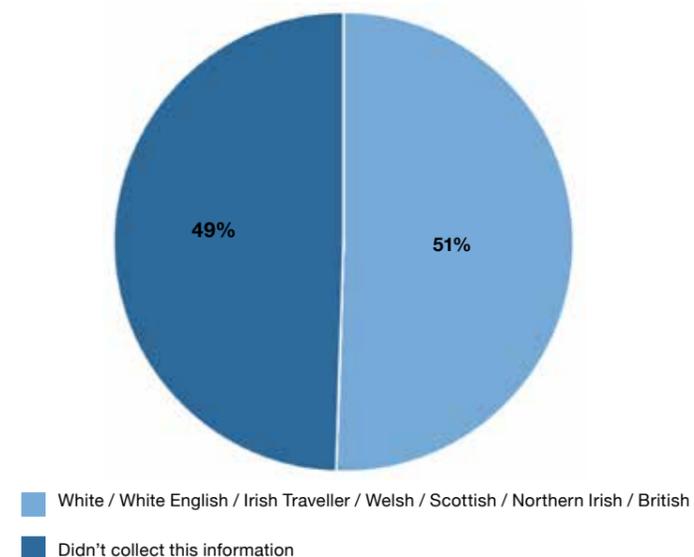
Across Wales, 79% of people using Shared Lives are working age adults, with older people making up the remaining 21%. In recent years Shared Lives schemes in England have extended to include a third age category of 16-18 years. This remains the smallest group

but has rapidly increased since its inception, and now accounts for 1% of those people using Shared Lives in England. In Wales, this would require a change to the regulations, and may be addressed in new legislation and regulations over the next few years.

Gender of people using Shared Lives



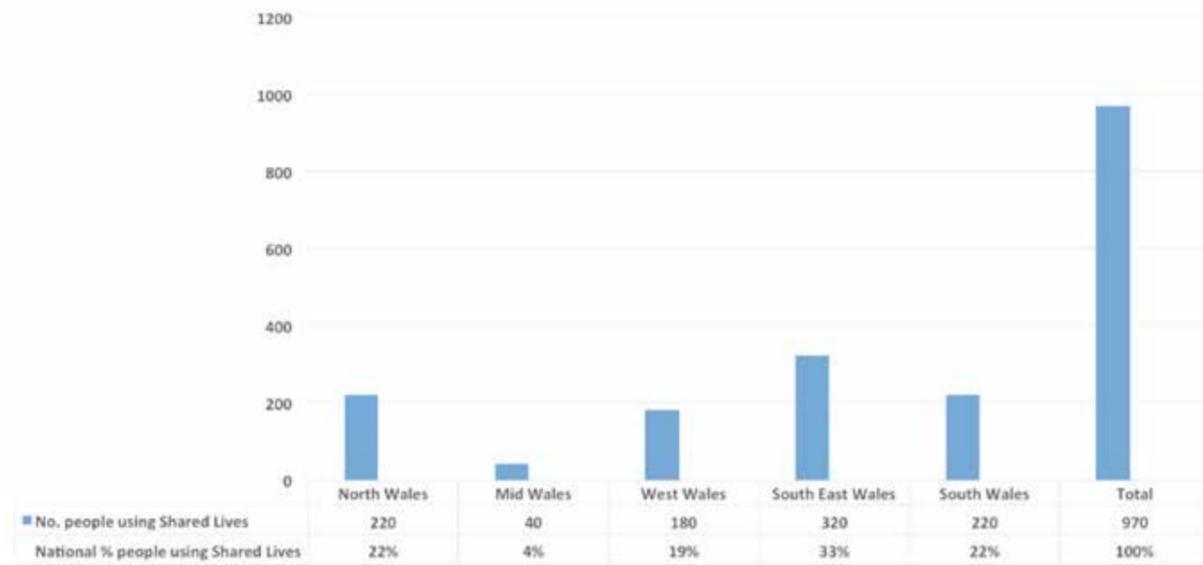
Ethnicity of people using Shared Lives



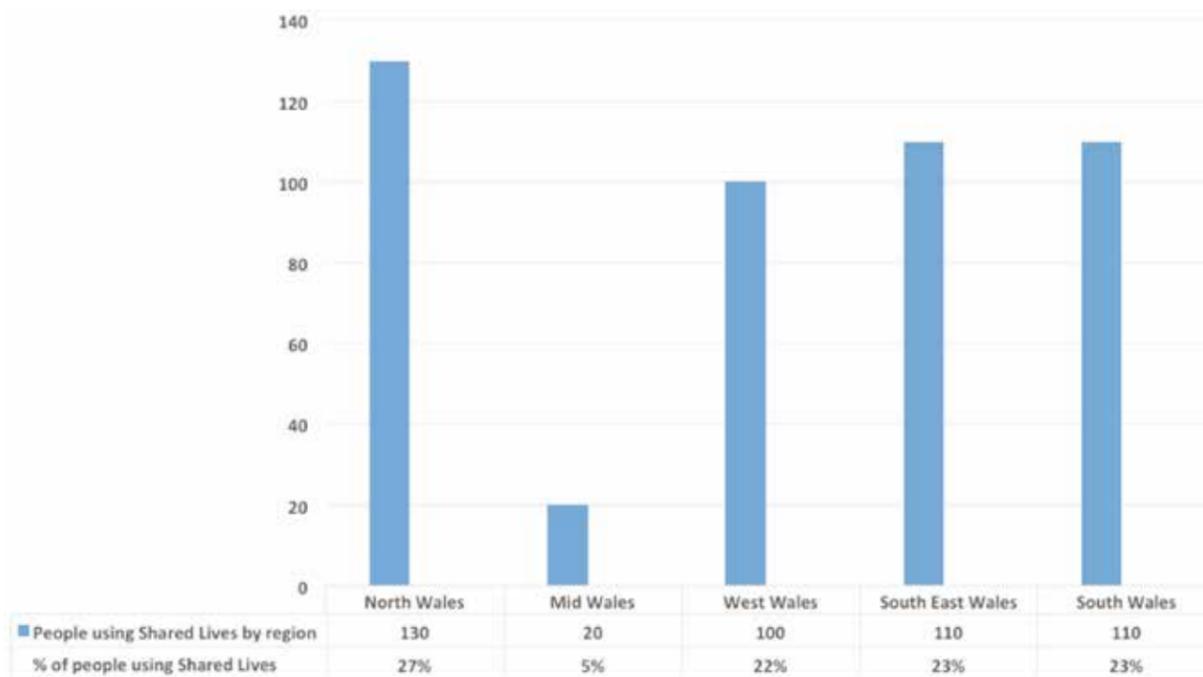
Regional variation for people using Shared Lives

There is much variation in across Wales in numbers of people using the service and the size of schemes. In the North, South East and West of Wales, local authorities have established partnerships to jointly provide or commission Shared Lives schemes which have been successful and reduce overheads for individual areas.

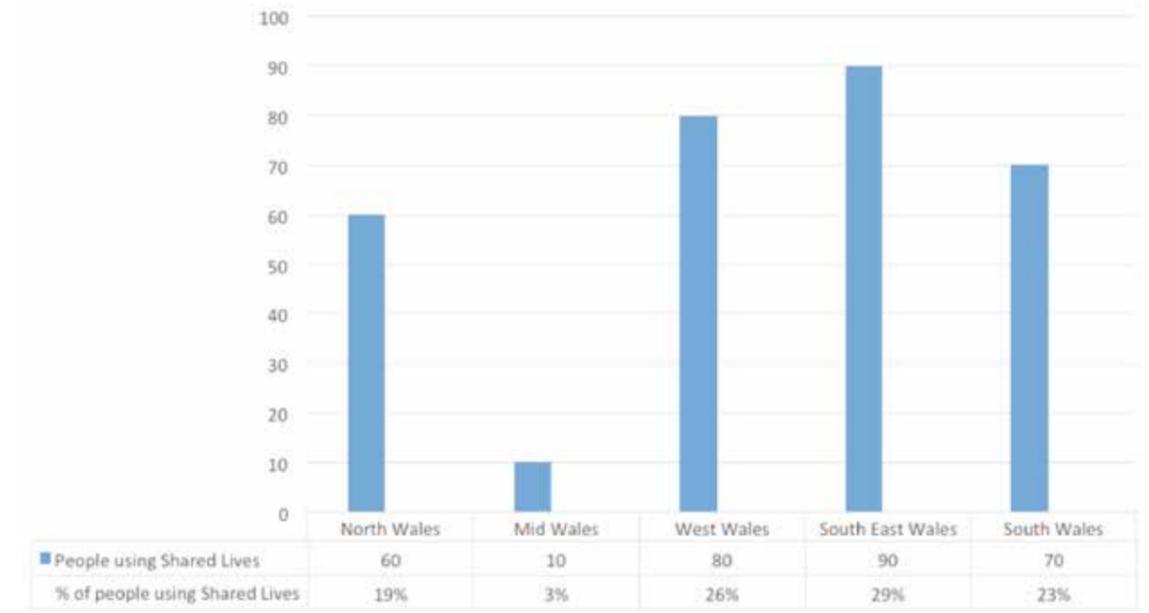
People using Shared Lives by region



Regional comparison of live in Shared Lives arrangements



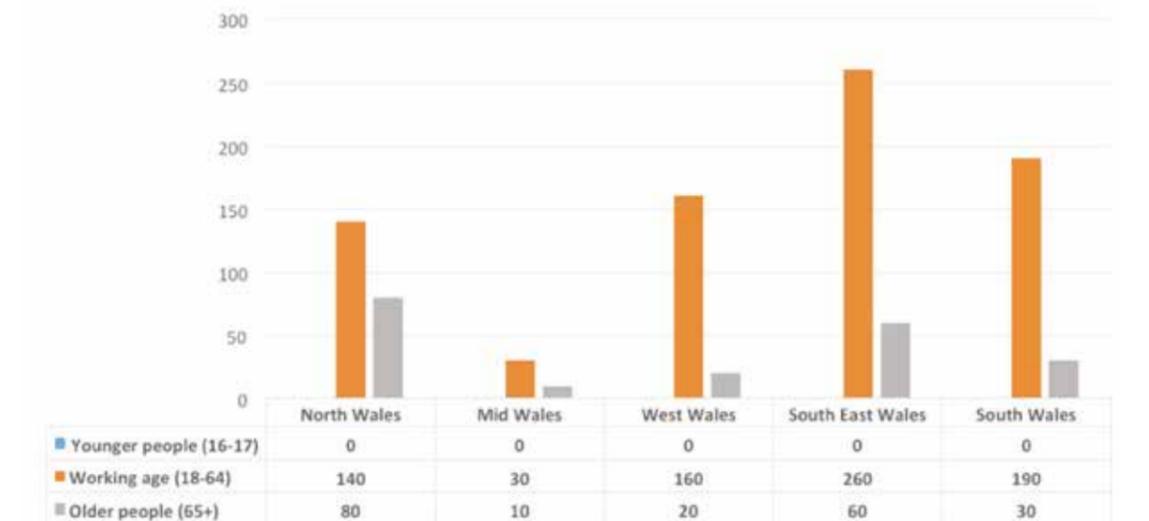
Regional comparison of short break Shared Lives arrangements



Regional comparison of day support Shared Lives arrangements



Regional breakdown by age



Shared Lives carers

Shared Lives carers come from all walks of life, and choose to care for a wide variety of reasons. Potential Shared Lives carers are given full training by the local Shared Lives scheme and go through a rigorous process of approval to ensure the safety and wellbeing of those being cared for and that of the Shared Lives carer and their family. Formal experience of caring is less important than motivation, commitment and strong values, although at least a third of Shared Lives carers have some background in health and social care. Being a Shared Lives carer is a way of life not just a job. Shared Lives carers need to have the right personal qualities - they need to be flexible, empowering and positive and have a person centred approach. This means the willingness to offer time, encouragement and a stable and supportive environment along with a belief in helping people to pursue ordinary life chances and take positive risks, with the back-up of a long-term

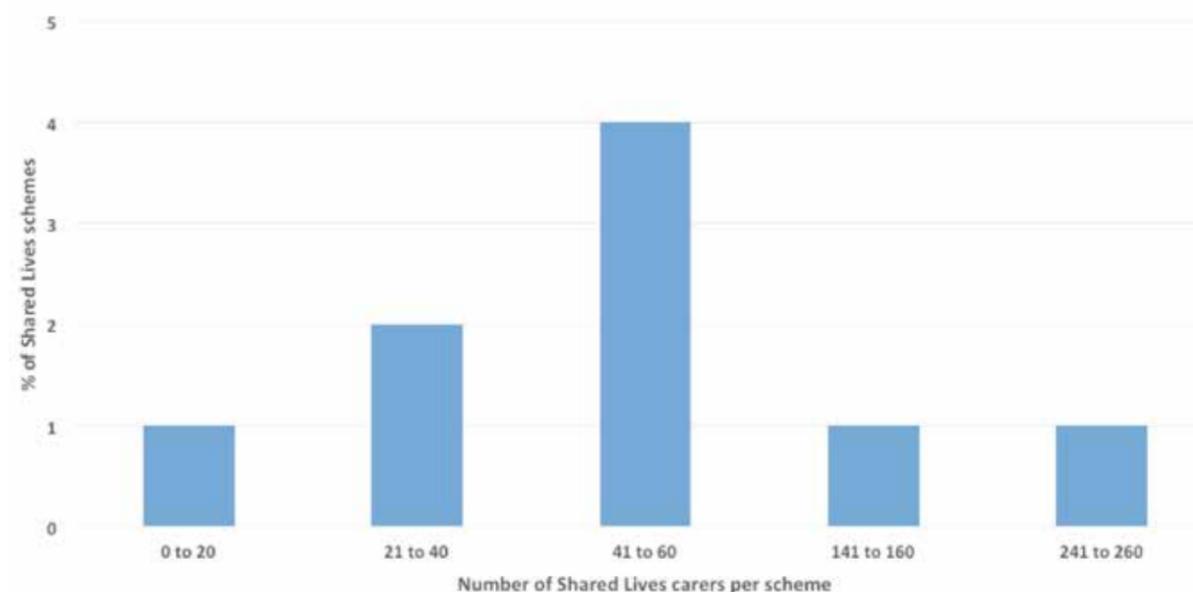
caring relationship. Shared Lives carers are self-employed and use their own home as a base. Rates of payment are set by the local authority or scheme itself and vary depending on location and the needs of the person living in the Shared Lives arrangement. Shared Lives carers receive payments to cover some of their time, rent and a contribution towards the running of the household – such as energy bills and food. Shared Lives carers typically provide a great deal more than they can be said to have been paid for and are adept at thinking creatively and spotting potential health and wellbeing problems at an early stage. They also involve family and friends who may contribute without payment. Shared Lives carers are passionate and dedicated about the support they provide and are the reason why Shared Lives is such a powerful and effective form of care in our community.

Seven Shared Lives schemes provided detailed data in this survey about Shared Lives carer numbers by category of support provided: live in, breaks and day support. Taking the data from these seven Shared Lives schemes as being representative of the Shared Lives sector as a whole it can be estimated that in Wales:

- There are 670 Shared Lives carers
- 470 provide live in support
- 200 solely provide breaks and day support
- 88% of schemes have Shared Lives carers offering live in support
- 100% of schemes have Shared Lives carers offering short breaks and day support

The smallest scheme in the survey has just nine live in Shared Lives carers. The largest single scheme has 256 Shared Lives carers working across its local council areas offering both live in and short breaks arrangements. The majority of schemes across Wales have between 41 and 60 Shared Lives carers. Mid Wales has the smallest number of Shared Lives carers with just 30, but this reflects the fact there is just one scheme in this sparsely populated area.

Number of Shared Lives schemes by number of Shared Lives carers



Characteristics of Shared Lives carers

Shared Lives schemes were asked to provide any information that they collected on the demography of their Shared Lives carers. Shared Lives carers are self-employed and many schemes do not routinely hold detailed demographic data on their approved Shared Lives carers. Unfortunately, no standardised information is therefore available across the sector, however scheme managers that provided data have reported that:

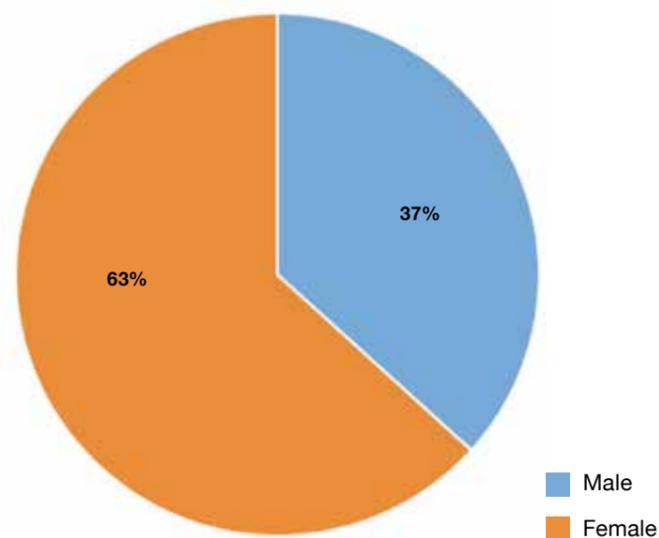
- 84% Shared Lives carers were of working age (18-64), and 16% were older people (aged 65 and over).
- 63% of Shared Lives carers are female and 37% male. This shows that there are significantly more men involved in delivering care and support in Shared Lives compared to about 19% of men in the UK national social care workforce.
- Shared Lives carers tend to be slightly more ethnically diverse as a group than the scheme workforce. However, from the data that was available, the vast majority of both Shared Lives carers, users, and workers tend to be from White/British background. More work must be completed by schemes and Shared Lives Plus to help offer a real alternative to those from the diverse range of backgrounds which make up Wales today.

Shared Lives carers by age, gender, ethnicity

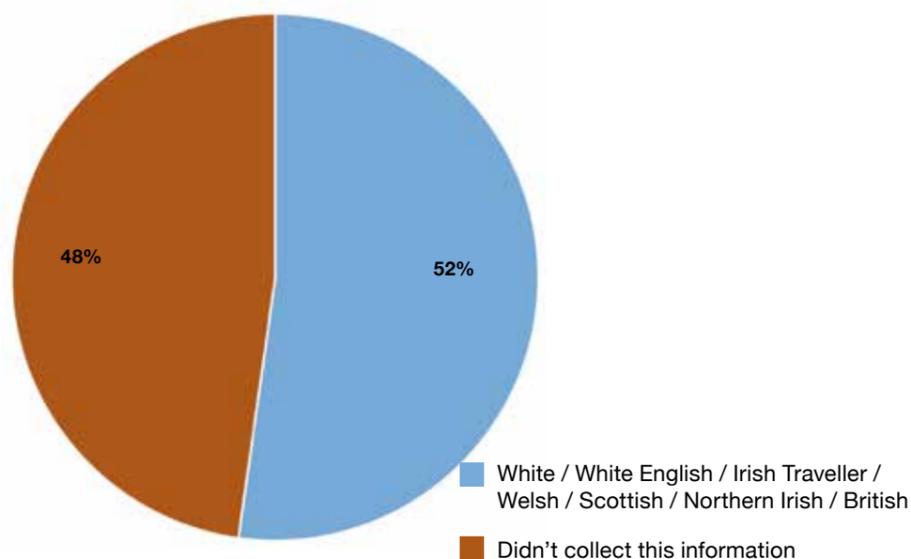
Age

Age Groups	No. Shared Lives carers	%
Working age	570	85%
Older People	110	16%
Total	670	101%

Gender of Shared Lives carers



Ethnicity of Shared Lives carers



Jackie, Janet & Sallie

– SE Wales

Jackie and Janet had lived together for seven years in a supported living complex, along with their pet budgie Gandalf. The two women were referred to the scheme together with the intention of one sessional carer supporting them both to gain confidence in daily tasks such as cooking, cleaning and bill paying. The support of their Shared Lives carer, Sallie, has had a huge effect upon Jackie's confidence in particular. Before starting sessional support Jackie felt really nervous about cooking her own meals. Sallie has helped to show Jackie different cooking methods and recipes.

The three women enjoy regular days out together, and next on Jackie's to do list is to go on holiday in 2016. What is clear about this arrangement is how effective Sallie's helping hand has been in Jackie's life. Through some development of domestic skills such as cooking and bill paying Sallie has increased Jackie's confidence which had a truly positive effect on her life.

When asking Jackie how she feels about the support she has from her match with Sallie and her experience of Shared Lives she responds with "great, absolutely wonderful. I have never been so happy in all of my life".

Number of Shared Lives carers by type of Shared Lives arrangement provided

Region	Live in	% of Shared Lives carers	Short breaks and day support	% of Shared Lives carers
North Wales	120	25%	10	5%
Mid Wales	20	4%	0	0%
West Wales	80	17%	0	0%
South East Wales	170	35%	120	63%
South Wales	90	19%	60	32%
Total	480	100%	190	100%

Gayle, Janice and Terry

– Merthyr Tydfil

Before Shared Lives, Gayle was living at home with her parents. She decided it was the right time for change, but wanted the continued familial type support she had at home, due to having Myalgic Encephalitis. This led her to Shared Lives.

Gayle has been living with Janice, Terry and their children for over two years now and it is clear that it was a match made in heaven.

When deciding what she wanted in a Shared Lives arrangement, at the top of her list was a Christian family she could share her faith with, to remain in the Merthyr area to be close to her family and friends and also, having a black and white cat.

She met with Shared Lives worker Kathryn Williams who, when hearing her wish list, felt she had the perfect match.

Terry and Janice became approved carers with the scheme in December 2012. They are a Christian family with four children. Janice has had a long career as a nurse and Terry is a paramedic. The family live in Merthyr and are just a short car journey away from Gayle’s family home. They also have a black and white cat named Felix.

When they met, they all clicked immediately and Janice remembers feeling that “everything had fallen into place.” As Gayle’s family live close by they are able to visit regularly and Gayle sometimes goes home to stay with them.

Gayle, Terry and Janice all feel that their faith has been very important in bringing them together. The relationship between them feels very natural and Gayle is quite clearly considered to be a part of the family.

Gayle explains that the Shared Lives placement has provided her with “the best of both worlds” as she has the benefits of ordinary household life as well as her own space and privacy.

Shared Lives scheme workforce

Shared Lives schemes look after the administration of Shared Lives and run the approvals and matching processes to give Shared Lives arrangements the best chance to succeed. They also provide training and ongoing support and guidance for Shared Lives carers.

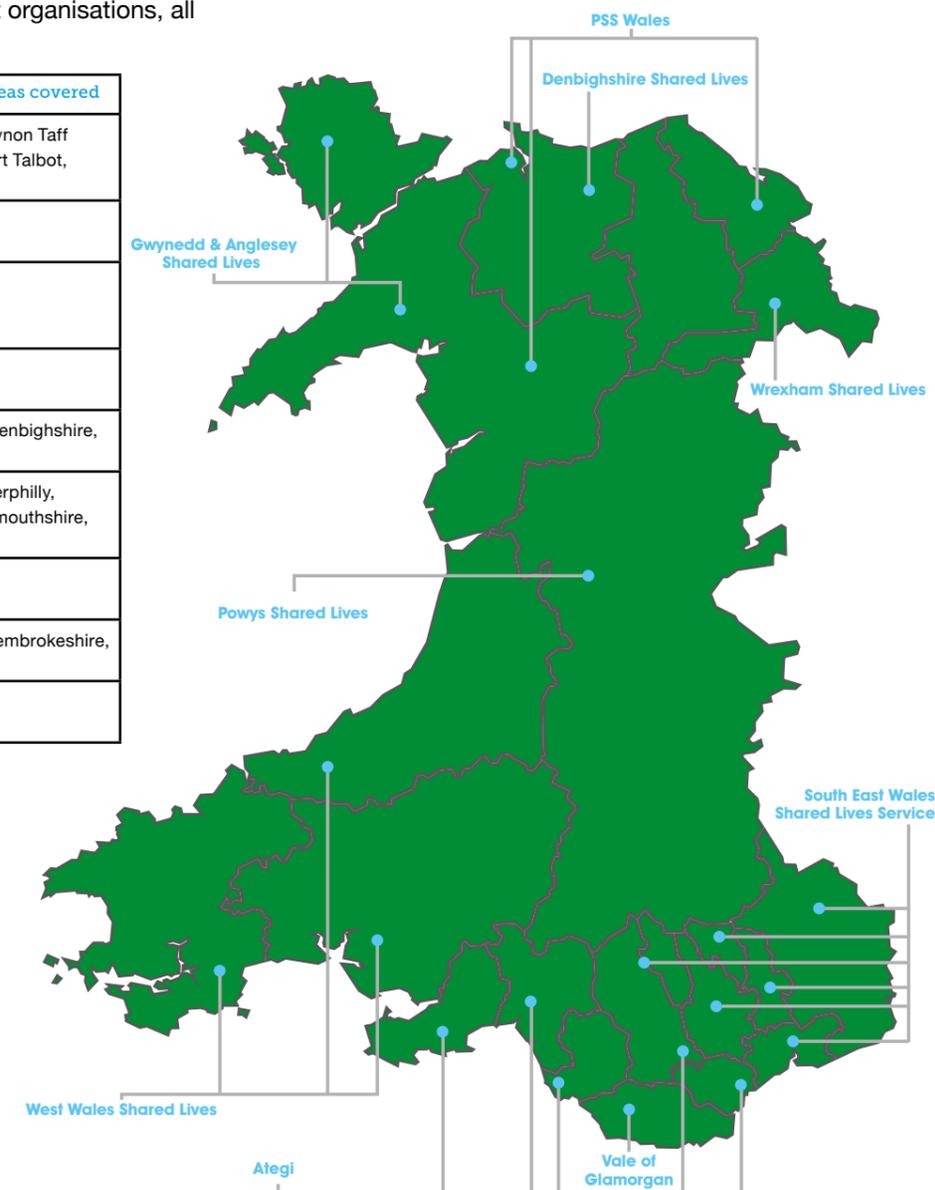
The matching process is at the heart of Shared Lives – making sure that the arrangement is the best possible fit, looking at shared interests and personalities so that each arrangement has the best chance of success for both the Shared Lives carer and the person being cared for.

Shared Lives schemes can be either run by a local authority or independent organisations, all

schemes are regulated by the government’s social care inspectors, the Care and Social Services Inspectorate Wales, and have to follow the same rules to ensure the safety of those being cared for. There are nine Shared Lives Schemes in Wales operating across five regions, covering all of the twenty two local authority areas with a responsibility for adult social care. Some Shared Lives schemes provide services to more than one local authority area, and in some circumstances schemes overlap in the coverage.

The map below shows Shared Lives schemes across the country

Scheme Name	Local Authority areas covered
Ategi	Cardiff, Rhondda Cynon Taff, Swansea, Neath Port Talbot, Bridgend
Denbighshire Shared Lives	Denbighshire
Gwynedd & Anglesey Shared Lives	Gwynedd, Anglesey
Powys Shared Lives	Powys
PSS Wales	Conwy, Flintshire, Denbighshire, Gwynedd
South East Wales Shared Lives Service	Blaenau Gwent, Caerphilly, Merthyr Tydfil, Monmouthshire, Newport, Torfaen
Vale of Glamorgan	Vale of Glamorgan
West Wales Shared Lives	Carmarthenshire, Pembrokeshire, Ceredigion
Wrexham Shared Lives	Wrexham



Staffing and staff turnover

Shared Lives schemes in Wales are delivered by both Local Authorities and voluntary sector organisations, with a move to contracting out of the Local Authority remit in recent years. This combination of delivery approaches provides Shared Lives Cymru with a rich mix of experience and expertise and will no doubt be an area of interest for future data gathering.

Shared Lives staff demonstrate a high level of loyalty and dedication with the most common reason for joining the sector being a 'new challenge'. Other themes cited by scheme workers for choosing to work for a Shared Lives scheme included 'Interest in Shared Lives', 'Good reputation of scheme', and interestingly an 'alternative to case management'. On the other side, whilst there was relatively low churn rate of staff, reasons for leaving included 'new opportunities' and 'work related stress'. Over the period that this report examines, 6 new staff joined schemes in Wales and only 1 left. The highest influx of staff seen was in South East Wales where half of the new staff can be accounted for, reflecting the significant size of the scheme in that region of Wales and the growth it has witnessed.

Schemes vary significantly in size with between three and seventeen members of staff – most commonly schemes have members of

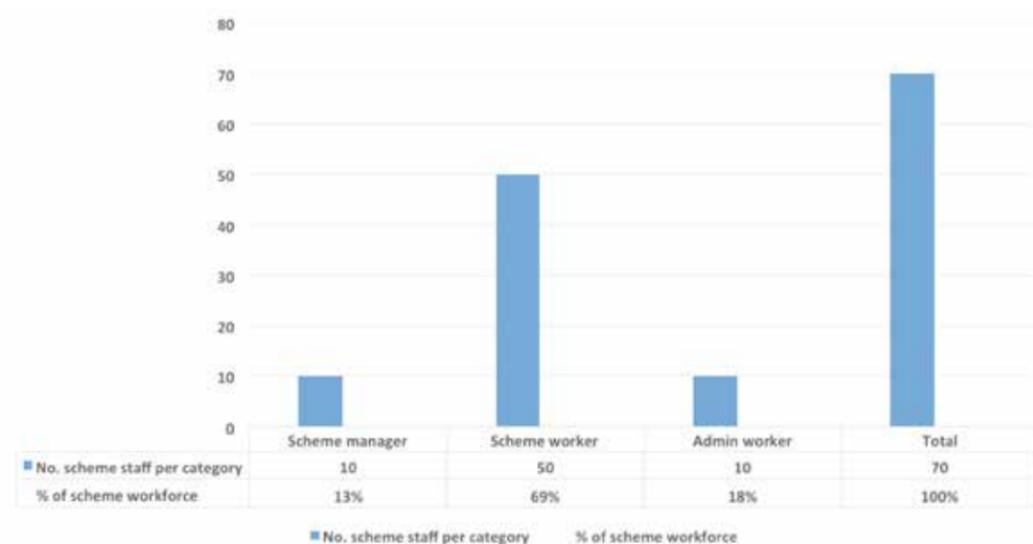
staff including a manager and co-ordinators. Around 83% of schemes also have a dedicated administrative worker.

There is some regional variation with schemes from the North likely to have fewer members of staff, and schemes in the South East and West regions tending to have more staff. There are around 57 staff working for the nine schemes across Wales. On average each scheme in Wales has one member of staff for every nine Shared Lives carers registered with that scheme. Shared Lives Plus recommend that each scheme should have at least one member of staff to twenty five arrangements. All schemes have one manager, West Wales has the highest number of coordinators while Mid Wales has the lowest.

It is interesting to note that about half of all scheme managers in Wales have other responsibilities outside of the Shared Lives scheme.

Staff job titles are not consistent across all schemes, some may be called coordinators, whilst others are officers carrying out the same duties within their role. A total of seven Shared Lives schemes provided detailed data on their levels of staffing for Shared Lives scheme managers, Shared Lives workers and if they had dedicated admin support.

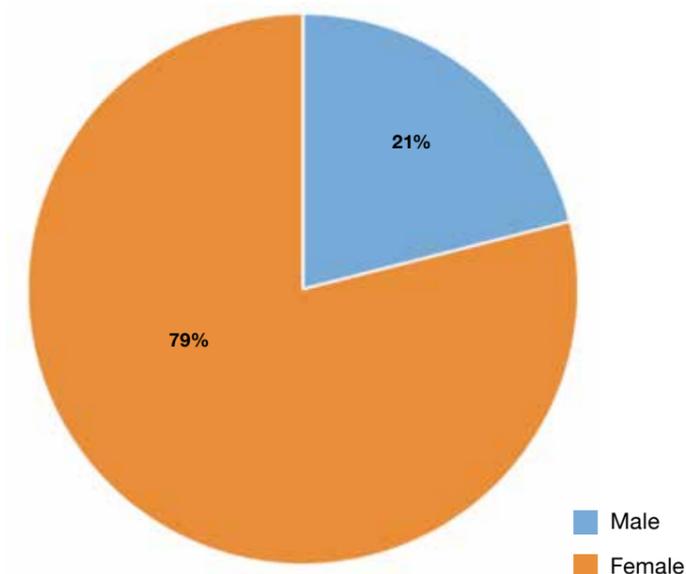
Number of Shared Lives scheme staff by worker type



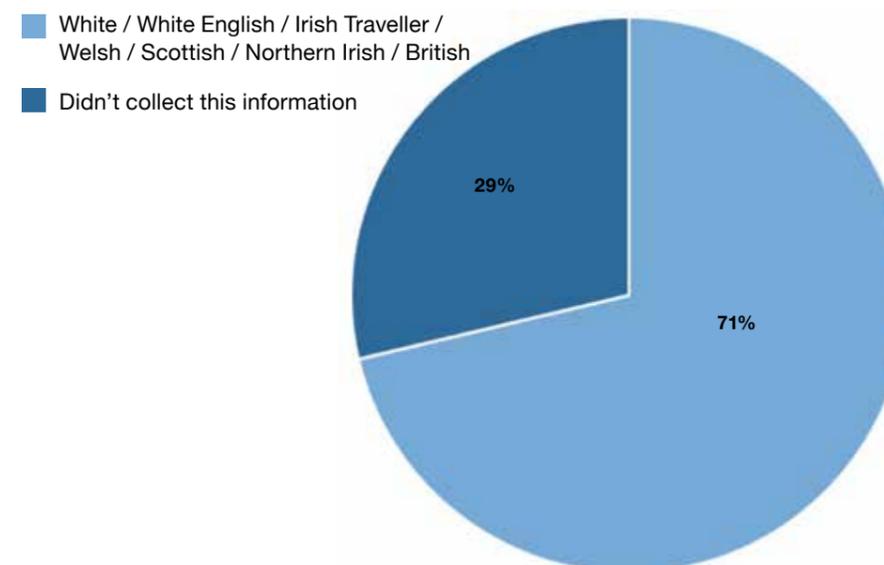
People working for Shared Lives by age, gender and ethnicity

- All Shared Lives staff are adults of working age.
- Of the 57 scheme workers in Wales 12 are male and 45 are female.
- The average ratio of Shared Lives scheme worker to Shared Lives carer within each scheme in Wales is 1:9

Gender of Shared Lives scheme workers



Ethnicity of Shared Lives scheme staff





"I am a full time Shared Lives carer, but I don't look upon it as a job. I get a huge amount of satisfaction from it."

Bryan & John

- Newport

Bryan & John are Shared Lives carers from Newport. They currently support two people in live in arrangements and also offer short breaks.

John says "I am a live in Shared Lives carer, but I don't look upon it as a job. I get a huge amount of satisfaction from it. Often, people come from not very happy backgrounds and it's really nice to be part of their development. The two guys we are supporting now are really part of the community. People in shops or the pub tell me "I saw your Alan or Phil today" or

the neighbours tell me that they were chatting to them on the bus. It's really good because if anything happens, we would know about it. They both have mobiles as well which they have been taught to use. We also have a wonderful relationship with family members. Alan regularly visits his sister's house – he goes there on the bus and gets taken out for lunch. His family know that this is Alan's home and they are more than welcome to pop in and visit him here in his own home environment too.

Spotlight on South East Wales



**SOUTH EAST WALES
SHARED LIVES SCHEME**
**CYNLLUN CYSYLLTU
BYWYDAU
DE DDWYRAIN CYMRU**

South East Wales is covered by one scheme known as the South East Wales Shared Lives Service (SEWSLS).

SEWSLS comprises six local authorities working together to deliver Shared Lives services to vulnerable adults across SE Wales, and includes; Blaenau Gwent County Borough Council, Merthyr Tydfil County Borough Council, Newport City Council, Caerphilly County Borough Council, Monmouthshire, and Torfaen County Borough. Interestingly, Merthyr Tydfil is not in SE Wales but as a small Local Authority wanted to join forces with other small authorities to maximise impact. The other five Local Authorities are exactly contiguous with a Local Health Board of which there are 7 in Wales. The scheme provides a full range of services, including; live in, short term, respite, emergency, and sessional support.

Having formed as a new partnership between the local authorities 3 years ago, the service has gone from strength to strength and now stands as the single largest scheme in Wales accounting for nearly half of the 970 people using Shared Lives across Wales.

The South East clearly dominates in its support for a wide range of categories, however still has scope to develop support for other groups of people including people with drug and alcohol issues or young people in transition to adulthood.

Development & Growth of Shared Lives in Wales

This is the first time such an in-depth study of Shared Lives in Wales has been undertaken. It paints an incredibly positive picture, one that has grown rapidly to help ensure hundreds of vulnerable adults across the country have real choice in how they are supported, and enjoy the opportunity of living a more typical family life. The picture is also one of immense opportunity, and at the end of 2015 Shared Lives stands on the precipice of change in Wales as the whole health and social care landscape sets to shift forever within a new legislative framework underpinned by the search for innovation and better outcomes. If Shared Lives is to move from being a much loved service enjoyed by hundreds, to one that is cherished by thousands as a mass market proposition in Wales then it is imperative to take advantage of this moment.

The past year has seen a significant growth, not just in the numbers of people using Shared Lives, but in the variety of social care needs of the people who use the service. More Shared Lives schemes are offering short breaks and day support as well as live in arrangements, making it a more attractive offer for a wider range of people looking for support.

This report demonstrates that Shared Lives is already a significant and highly effective part of the social care system. What is now needed is a concerted effort to drive forward this way of living experienced by the few, to one that can be enjoyed by the many.

