

# State of the Nation: Shared Lives in Wales

### February 2020



John with Jane, Shared Lives carer



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### **About Shared Lives**

A Shared Lives carer shares their home and family life with someone who needs support to live well and independently. The support they offer is flexible, tailored to the needs of the individual. It can be as little as a few hours a day once or twice a week, overnight stays and respite for family carers, or a long-term relationship where the person moves into the Shared Lives carers home. The care they provide is monitored by Shared Lives schemes that are regulated and inspected by the Care Inspectorate Wales to ensure high standards.

### Foreword



Julie Morgan AM, Deputy Minister for Health and Social Services

I am pleased to introduce Shared Lives Cymru's State of the Nation 2020 Report. Shared Lives schemes continue to deliver a positive model of care for people with often complex needs, whilst supporting them to live as independently as possible.

Reflecting upon 2018-19, Shared Lives carers now support over 1,100 individuals for the first time, a clear indication that people, including commissioners of services, increasingly know about and understand the benefits of its support.

Shared Lives schemes continue to provide a whole range of care and support for those in Wales who need it most. Through our Intermediate Care Fund (ICF), 2016 saw the launch of the Shared Lives Health Initiative, a preventative early intervention service delivering respite breaks and reablement schemes. This initiative continues to grow and in 2018/19, 117 more people used Shared Lives services for short breaks than the previous year – an increase of 7 per cent.

Shared Lives receives funding from the Welsh Government's Third Sector Sustainable Social Services grant (2016-20), to support older people. In 2018/19 more than 400 people, just over 36 per cent of people using Shared Lives services, were aged 50 plus. They have led the way offering day support to people with dementia, to help them stay active in the community.

All of this good work depends of course upon the wonderful people who choose to become Shared Lives carers, which is why I am pleased to see a 14 per cent growth in active Shared Lives carers over the past three years, with 81 recruited in 2018/19. The work Shared Lives carers do is invaluable, their compassion and support is remarkable.



Finally, I want to reiterate how important it is for us in Wales to make sure we are and continue to be, a caring nation, because everyone deserves to be valued and helped when they need it, to support people to live their "best life".

### Introduction



Babs Lewis, Rheolwraig Datblygu Cymru, Wales Development Manager

#### Shared Lives: meeting the challenge of integrated care

More than a thousand people are now supported by Shared Lives providers in Wales – a 24% growth in the last few years. For the first time, a Shared Lives scheme has won health funding for integrated support for people with mental ill-health; there are new services to support people with dementia in Gwynedd & Anglesey & services are being expanded in Rhondda Cynon Taf. Across Wales more short-breaks and sessional support is now being offered than ever before to prevent ill-health and help people live independently. Schemes have also recruited and approved 203 new Shared Lives carers.

The picture isn't all positive. Excellent progress in South East and North Wales overlay areas where lack of investment holds back growth. Direct funding from one health board is welcome, but others need to follow. Shared Lives Plus has worked with local authorities and health boards to secure future growth. Schemes too are supporting each other sharing knowledge and experience.

There is more to be done to develop Homeshare – the service that matches people with spare rooms, with people happy to lend a hand around the house, in return for affordable, sociable accommodation. Also, to work with Welsh Government to extend our services to young adults aged 16 and 17.

The Shared Lives Plus Development Team, with Welsh Government support, look forward to further growth in Wales, working with our membership, commissioners and the people using services to create more responsive, personalised and flexible care for the future.

For more information, contact Kathryn Morgan, Swyddog Datblygu dros Gymru/Wales Development Officer, 07867 452158, <u>kathryn@sharedlivesplus.org.uk</u>



### **Key messages**

- New, innovative, flexible Shared Lives services are now available in Wales, with thousands of hours of early intervention, prevention support being delivered in South East Wales
- If all schemes increased support for older people in line with the rise achieved by South East Wales Shared Lives more than 100 more older people could be supported
- 100 extra older people using Shared Lives support to stay independent in the community compared to residential care with nursing would save more than £1 million1 a year
- Shared Lives services have grown by 24% since 2015/16 with 1,118 people now accessing Shared Lives support to stay independent if this rate of growth persists another 268 people will be supported in Shared Lives by 2023
- Shared Lives in South East Wales has been commissioned by Aneurin Bevan Health Board to provide mental health crisis support – a first in Wales, leading the way for others.

<sup>&</sup>lt;sup>1</sup> Calculated on the cost of Shared Lives Health Initiative funding of £581/week/person, compared to residential care average rates of £40,744/annum or £783/week/person, an average rate for residential with some nursing care based on Laing Buisson Care of Older People UK Market Report 29th edition 2018 calculated via Paying For Care website <u>https://www.payingforcare.org/calculators/residential-care-costs/</u> accessed 3.12.19. Rates vary depending on area and type of care required Calculation:

Shared Lives care- £581 (weekly rate) x 100 people x 52 weeks (annual care) = £3,021,200Residential (nursing) - £783 (weekly rate) x 100 people x 52 weeks (annual care) = £4,071,600Saving £1,050,400

### Why commission Shared Lives?

#### Jo Williams, Assistant Director Adult Services Caerphilly,

explains why six local authorities are working with the Regional Partnership Board to expand Shared Lives services to deliver innovative care that helps people live well for longer. Local authority-based South East Wales Shared Lives scheme has grown consistently since launching the integrated Health Initiative in 2016

"Since 2012, when the six local authorities entered into a partnership in South East Wales to develop Shared Lives across the region, the benefits of Shared Lives have been proved. In the future we will be offering Shared Lives to more people and we will continue to develop our integrated working with health, focusing on prevention and supporting individuals to maintain wellbeing in their own homes and communities.

Shared Lives has an important part to play in reducing loneliness and isolation and supporting people to live fulfilled lives.

The South East Wales Shared Lives Scheme is going from strength to strength, offering highly personalised care and support to a growing number of people. We are seeing individuals achieve significant positive outcomes.

There have been some notable developments in the last year. Working in partnership with Aneurin Bevan University Health Board the scheme has established a Shared Lives service for individuals experiencing mental health crisis. The Health Initiative, providing preventative and hospital discharge arrangements, continues to grow. We are increasing Shared Lives opportunities for people living with dementia. The scheme as a whole has recruited more carers and provided more arrangements than in previous years.

The scheme has adapted and developed to ensure it continues to meet the needs of people living in South East Wales, with a focus on promoting wellbeing, choice and independence. Offering the flexibility of long term, respite, and sessional arrangements, Shared Lives is able to adapt to each person's needs and chosen personal outcomes while also being cost effective and locally delivered."

### **Key statistics**

### Number of people using Shared Lives services

For the first time in Wales, Shared Lives services help more than 1000 people in 2018/19:

- 1,118 people supported by Shared Lives carers
- a 14% increase (136 people) on the previous year<sup>2</sup>
- a 24% rise since 2015/16<sup>3</sup>

#### How people use Shared Lives

The trend over the last year has been away from long-term, live-in care to short-break or respite support to help people stay independent in the community for longer.

Short breaks are also increasingly available as reablement for people managing illhealth, older people and family carers. 117 more people used the service for shortbreaks now than the previous year – an increase of 7% - although most people in Wales still use Shared Lives for long-term care.

- 508 people (45%<sup>4</sup>) live with Shared Lives carers down by 8% on 2017/18
- 412 people (37%<sup>5</sup>) enjoy short-breaks and respite up by 7% on 2017/18
- 198 people (18 %<sup>6</sup>) use Shared Lives for day support same as previous years

<sup>&</sup>lt;sup>2</sup> 982 People supported 2017/18 compared to 1118 supported 18/19 an increase of 13.85%

<sup>&</sup>lt;sup>3</sup> 900 baseline in 2015/16 to 1118 people supported in 2018/19 = 24% rise over four years

<sup>&</sup>lt;sup>4</sup> 524 people (from a total 982) lived-in 2017/18, compared to 508 (total 1118) lived-in 2018/19 a decrease of 8% on the previous year

<sup>&</sup>lt;sup>5</sup> 295 people (from a total 982) had short-breaks/ respite in 2017/18, compared to 412 (total 1118) in 2018/19 a rise year on year of 7%

<sup>&</sup>lt;sup>6</sup> The percentage of day support remained stable from 163 or 17 % of the total 982 in 2017/18 to 198 or 17% of the total 1118 in 2018/19





- 1. People Supported Long-term
- 2. People Supported Short-breaks
- 3. People Supported Sessional
- 4. Total People Supported 2018/19

### Age of people supported

Many Shared Lives schemes now offer support to older people, including day support for families managing dementia. In 2018/19, just over 36% of those using the service were aged 50+ that's 409 people, compared to 21% young adults (18 – 24 years).

The percentage of older people supported has increased significantly with a 27% rise in the number of older people supported from 321<sup>7</sup> in 2016/17 to 409 in 2018/19. This includes 173 of the oldest age group.

# Growth in support for older people and people living with dementia

The most significant growth of Shared Lives care in Wales has been in short breaks and respite to help older people and those with dementia manage better in the community. In South East Wales Shared Lives there's been a 32% growth<sup>8</sup> in support

 <sup>&</sup>lt;sup>7</sup> Figure for 50-65 age group in 2016/17 is an estimate based on 16% of 955 (total supported in Shared Lives 2016/17) = 153, which when added to returns for the 65+ group of 168 = 321 This estimate reflects a different way of collecting age statistics in 2015/16 which did not account for 50-65 age group. The percentage increase from 321 over 50s supported in 2016/17 to 409 in 2018/19 is 27%
<sup>8</sup> From 54 (50-64 age group) + 61 (65+age group) = 115 in 2017/18 to

<sup>61 (50-64</sup> age group) + 87 (65+age group) = 151 in 2018/19 a 31% increase & a 43% increase in the oldest 65% group

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for people over 50 since 2017/18, and a 42% growth in support for people over 65 years of age.

If all schemes increased support for older people in line with the rise achieved by South East Wales Shared Lives over 100 more older people would be supported<sup>9</sup>

Across Wales support for older people this year has risen by 6.5% from 384 (17/18) to 409 (18/19)



<sup>&</sup>lt;sup>9</sup> Taking 2018/19 figures 32% of 165 = 53 (50+ group 231- 64 (SE Wales scheme) = 165), 42% of 91= 38 (65+ group 178 – 87 (SE Wales scheme) = 91), total rise in 50+ supported 101

### **Shared Lives carer statistics**

- Active Shared Lives carers are up by 14% growth in the last three years (2016/17 to 2018/19) from 738 to 842, a rise of 104 Shared Lives carers
- Recruitment figures show 203 new Shared Lives carers approved from 2016/17 to 2018/19, 81 new carers recruited in 2018/19 alone

### People behind the statistics:

#### New Shared Lives Carer Warren, Wrexham, Shared Lives PSS Cymru

What's the best background for a Shared Lives carer - someone who's been an entertainer from the tender age of four and trod the boards with legends like Barbara Windsor? Not the CV you were expecting? Well think again – Shared Lives carers need a capacity to care, life experience and a willingness to train with a Shared Lives scheme to deliver the best support possible.

Warren, a Shared Lives carer in Wrexham for PSS Cymru Shared Lives, has those qualities in abundance. By the time he came to Shared Lives he'd already been a foster carer and adopted two young people, Anthony and Emily. He says: "I want the people I

support to have good memories, to see what family life can be. I had a lovely upbringing and have nothing but good memories. That's something they don't have." Now he's been matched with Jamie, a young man who's experience of care is littered with broken arrangements, often because of his challenging behaviour. Warren says: **"It's about breaking the cycle, providing young people with the respect and stability they haven't had so they don't have to repeat their parent's mistakes."** Jamie can express himself now and, with the support of Warren's adopted

children, he has a nurturing home. And Warren always has PSS Cymru Shared Lives' support and training when he needs it - along with his capacity to care, it's a winning recipe. Left to right Jamie, Emily, Warren and Anthony







#### Sharing days: Glenys & Jill, Wrexham

Glenys wasn't feeling too well when we met to talk about Shared Days support in Wrexham. She'd had to call the paramedics after a fall a few nights earlier - the kind that might have ended in a hospital. But Glenys decided to stay at home. She felt confident she'd manage with her Shared Days support twice a week and a few hours domiciliary care. She says: **"I'm very lucky. I've had such kindness. It's the companionship that makes the difference. It stops me feeling isolated."** 

And, although their usual outing for lunch or to shop wasn't on the cards, having Jill around helped keep her spirits up. There

was practical help too. Jill spotted some things that might help Glenys recover and, with the PSS Cymru Shared Lives scheme officer, was able to feedback to the other services supporting Glenys stay independent. Glenys says: **"It is all about confidence. I know one day I'll have to sell up, but I want to manage as long as I'm able."** 

Glenys knows what it is to care for people. She nursed her husband after a heart attack, looked after a much-loved Aunt when she developed dementia and cared for her mother. Her own health failed when her mother died. She had a stroke, affecting her speech and mobility. It robbed her of her confidence, but she fought back to live independently, and her Shared Days support makes all the difference. She said: **"Shared Lives is wonderful. The ladies that come here are friends they look after me. Without them I wouldn't have the confidence to go out."** 

"Shared Lives comes here and makes it possible for me to carry on living, doing the things that matter. Otherwise I'd be stuck here day after day with just the occasional visitor."

She hopes she'll recover from her fall, and while she has Shared Lives support she knows she doesn't have to make any hasty decisions. She can manage her health herself until she feels well again.







#### Shared Lives for good health: Jen and Rachel

It took two years hard work and application for Jen to take control of her health and she couldn't have done it without Shared Lives support.

When Jen first moved in with Rachel, her Shared Lives/ adult placement carer in Bridgend, she was a dress size 28. Her weight affected her health and confidence. She didn't go out, had few friends and needed daily insulin injections. With Rachel's help she began to eat regular healthy meals that were portion-controlled. Rachel supported her to be more active and steadily the weight dropped off. Now a size



14, Jen's been able to reduce her diabetic medication and feels the condition is more manageable. She's confident, has made friends and loves to get out and about.

Rachel, a Shared Lives carer with ategi, has supported Jen for 15 years. **"My life** changed and I went through a bit of an upheaval. Shared Lives gave me the chance to work flexibly, bringing up my children and giving someone else opportunities at the same time".

Rachel supports two people in Shared Lives whilst raising her three children and studying for a degree. **"I'm pleased to give people choice, seeing them flourish is very rewarding.** Allowing people dignity and to protect their rights is important to me. Shared Lives gives you a purpose and the benefits are two-fold".

Jen's health and wellbeing have improved dramatically, now she enjoys yoga and tai

chi. She volunteers and has many friendships. "I walk the dogs, care for the chickens and help around the house. I'm in touch with my family and stay on weekends. This year I'll be going on a Caribbean cruise with Rachel and her family! This is my second home and Rachel's like a Mum to me".



#### Shared young lives: Callum and Andy, Powys

Callum lives a busy, independent life with Shared Lives carer Andy and his family. Before Powys Shared Lives scheme matched them, Callum had been in residential college and a series of foster placements. Callum says: **"I had some problems in the past with the amount of times I had to move, but since I came here things have really turned around for me." Andy says: "It was easy for us having someone else here. Callum came in the holidays, we got to know him. It seemed natural for him to live here."** 

Since moving in Callum has applied for his passport with Andy's help. Andy says: **"We did the paperwork, but Callum had to do a face to face interview. I went in** with him but couldn't speak. I was so proud when I saw how he handled it. He was fantastic."

Callum – a talented artist - was keen to travel to the USA

to a fandom convention for My Little Pony. He loves the friendship group and, on his trip, met many of the characters and the writer Meghan McCarthy. It was the trip of a lifetime.

He's started work too in a local Gaming Hub supporting people with autism. It's not all plain-sailing, as Callum grows in confidence, he also wants more independence, but Andy always has Powys Shared Lives to call on for support as their relationship develops. Now Callum's looking to the future. He's keen to develop the skills he needs to live independently. With Andy's help, he's become a very different young man to the one that came to stay in the school holidays.

#### See a film of Callum and Andy together https://en.powys.gov.uk/article/1901/Supporting-adults-Shared-Lives











#### Moving on: Sophie and Jenny, Vale of Glamorgan

Sophie's moving on – after four years support from Vale of Glamorgan scheme - she's got the keys to her own front door. Sophie was matched with Jenny by the Vale scheme as a teenager and has featured regularly in reports and attended many Shared Lives events. She felt ready to move this summer and is now looking forward to her first Christmas in her flat. She says: **"I always wanted to be independent. I loved living with Jenny – she was like a second mum – and I learned a lot but having a place of my own was always something I wanted."** 



With Jenny, Sophie was able to develop the skills she needed to live independently. Things like washing and ironing, shopping and cooking – all vital for the future. She also had the time, freedom and support to take on challenges and achieve ambitions before settling into her own home.

When she was ready to move on, the Vale of Glamorgan scheme worked closely with local authority colleagues to find a flat near family and friends. The scheme also made

sure when Sophie first moved in Jenny was on hand regularly to offer support. Sophie says: "One of the things I learned from Jenny when I was younger was to ask for help when I needed it and not to be scared. It did feel a bit strange at first being in your own place, but it is really special."

Her first-floor flat has breath-taking views over the city and countryside below, while inside Sophie's created the welcoming home she always wanted.





Who can say what makes a fulfilling life – as Matthew and Catrin reel off the places they been, the things they've seen and done, it is hard not to think some of us are missing out!

Catrin's a campaigner, happy to talk to local MPs, Assembly Members and others to get support for projects, including the local foodbank. She's also determined to use her right to vote.

Matthew is active too, helping at a charity to ensure no children go hungry in the holidays. He's also sat on the panel to approve new Shared Lives carers.

Life isn't all work though. They're keen theatre-goers and have seen a wealth of Royal Shakespeare Company productions, with top-flight actors, David Tennant, Ian McKellan, Patrick Stewart.

Shared Lives carers' Yvonne and Mark make this possible. Catrin and Matthew came to the family as babies, but in their forties, funding was withdrawn. Yvonne and Mark found out about Shared Lives and campaigned to get it for them.

#### Left to right: Matthew, Mark, Yvonne and Catrin

Now, with a handful of others, they're leading the way establishing Shared Lives as a long-term option for people in Wrexham.



As for being Shared Lives carers, Mark says: "It's a matter of focussing on the positives, not dwelling on things that are difficult. There's a lot we can do, and we do it together as a family."





#### A Safe Step into Adulthood: Kieron and Fay

When Kieron, 18, explains about his life in care, he describes it calmly and with maturity. Since the age of 7 he has lived in five different carer situations including his current home where he lives with his Shared Lives carer, Fay.

What matters to Kieron is: being treated as an adult, having a voice, being able to enjoy the things that are important to him, to have new experiences and learn from them. "I feel settled, safe and secure".

When he first heard about Shared Lives he was unsure about what it would be like. The well-planned transition and careful matching by the South East Wales Shared



Lives scheme enabled him to settle in quickly in his new Shared Lives home.

"I moved from Foster care into Support lodgings with three others but our needs were completely different. Shared Lives after only four months, has given me freedom and

space to make my own decisions, make mistakes and learn from them, as well as opportunity to learn new skills. At 15, I wanted to make my own decisions but felt restricted, I missed out on opportunities I could see other boys my own age having. I was treated differently which made me feel different to other people. I felt frustrated".

Kieron is a young man with aspirations to travel and compose his own music. His inspiration came from an American artist who had a troubled childhood, didn't always follow the right path but found success in music. "I would recommend Shared Lives, I have my own space, I'm taking the step into adulthood in a safe, supported environment that will enable me to learn the skills to live independently in the future".





### **Shared Lives schemes across Wales**

Local authorities	Local Health Board	Shared Lives scheme
covered		
Cardiff	Cardiff and Vale University	ategi Shared Lives
	Health Board	https://ategi.org.uk/
		Unit 6 Ty-Nant Court, Cardiff
Rhondda Cynon Taf	Cwm Taf University Health	CF15 8LW
	Board	029 2081 4800
Swansea, *Bridgend, Neath		SLSWales@ategi.co.uk
Port Talbot	Abertawe Bro Morgannwg	
	University Health Board	
	(From 1 <sup>st</sup> April 2019	
	'Swansea Bay UHB')	
Denbighshire	Betsi Cadwaladr University	Denbighshire Adult Placement
	Health Board	https://www.denbighshire.gov.u
		k/en/resident/health-and-
		social-care/carers/shared-
		lives/shared-lives-carers.aspx
		If you would like more
		information or advice, you can
		visit a Talking Point or contact
		the Single Point of Access.
Gwynedd Ynys Mon	Betsi Cadwaladr University	Cysylltu Bywydau Gwynedd a
(Anglesey)	Health Board	Mon
		Adult Placement Scheme Office,
		Cae Penarlag, Dolgellau,
		Gwynedd. LL40 2YB
		01341 424440 / 01341 424379
		adult.placement@gwynedd.gov.
		<u>uk</u>



Powys	Powys Teaching Health Board	Shared Lives Powys https://en.powys.gov.uk/article/ 1901/Supporting-adults- Shared-Lives Shared Lives Powys, The Gwalia, Ithon Rd, Llandrindod Wells, Powys, LD1 6AA 01597 827247 shared.lives@powys.gov.uk
Conwy, Denbighshire, Flintshire, Gwynedd, Powys, Anglesey (Ynys Mon)	Betsi Cadwaladr University Health Board	PSS – Person Shaped Support http://psspeople.com/contact- us/pss-wales Unit 5430, Abergele, North Wales Business Park, Conwy, LL22 8LJ. 01745 828000 wales@pss.org.uk
Blaenau Gwent, Caerphilly, Merthyr Tydfil, Monmouthshire, Newport, Torfaen Rhondda Cynon Taff, Merthyr Tydfil	Aneurin Bevan University Health Board Cwm Taf University Health Board	South East Wales Shared Lives https://www.caerphilly.gov.uk/s haredlives Penallta House, Ystrad Mynach CF82 7PG 01443 864586 Email via website
Vale of Glamorgan	Cardiff and Vale University Health Board	Vale of Glamorgan Adult Placement Service https://www.valeofglamorgan.g ov.uk/en/living/social_care/adul t_services/adult_placement_ser vice/Adult-Placement- Service.aspx 01446 700111 C1V@valeofglamorgan.gove.uk
Carmarthenshire, Ceredigion, Pembrokeshire	Hywel Dda University Health Board	West Wales Shared Lives http://westwalessharedlives.uk/ Block 8 Parc Dewi Sant Job's Well Road, Carmarthen SA31 3HB 01267 246890



### **About Shared Lives Plus**

We are the UK's only membership network for supportive shared living, for everyone involved in Shared Lives and Homeshare, which we promote with local and national governments. We believe everyone should be able to choose who they spend time with - and do what matters to them. We want to reduce loneliness and help make our communities more connected. We offer guidance, best practice, a community of people sharing their lives, legal advice and insurance.

In addition to being the UK network for Homeshare with 23 organisations across the UK, we are the voice for the UK's Shared Lives sector with 150 scheme members and 5000 Shared Lives carer members.

In Wales, over the last three years, we have been supported by Welsh Government through the Sustainable Social Services Third Sector Grant. Shared Lives Plus is funded by its membership and several significant project grants, including the UK Government, NHS England, Big Lottery Fund, Accelerating Ideas and Nesta, Lloyds Bank Foundation of England and Wales, Pears and Dunhill Medical Trust.

## Methodology

This is the sixth annual report on the state of the Shared Lives sector in Wales. In 2018/19 there were eight schemes in Wales – all members of Shared Lives Plus. Seven of the schemes responded to the survey covering all 22 local authorities in Wales.

Schemes provided comprehensive information, although data on age and support need was collected differently in different authority areas.

# Acknowledgement

We would like to thank all member schemes for their participation in the compiling of this report and the Shared Lives carers who took part in interviews and supported the Shared Lives Plus Development Team throughout the year.





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