SHARED LIVES/ADULT PLACEMENT IN WALES 2013
Caring for people in Wales

751 service users in last 12 months.

237 new successful referrals

- Learning Disability (76%)
- Mental Health (12%)
- Physical Disability (2%)
- Older People (2%)
- Elderly Mentally Ill (7%)
- Substance Abuse (1%)
- Dual Diagnosis (0%)
- Autism (0%)

Source: Shared Lives in Wales, 2013, Shared Lives Plus
Comparing Shared Lives with Residential

Residential Settings • Shared Lives

In Carmarthenshire the West Wales Adult Placement Scheme delivers 50% of the respite provision for people with Mental Health and Learning Disabilities for only 12% of the total cost!

Source: Shared Lives in Wales, 2013, Shared Lives Plus

Potential Savings

10 new long term Shared Lives arrangements generate potential per annum savings of between...

£23,400

£517,400

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Foreword

By Alex Tanner, Shared Lives Service User

Adult Placement (AP)* is an alternative model of support for vulnerable adults who may otherwise be placed in care homes. For me, AP is about going to an ordinary family and getting support to achieve what I want to do. But what does ‘ordinary’ mean? AP carers may not be ‘ordinary families’ in the strict sense of the phrase; they may be single people or couples, but they all lead ordinary lives. AP is such a diverse service and to simplify it would be to take away the details. This would not do it justice.

I have been receiving services from AP in West Wales since November 2009. AP suits me because of the flexibility it offers. It provides me with the opportunity to meet new people, try new activities and see how other people live. The activities that I have been doing with my AP carer include learning to cook, going swimming, riding my bike and going out to see films.

I am also the Vice Chair of the West Wales Consultative Group and in October 2011, I co-chaired the UK Shared Lives Plus Conference in Cardiff. In February 2012, I chaired the ‘service user / carer’ panel that was involved in the recruitment of the Wales Development Worker who authored this report. The position is funded by the Welsh Government and was established in response to an identified need to improve AP services across the whole of Wales.

For too long, we have not known exactly what AP services were being provided in Wales, by how many AP carers, or for how many vulnerable adults. The report provides an overview of the extent of current AP service provision in Wales. It also provides information about how AP schemes function and, in doing so, identifies what some of the challenges and demands are for those schemes now in and in the future. It also shows which places have a large amount of AP carers already, as well as places where further expansion is possible. All of the information is backed up by a wealth of statistics. Hopefully, you will enjoy reading the report and it will be useful to you.

I would like to thank everybody who contributed to the report, in particular the Wales Development Worker for collating and structuring the data herein.

Alex Tanner
(Service User, West Wales AP Scheme)

* Alex has used the term ‘Adult Placement’ throughout as he thinks this is the term that best describes the ‘model of support’ outlined in the first paragraph. However, the term ‘Shared Lives/ Adult Placement’ is used in the report to reflect the terminology used by schemes in Wales.
Introduction

Shared Lives Plus

Shared Lives Plus is the UK network for family-based and small-scale ways of supporting adults. Its membership includes Shared Lives carers and schemes, Homeshare programmes and micro-enterprises. Shared Lives Plus works with its members to:

• provide resources, training, insurance and one-to-one support;
• enable members to talk to, support and learn from each other;
• ensure that members can act as a network to influence national and local decision makers and the development of a more personalised social care system;
• raise awareness of the value of members’ work;
• commission research and strengthen the evidence base for our work.

In 2012, Shared Lives Plus received a funding grant from the Welsh Government for the post of a Wales Development Worker. The purpose of the role is to promote the Shared Lives model of care across Wales and to give a national voice to Shared Lives schemes. One of the first steps of the Wales Development Worker was to gather information from local schemes and to provide an accurate picture of the Shared Lives provision in Wales, which is presented in this report.

Shared Lives Plus history – from Adult Placement to Shared Lives

NAAPS (originally the National Association of Adult Placement Schemes) was launched on 30 June 1992 as the umbrella body for adult placement, now known as Shared Lives.

As the years progressed adult placement became increasingly tightly defined and services that did not quite fit the adult placement definition moved across to become associate members of NAAPS. In February 2008, after wide consultation, the membership decided that the words ‘adult placement’ should be replaced with the term ‘Shared Lives’, a term which indicated the mutuality of the arrangements. However, this was not reflected in the review of the regulations in 2010 and as a result a number of schemes in Wales continue to use the term Adult Placement. To reflect this Shared Lives/Adult Placement will be used throughout this report.

Shared Lives Plus now has 129 Shared Lives schemes as members and over 3,500 Shared Lives carer members – a number which increases every year.

In October 2011 NAAPS was renamed Shared Lives Plus.

In 2012, Shared Lives Plus received a funding grant from the Welsh Government for the post of a Wales Development Worker. The purpose of the role is to promote the Shared Lives model of care across Wales and to give a national voice to Shared Lives schemes. One of the first steps of the Wales Development Worker was to gather information from local schemes and to provide an accurate picture of the Shared Lives provision in Wales, which is presented in this report.
Shared Lives in Wales

From the early 1990s adult placement providers in Wales got together with each other and with colleagues across the UK to share ideas and to contribute to the growth and improvement of adult placement services.

The Welsh Branch of NAAPS met quarterly and representatives attended the UK Committee meetings but it was the beginnings of a clear regulatory framework in 2002/03 that led to NAAPS strengthening and becoming more organised. A devolved Welsh Assembly with autonomy over Health and Social Care issues resulted in specific regulations and National Minimum Standards for Adult Placements in Wales. The challenge of consultation around the proposed regulatory framework energised NAAPS members in Wales to form a strong and influential voice with Assembly Officers as well as with the inspectorate.

At the same time NAAPS formalised its charity status and a clear structure was introduced that recognised each country in the UK as having separate though comparable issues and challenges to face. The NAAPS Board of Trustees was constituted with ring-fenced seats on the Board for each of the four UK countries ensuring that members in Wales had a strong voice at strategic level. One of the first benefits of this was the development of the NAAPS Welsh Language Scheme in 2005.

Renamed to reflect the change in name of NAAPS, the Shared Lives Plus/ Cysylltu Bywydau Cymru Committee in Wales has a positive relationship with Welsh Government officials, senior officers in CSSIW and a positive dialogue with the Care Council for Wales. The Committee in Wales has representation currently from each of the 12 registered Shared Lives schemes including a ring-fenced seat for a Shared Lives carer from within each scheme.
The Shared Lives model of care

Shared Lives/Adult Placement is a regulated form of social care delivered by Shared Lives/Adult Placement carers who are approved by a registered Shared Lives/Adult Placement scheme.

Shared Lives/Adult Placement carers are recruited and approved through a rigorous assessment process which is itself subject to quality assurance by an independent panel. Shared Lives/Adult Placement always involves the Shared Lives/Adult Placement carer sharing their home and family life with the person using Shared Lives/Adult Placement. It can be offered to anyone aged 18 (or in some cases 16) or over.

Shared lives/Adult Placement care may include:

- long term accommodation and support or
- short breaks or other time limited live-in support, such as intermediate care or
- day time support.

A maximum of three people may be supported at any one time by a Shared Lives/Adult Placement carer. Shared Lives/Adult Placement arrangements always involve the following processes, all of which may also be found in other forms of regulated and unregulated care and support:

- Matching: Shared Lives/Adult Placement arrangements are formed using a matching process which involves participants getting to know each other at their own pace, before making any long term commitment to sharing home and family life.

- Monitoring and safeguarding by the Shared Lives/Adult Placement scheme: the registered scheme manager remains ultimately responsible for the quality and safety of care and support in every Shared Lives/Adult Placement arrangement.

- Self-employment: Shared Lives/Adult Placement carers are self-employed and can access the Shared Lives tax break. Shared Lives/Adult Placement carers are not paid by the hour and they do not work to a fixed schedule. They are paid in line with the expectations set out in the agreement. Shared Lives/Adult Placement carers do not directly employ staff to help them provide care.

- Payment for care is made to the scheme not the carer: whether the care and support is funded using Direct Payments, people’s own money or is commissioned by the council or NHS, the registered scheme receives payment for the care provided and pays the self-employed Shared Lives/Adult Placement carer. People using Shared Lives/Adult Placement are assessed to pay their contribution under Fairer Charging rules.

- Any longer term accommodation provided is arranged under a licence to occupy. People living in Shared Lives/Adult Placement arrangements may pay for their accommodation using Housing Benefit and pay their contribution towards food, utilities etc from their benefits or other income.

Some Shared Lives/Adult Placement schemes and individual carers may be involved in other activities which don’t involve the sharing of the home and family life of the carer but are in effect micro enterprises run from the homes or in the local community of a Shared Lives/Adult Placement carer. A couple of examples of these are given later in this report (Section 2. Shared Lives in Real Life)
Policy context

The Shared Lives/ Adult Placement model of care can meet a number of strategic aims and goals set up by the Welsh Government and the UK Government.

The Welsh Government’s **One Wales, One Planet** strategy places wellbeing amongst one of its key themes. It sets out ‘a vision of sustainable, attractive communities in which people live and work, have access to services, enjoy good health and can play their full roles as citizens’. Shared Lives/ Adult Placement is a model of care that goes beyond providing support and care to vulnerable individuals. It supports the development of sustainable and vibrant communities.

It achieves this in the following ways:

- **Shared Lives/ Adult Placement arrangements match people with disabilities or ill health with ordinary families who include them in their lives and introduce them to their extended networks. By including service users in ordinary families, Shared Lives/ Adult Placement arrangements normalise disability and reduce the stigma associated with disability and ill health.**

- **Service users who receive care from Shared Lives/ Adult Placement experience a range of positive outcomes including improved emotional and physical wellbeing, increased confidence, self-esteem and independence. They receive highly personalised and citizen-directed support in an area and a household of their choice. As a result, service users are able to remain close to their family and their support networks.**

- **Shared Lives/ Adult Placement carers enjoy fulfilling employment through supporting and caring in their local community and playing an active role as citizens. Shared Lives/ Adult Placement offers the opportunity for people to become self-employed and remain in their local area. This is of paramount importance for rural communities in Wales that are often driven to urban centres in search of employment. Shared Lives/ Adult Placement carers are self-employed individuals who deliver care in their own homes and in their own community. As a result, Shared Lives/ Adult Placement facilitates a shift from big government and government-run services to communities of individuals who are involved in the planning and the delivery of local services.**

- **Shared Lives/ Adult Placement encourages people to get along and treat one another with respect and dignity in line with the Community Cohesion Plan for Wales.**

Shared Lives/ Adult Placement arrangements have been delivering responsive and person centred services that are envisaged in the Welsh Government’s **Sustainable Social Services for Wales: A Framework for Action** white paper. Shared Lives/ Adult Placement carers become experts in the individual’s needs and how to best meet these.

Shared Lives/ Adult Placement provide highly personalised arrangements where decisions about support and care are made in partnership with the service user. The matching process takes into account service users’ wishes on where they want to live and the type of household they want to live in. The process also ensures that wherever possible the service user and the Shared Lives/ Adult Placement carer share the same interests and that the carer can support the service user to pursue their hobbies and interests.
‘We look not for independence and separateness, but for inter-dependency with those around us’, the paper states, and this is precisely our ethos. Shared Lives/Adult Placement supports service users to lead independent and fulfilling lives but independence doesn’t have to mean ‘living alone’.

Currently the majority of Shared Lives/Adult Placement arrangements are provided to adults with learning disabilities. Launched in 1983, the All Wales Strategy aimed to develop comprehensive local services for people with learning disabilities and to provide better access to ordinary community resources. The strategy focused on three main principles:

• the right to an ordinary life within the community
• the right to be treated as an individual
• the right to additional help and support in developing their maximum potential

These three principles have permeated through the development of future strategies for people with learning disabilities in Wales. The Shared Lives/Adult Placement model of care has and continues to deliver on these key values of providing people with ordinary and supported lifestyles in their communities.

Looking into the future, a number of Shared Lives/Adult Placement schemes expressed their aspirations to diversify the services that they deliver to include people with dementia. Such development plans could support the Welsh Government’s aim to develop Dementia Supportive Communities which ‘have the capacity to support people affected by dementia so they can enjoy the best possible quality of life’. Shared Lives/Adult Placement take a whole community approach in the care of individuals with support needs. In addition, Shared Lives/Adult Placement carers provide the stability and consistency in care that many older people with dementia require.

Finally, the Shared Lives/Adult Placement model of care can deliver value for money and significant savings for Local Authorities and government budgets, which are demonstrated in this report.

David – Swansea Scheme

David first came to Shared Lives/Adult Placement in December 2004 at the age of 68. Until then he had spent most of his life in institutions. In the 1980s, as a result of the All Wales Strategy, he was moved to a care home where they seem to have provided only for his basic needs. Apart from the friends he made among the other residents, David’s social life revolved around the day service.

Living with a family has transformed David’s life and he seems to be perpetually smiling. David is a very quiet gentleman who rarely initiated conversations when he first went to live with the Shared Lives/Adult Placement family but he is much more talkative and relaxed and feels able to join in conversations voluntarily without having to be encouraged to do so.

The Shared Lives/Adult Placement carers have a large extended family, including young grandchildren, who are frequent visitors to David’s home and he enjoys being an honorary uncle to the children.
Andrew – Ategi Shared Lives Scheme

Andrew is 44 years old and lived with his mum and dad all his life until a year ago. His mum suddenly became unwell and sadly died leaving Andrew to be supported by his dad. They have a great relationship but Andrew needs to have someone with him most of the time to explain things and to make sure he doesn’t wander off. Though Andrew can manage his own personal care, he needs someone to remind him to shower or clean his teeth. He also needs someone to help him contribute to preparing meals and doing his laundry, all of which was too much for his dad to cope with.

Andrew and his dad talked to a care manager about the kinds of places he could live. They were both very uncertain about the idea of supported living or residential settings as Andrew had no experience of sharing his space with a number of people. Andrew also became unsettled and withdrawn if he spent time with a number of different people. Andrew’s care manager knew about Shared Lives/Adult Placement so sat down with him and his dad to write down all the things Andrew would need support with; what he liked; what he didn’t like and any areas that may cause a risk to Andrew or a Shared Lives/Adult Placement family.

Having talked things through with the Shared Lives/Adult Placement carers, Brian and Mary, an introduction was arranged and they hit it off immediately with Andrew. He and Brian shared a wicked sense of humour and soon realised that they both supported the same football team but that Andrew had never been to watch them play. After several visits and two very positive weekend stays Andrew and his dad decided that it would suit Andrew to move in with Mary and Brian.

Through meeting Mary and Brian’s friends and family, Andrew became more confident with people and now looks forward to their family get-togethers and regular evenings at the social club. Andrew and Brian are now season ticket holders for their local team. Andrew sees his friends most days and invites his best friend over from time to time. Though he enjoys the day centre he has started a part time job two mornings a week helping a local shop keeper. Andrew and his dad speak frequently on the phone and they both look forward to Andrew’s visits to his dad every week. They plan to go away together for a fortnight in the Autumn.

The Shared Lives/Adult Placement Scheme worker visits regularly to make sure that Andrew, Mary and Brian are getting on well and that they continue to enjoy their lives together. Mary and Brian see Andrew as a real part of their extended family and can see that he has been welcomed by friends, family and neighbours.
Shared Lives/ Adult Placement to Independence

Linda – West Wales Scheme

Linda had been living with Pam for many years, during which time Linda had been supported to develop her self-confidence and independent living skills. She recently reached her ultimate goal and moved into her own flat.

Linda has been a very active individual within the world of Shared Lives Adult Placement participating in consultation on the review of regulations with the Welsh Assembly Government’s highest policy makers. She is able to make her feelings known and is also able to advocate in various meetings on behalf of other individuals to ensure that her and others’ rights are represented.

Pam acknowledges that during the time that Linda has been living with her, they have supported each other through good and bad times. For example, Pam has recently had a period of illness where she felt that Linda had provided her with invaluable support and understanding; in return Pam has supported Linda to rebuild relationships with her family as contact had been very difficult for many years.

Pam explained that she felt they worked well together as a team, and that their friendship will continue for many years to come, even though Linda has now moved on to live in her own flat. Linda enjoys visiting Pam and she is reassured that Pam is on the end of the phone should she need help.
Day support

Evan & Rhiannon – PSS TRIO scheme for people with dementia

Evan had not been out of his house for over a year having lost his confidence. With the support of a TRIO Carer, Evan is now matched with someone who shares his interest in music, nature and especially gardening. They both regularly visit the PSS allotment and local garden centres together.

‘Evan had very little social contact prior to accessing day services and was unable to leave the house without support. He had lost confidence due to his cognitive impairment and poor mobility. Evan is now able to go out and is paying his own bills and is able to do his own shopping where previously he was relying on home carers. His mobility has been steadily improving and through accessing the allotment has grown in confidence”

Shared Lives carer

‘I have something to look forward to now and I can’t ask for more - It gets me out of the house and it couldn’t get any better!’

Evan

Rhiannon was diagnosed with Alzheimer’s type Dementia in 2007 and began to experience episodes of paranoia and anxiety, believing people were entering her home and stealing things from her. She lived alone and had become socially isolated as her brother lived some miles away. Rhiannon was a very independent person and wanted to remain so for as long as possible and initially was extremely reluctant to accept any kind of support. Eventually, through guidance and reassurance from the PSS TRIO Scheme, Rhiannon was matched with another lady with a similar background and interests, who was also a Welsh speaker, and they have now become good friends.

‘I enjoy the ride out and look forward to the company; I don’t know what I would do without it!’

Rhiannon
**Micro-enterprise**

Tony is a metal sculptor. He and his wife Helen have run 4 successful day service projects working with small groups of vulnerable adults in his workshop at their home in Cych Valley in Pembrokeshire.

Their latest project was the golden dragon guarding the gateway to Newcastle Emlyn castle. It has involved 4 service users, Craig and Wyn from Pembrokeshire and Jean and Rhian from Carmarthenshire working with Helen and Tony to create the golden dragon. One of the highlights of the project was on Thursday 20th January 2011 when Gwenda Thomas, Deputy Minister for Social Services, Welsh Assembly Government visited Newcastle Emlyn and met everybody involved in the project and was able to admire the dragon for herself.

The Minister commented “I have been extremely impressed by what I have learnt about Adult Placement and am very humbled by the work of the Adult Placement carers. It is good to see councillors, officers and Adult Placement carers from Pembrokeshire, Ceredigion and Carmarthenshire here today. This is a model of how working together can provide excellent outcomes for those using Adult Placement services and for their families.”

As with all projects that Helen and Tony have been involved with, the outcomes for all concerned, especially service users, have been great with everybody being able to take a great deal of pride from their achievements. The outcomes are perhaps best summed up in comments made by service users:

“*I have enjoyed coming to work on the dragon project. It has been interesting to learn new skills such as bending, filing and cutting metal. I look forward to seeing the dragon in its permanent location. I am sure it will be a lasting monument.*”

“*I have learnt to use different tools in the workshop. I like bending the rods best. Working with Tony is good.*”

“*I have enjoyed seeing the dragon grow each week and also lunch break when we can all have a chat around the table.*”

For both Craig and Wyn this project has been their first experience of Shared Lives/Adult Placement. Family members and others have commented on the change that they have noticed in both Wyn and Craig in terms of their confidence and ability to relate to others. On finishing the project Craig’s father has phoned Helen and Tony to give his thanks and appreciation for the work that Craig has achieved. Craig is now beginning a work training placement in a woodwork company.
Shared Lives/ Adult Placement Schemes in Wales

There are the 12 following schemes currently in Wales. The oldest scheme in Wales has been running in Swansea for 28 years whilst the newest scheme is the South East Wales Adult Placement Scheme (SEWAPS) which became operational in April 2012.

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<th>Type of area</th>
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<td>Urban</td>
<td>Local Authority</td>
<td>1 Manager with additional responsibilities, 1 Officer, 1 P/T Officer</td>
</tr>
<tr>
<td><strong>West Wales Scheme</strong></td>
<td>Carmarthenshire, Ceredigion, Pembrokeshire</td>
<td>Rural</td>
<td>Local Authority partnership between 3 authorities</td>
<td>1 Manager, 1 Deputy Manager, 7 Officers &amp; 1 P/T Officer, 1 Finance Officer, 2 Initial Assessment Officers &amp; 1 P/T Officer, 1 Support Officers &amp; 1 P/T Support Officer</td>
</tr>
<tr>
<td><strong>Vale of Glamorgan</strong></td>
<td>Vale of Glamorgan</td>
<td>Urban/rural</td>
<td>Local Authority</td>
<td>1 Manager, 1 Deputy Manager, 3 Officers</td>
</tr>
<tr>
<td><strong>Wrexham</strong></td>
<td>Does not have any arrangements</td>
<td></td>
<td>Local Authority</td>
<td>1 P/T Manager with additional responsibilities</td>
</tr>
</tbody>
</table>
Shared Lives/ Adult Placement Arrangements in Wales

In the last 12 months, Shared Lives/ Adult Placement schemes in Wales worked with 512 carer households. In some households more than one person is an approved Shared Lives carer which brings the total number of carers approved by Shared Lives schemes to 676. Over the 12 month period, these 676 Shared Lives carers provided 1,423 long-term and short-term arrangements and 127 day support arrangements. The total number of nights provided by 7 schemes was 85,985.

As the sizes of the schemes vary, so do the number of arrangements that they provide. The table below includes the total numbers for the whole of Wales as well as an indication of the range of variation by providing the lowest as well as the highest numbers currently in Wales. More detailed information is provided in the attached map (appendix 1)

<table>
<thead>
<tr>
<th></th>
<th>TOTAL</th>
<th>Lowest</th>
<th>Highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared Lives households</td>
<td>512</td>
<td>13</td>
<td>132</td>
</tr>
<tr>
<td>Service users supported</td>
<td>751</td>
<td>12</td>
<td>207</td>
</tr>
<tr>
<td>Arrangements</td>
<td>1,423</td>
<td>15</td>
<td>451</td>
</tr>
</tbody>
</table>

11 Shared Lives schemes were interviewed for the purposes of this report. A meeting was held with the Wrexham scheme but as the scheme has not been able to recruit any Shared Lives/ Adult Placement carers since it has been set up, no data was collated from the scheme.
Service cost

The research *A Business Case for Shared Lives* found that Shared Lives/Adult Placement arrangements not only deliver better care, fairness and opportunity for service users, they also provide better value for money. Compared to the national unit cost of residential care, Shared Lives can deliver potential savings of up to 60% for people with learning disabilities, 10% for older people and 30% for people with mental health issues.

- 10 new long term arrangements generate savings of between £23,400 (older people) and up to £517,400 (learning disabilities).
- Potentially a new scheme for 85 people costs £620k over 5 years, with savings of nearly £13m (reduced use of more costly alternatives).

The research was undertaken in South East England and a more specific cost benefit analysis utilising Welsh data needs to be undertaken to develop a Business Case for Wales.

Some initial figures demonstrate the savings that Shared Lives/Adult Placement arrangements can deliver. In Carmarthenshire the West Wales Adult Placement Scheme delivers 50% of the respite provision for people with mental health and learning disabilities for only 12% of the total cost.

<table>
<thead>
<tr>
<th>Provision</th>
<th>Cost</th>
<th>Unit cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>West Wales Shared Lives/Adult Placement Scheme</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>89 service users</td>
<td>£159,381</td>
<td>£51.23</td>
</tr>
<tr>
<td>3,111 respite nights</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Residential Settings</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>85 service users</td>
<td>£995,619</td>
<td>£325.47</td>
</tr>
<tr>
<td>3,059 respite nights</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Schemes across Wales operate various payment models. For example some schemes pay a flat rate to all Shared Lives/Adult Placement carers whilst five schemes operate a banding system to reflect the different levels of support provided by the carers. This allows for Shared Lives/Adult Placement carers who provide higher levels of care – for example personal care – to be remunerated for that additional support. However, one scheme argued that often service users who are considered to have lower needs because they are mobile and independent are more likely to get themselves into trouble by ‘mixing with the wrong people’ and take unnecessary risks. As a result, this may mean that Shared Lives/Adult Placement carers provide higher level of support, which is not always financially acknowledged.

Some schemes also expressed concerns that a banding system may discourage Shared Lives/Adult Placement carers to support service users into independence. PSS puts strong emphasis on promoting independence and this is explained to Shared Lives/Adult Placement carers from the start so that they are aware of the fact that arrangements may be temporary or that their payments may reduce with time. The Vale of Glamorgan Scheme has an agreement with the housing department so that service users who are ready to move to independence have a ‘golden status’ and are given priority access to social housing.
If we remove the two payments at either end of the spectrum, the average payment to Shared Lives carers in Wales is £365. However, benchmarking and cost comparison across schemes was difficult to establish, as the way in which schemes pay carers varies significantly. Payments are made up of the following components:

<table>
<thead>
<tr>
<th>Cost</th>
<th>Liability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fee for care &amp; support</td>
<td>Community Care Budget (service user assessed under Fairer Charging to contribute to this)</td>
</tr>
<tr>
<td>Contribution towards rent</td>
<td>Service user via Housing Benefit</td>
</tr>
<tr>
<td>Contribution towards food &amp; utilities</td>
<td>Service user using their own income or recovered through Fairer Charging</td>
</tr>
<tr>
<td>Personal care</td>
<td>• No additional payment paid – one flat fee</td>
</tr>
<tr>
<td></td>
<td>• Additional component paid on top of the flat fee</td>
</tr>
<tr>
<td></td>
<td>• Care component incorporated into a higher band</td>
</tr>
<tr>
<td>Respite</td>
<td>• Social Services budget for 56 weeks to incorporate 4 weeks of respite. During this period both the Shared Lives carer and the respite provider receive payments from the Local Authority.</td>
</tr>
<tr>
<td></td>
<td>• Shared Lives carers receive higher payments to allow them to purchase respite for service users when they need to</td>
</tr>
<tr>
<td>Core cost</td>
<td>• Management charge added onto main fee</td>
</tr>
<tr>
<td></td>
<td>• Separate funding grant to run the scheme</td>
</tr>
</tbody>
</table>

*These are paid by the Local Authority*

Denbighshire service user contributions are provisionally set at the beginning of the arrangement. After the first three months and then annually they are reviewed to reflect the actual bills and expenditures of the household. In the SEWAP Scheme service users receive a Licence Agreement that has an exact breakdown of service user contributions (service charges) which include:

- Lighting and heating
- Telephone (facilities and equipment)
- Carer cleaning
- Laundry
- Food
- Water rates

Finally, the core costs for running the schemes which include staffing, office rents, expenses etc are not included in these calculations. Third Sector providers may add a management charge on top of the cost of an arrangement. Other providers may get an annual grant from the local authority that covers all the running costs.

The Powys scheme – although part of the Local Authority – operates on a unique business-like financial model. The scheme has received a start-up loan from the Local Authority and a subsequent developmental grant from Supporting People. These have been used to grow the scheme and generate revenue. The revenue was subsequently used to pay off the loan and to sustain growth.

Only one scheme has experience with Direct Payments. At the moment it funds two arrangements in this way but hopes to expand on the model, as it would allow the scheme to provide flexible support without having to enter agreements with different local authorities. Although the service user is buying the service directly, the arrangement is set up and monitored by the scheme.
Shared Lives/ Adult Placement Carers

a. Population in Wales
The latest (2011) census puts the population in Wales at 3.06 million. The number of people in Wales aged 65 and over (562,544) was the highest seen at any census and it accounts for over 18% of the overall population.¹ The number of people over 90 now stands at 25,200, which is a 25% increase since the 2001 census. In addition, Wales had a higher percentage of residents with a long term health problem or disability than any England region - just under a quarter (23 per cent, 696,000).²

This ageing of the population in Wales will have an impact on the demand for social care services and could present an opportunity for growth for Shared Lives in Wales. A study undertaken by LE Wales on the provision of respite in Wales projects a 42% increase in the number of people who will require 20 hours of care by 2030.³

The population living in Wales predominantly identifies its ethnic background as white. The highest percentages of people from a non-white background are concentrated in the urban centres, Cardiff (19.7%), Newport (13%) and Swansea (8.5%).⁴ The definition of white background only includes English/Welsh/Scottish/Northern Irish/British and excludes any other white backgrounds.

According to a 2010 survey, 24.8% of people living in Wales report that they can speak Welsh. The percentages range significantly across the country, from 15.5% in Bridgend and Blaenau Gwent to 70.5% in Gwynedd. ⁵

b. Diversity of Shared Lives/ Adult Placement carers
The following section provides information regarding the background and diversity of Shared Lives/ Adult Placement carers. Some schemes do not collate such information so the breakdown only represents the data received. In each section the number of schemes that supplied data is presented.

i. Welsh Language
According to data provided by 10 schemes, 87 (16.4%) Shared Lives/ Adult Placement carers are Welsh speakers. Most schemes only included first language speakers but some were able to separate these into first language speakers (33) and people who have learnt Welsh (54). Appropriate cultural and linguistic matching is really important in Shared Lives/ Adult Placement arrangements. As one scheme pointed out, when Welsh speaking service users were matched with English speaking carers, the service users were unable to communicate their needs and their behaviour was unfairly labelled as challenging.

Recruitment for Welsh speaking Shared Lives/ Adult Placement carers in some rural areas has been challenging and a strategy should be developed to raise the profile of Shared Lives/ Adult Placement schemes in these communities.
ii. Gender

Based on the data supplied by 9 schemes, two thirds of the Shared Lives/Adult Placement carers are female. If we consider that a significant proportion of Shared Lives/Adult Placement carers are couples, this would suggest that most of the male carers provide support as part of a couple.

iii. Sexuality

Many schemes were not able to provide an accurate answer on the sexuality of their Shared Lives/Adult Placement carers. There were only 10 Shared Lives/Adult Placement carers identified as gay.

iv. Age

Over half of the Shared Lives/Adult Placement carers were older than 55 (data provided by 8 schemes). This is to be expected considering that providing Shared Lives/Adult Placement support requires a high level of commitment and stability from Shared Lives/Adult Placement carers, often including financial stability in the form of a spare room. People over 55 are most likely to find themselves in a position to be able to commit to Shared Lives/Adult Placement and to have the necessary space. However, the overrepresentation of people over 55 raises concerns about the sustainability of arrangements over a long period of time, particularly for younger service users.

v. Ethnicity

Only two Shared Lives/Adult Placement carers were from a Black and Minority Ethnic (BME) background. This accounts for 0.6% of the total number of Shared Lives/Adult Placement carers (based on the data of 9 schemes). This is significantly lower than the percentage of the non-white population in Wales (6.8%) and demonstrates the challenge of schemes to recruit carers from a BME background.
c. Shared Lives Plus membership

397 Shared Lives/Adult Placement carers (267 households) of the total of 676 carers (512 households) are Shared Lives Plus members. Some schemes pay for all their carers' membership, others pay both for membership and public liability insurance whilst others pay for the insurance of respite carers only. The approach of different schemes towards promoting the Shared Lives Plus membership means that it fluctuates mainly between two extremes.

d. Recruitment

In the last twelve months schemes received 150 applications from potential Shared Lives/Adult Placement carers.

Four schemes have actively not advertised for a number of years (up to 5 years). This is either because they have been getting sufficient interest through 'word of mouth' or because there hasn't been a need to seek new Shared Lives/Adult Placement carers for existing arrangements. Unfortunately, a number of schemes are working up to (or exceeding) their capacity and there is a reluctance to increase demand for services without adequate growth and resourcing of the scheme by local commissioners.

The most successful route for recruitment quoted by all the schemes is 'word of mouth' and the reputation of the scheme. Other recruitment tools used by schemes have been newspaper adverts, radio and TV adverts as well as leaflet drops to libraries, GP surgeries and community centres, leafleting in local areas such as a local supermarkets and local events. One scheme is considering targeting staff in the social care sector who are threatened with redundancies.

The Powys scheme was able to initially set up a number of arrangements without the need for recruitment. This was achieved by formalising existing informal arrangements and managing the transition from foster care and small residential care setting.

Some Shared Lives/Adult Placement carers have been introduced to the idea by their parents who cared for vulnerable adults in their homes whilst they were growing up. Shared Lives/Adult Placement carers talked about the value of their children growing up in a family unit that also included people with disabilities and additional needs. By including vulnerable adults in families and their extended networks and community, Shared Lives/Adult Placement schemes break barriers and remove the prejudice that these groups often experience.

Karen – West Wales Scheme

Karen – West Wales Scheme

Karen, from near Llandysul, has been a Shared Lives/Adult Placement carer for almost six years.

“In a way, it is my job, but it is also a way of life for me – I gain as many new experiences as they do. My children really enjoy having people to stay too. They think nothing of having people in their home, and class them as their friends also.

Being a Shared Lives/Adult Placement carer fits in with my life. You do need patience and understanding, and to be caring and flexible. If I was to give any advice to someone thinking of Shared Lives/Adult Placement, I’d say just go for it!”
Building real communities

However, this process doesn’t always happen across all socio-economic classes. One scheme pointed out that Shared Lives/Adult Placement carers from poorer socio-economic backgrounds are disadvantaged by the recruitment process, as they are required to bear certain expenses (safety certificates, adaptations) and there is a significant waiting period until they are approved. The precarious nature of Shared Lives/Adult Placement arrangements also means that Shared Lives/Adult Placement carers cannot rely on a steady income and poorer carers drop out. In addition, service users who are moved from Shared Lives/Adult Placement arrangements to independent living - often in deprived areas of social housing – have not had the opportunity to build appropriate networks within those communities and may feel vulnerable and isolated. The scheme is exploring the option of securing grants to support Shared Lives/Adult Placement carers who cannot afford all these additional costs so that there is a wider representation across the social classes.

Another scheme pointed out that the current recession has impacted on the availability of respite carers who have sought out other forms of employment to make ends meet.

55 Shared Lives/Adult Placement carers in Wales are ex-foster carers whilst 48 are former small residential home providers.

Simon – Transition

Simon has lived with the Dawes family since he was 8 years old and is now aged 23. In order for Simon to continue living as part of a loving and supportive family Tony and Lynne Dawes became approved Shared Lives/Adult Placement carers in September 2006. The very ordinariness of Simon’s placement, him being able to share the highs and lows of real family life, is perhaps what makes it quite extraordinary.

Simon is a sports fanatic and like many Welsh 23 year old men loves rugby, football and motorsports. However, Simon is fortunate enough not just to be able to watch these sports from the comfort of his own home but actively lives and breathes them. He has a work placement at Stebonheath, the home of Llanelli AFC where he is a valued member of the ground-staff. He is a passionate and committed member of Llanelli Warriors RFC picking up Man of the Match Awards on a regular basis. He indulges his love of motorsport by being a spectator at rally races and helping Lynne and Tony’s son prepare and maintain his rally car. In addition to this, Simon has also represented his country at the Winter Special Olympics in skiing competitions.

Anybody looking at the Dawes family would not recognise Simon as anything other than a member of the family. He proudly acted as usher at Lynne and Tony’s son’s recent wedding cutting a dash in a kilt and is now keenly looking forward to the arrival of a new baby to the family this Christmas.
e. Retention

All schemes talked about a very high level of retention of Shared Lives/ Adult Placement carers post approval with some arrangements being in place for many years – some over 20 years. But retention of new Shared Lives/ Adult Placement carers is also prevalent which assists the growth of schemes. For example, 47% of carers have been with the West Wales scheme since 2007 or before.

This seems to be the result of careful recruitment and matching. Many schemes talked about a process ‘weeding out’ individuals at an early stage of the assessment process by being very clear with people interested in becoming Shared Lives/ Adult Placement carers about the requirements of the role and the level of commitment required. PSS also attributed their high retention levels to the fact that carers had a sense of ownership in the scheme.

Shared Lives/ Adult Placement has a good record in adult protection and there have only 3 Shared Lives carers de-approved following POVA investigations. A number of carers drop out due to retirement or other personal, family or health issues.

Gwynedd Shared Lives/ Adult Placement carer, Helen Charlton won the Medal of Excellence from the City and Guilds in London.

After her presentation there, she was then “presented” with it again by Morwena Edwards (Head of Social Services) and Cnllr Paul Thomas Portfolio Leader for Healthy Gwynedd.

Helen Charlton was the first ever in Gwynedd to be awarded this medal!!
f. Training

Seven schemes use ‘Learning the Ropes’ including schemes that have adapted the manual or use only parts of it. ‘Learning the Ropes’ is the training manual developed by Shared Lives Plus. It includes learning opportunities linked to 25 knowledge and skills statements that Shared Lives/Adult Placement carers should acquire before becoming approved. Induction training into the role of a Shared Lives/Adult Placement carer varies across schemes. Some schemes explained that this may be done as part of the assessment process whilst other schemes provide a thorough induction training over a number of days, for example a weekend.

Standard training sessions will also include (list not exhaustive):

- First Aid
- Food Hygiene
- Health & Safety
- POVA
- Manual Handling

Whilst Shared Lives/Adult Placement carers working with service users who have specific needs may attend training sessions such as:

- Mental Health
- Epilepsy
- Dementia

A small number of Shared Lives/Adult Placement carers have also completed an NVQ qualification, although there is no requirement defined in Regulation.

g. Carers’ meetings

Shared Lives/Adult Placement carers’ involvement and participation in the scheme’s development varies across the nation. All schemes run regular carers’ groups. Many use the carers’ meetings as an opportunity to keep in touch with Shared Lives/Adult Placement carers and provide training.

- The West Wales Scheme has set up a Consultative Group that includes Shared Lives/Adult Placement carer representatives from the 3 Counties, service users and scheme officers. The group has its own terms of reference and is chaired by an independent chair.
- The Gwynedd scheme has separated groups in small localities due to the large geographical area that the scheme covers.
- PSS have run events such as ‘Who pays what?’ which generated a lot of interest amongst Shared Lives/Adult Placement carers. They also have a half hour session before structured meetings where carers discuss issues between themselves.
- The majority of Shared Lives/Adult Placement carers’ groups are organised and facilitated by the schemes. However, the Bridgend carers’ group has its own constitution and has set up its own charity that organises fundraising events and social gatherings.
Service users

In the last 12 months, Shared Lives/ Adult Placement carers provided support to 751 service users. They received 384 new referrals of which 237 were met.

a. Arrangements

During the same period, Shared Lives/ Adult Placement schemes provided 1,423 arrangements. At an initial count over half of these were short-breaks. The LE Wales research identified some gaps in respite provision that Shared Lives/ Adult Placement could aim to meet. Some of the areas where carer needs are particularly poorly addressed that were mentioned most frequently to LE Wales were:

- Those living in rural areas;
- Emergency respite services;
- Services for carers of those with mental health and dementia problems;
- Services for carers of those with complex needs;
- Services for carers of those with Autism Spectrum Disorder;
- Services for carers of younger adults (aged 25–40);
- Services for BME carers;
- Services for young carers;
- Services for carers of children and young people, particularly:
  - The transition to adulthood;
  - Those at the lower end of the autistic spectrum and those with challenging behaviour;
  - Day centre provision;
  - Provision for families to have short breaks together;
  - Asylum seeker/refugee children;vi

b. Diversity Monitoring

Many schemes do not hold monitoring data on service users. Information was gathered on only 257 service users. The gender of the service users is split almost exactly in the middle (male 128 – female 129).

- 5 service users (2%) were from a BME background
- 2 service users (0.8%) schemes identified as gay
- 28 (11%) service users were Welsh speakers (21 of these are supported by the Gwynedd Scheme)
- The age breakdown seems quite equally split across the three categories.

<table>
<thead>
<tr>
<th>Age Breakdown</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-34</td>
<td>78</td>
</tr>
<tr>
<td>35-54</td>
<td>85</td>
</tr>
<tr>
<td>55+</td>
<td>94</td>
</tr>
</tbody>
</table>
As in many parts of the UK, Shared Lives/ Adult Placement arrangements in Wales were predominantly provided to service users with learning disabilities (75%).

<table>
<thead>
<tr>
<th>Type of need</th>
<th>Number*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Disability</td>
<td>348</td>
</tr>
<tr>
<td>Mental Health</td>
<td>54</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>7</td>
</tr>
<tr>
<td>Older people</td>
<td>11</td>
</tr>
<tr>
<td>Elderly Mentally Ill</td>
<td>34**</td>
</tr>
<tr>
<td>Substance Misuse</td>
<td>3</td>
</tr>
<tr>
<td>Dual Diagnosis</td>
<td>1</td>
</tr>
<tr>
<td>Autism</td>
<td>3</td>
</tr>
</tbody>
</table>

* One of the schemes was not able to provide such data breakdown whilst another scheme provided incomplete data, which was therefore not included.

** The Trio Project delivered by PSS for people with dementia accounts for 30 of the 34 arrangements for Elderly Mentally Ill people.

**Emergency placements**

23 arrangements were emergency placements. One scheme has a highly skilled individual specifically delivering emergency support. He is paid in advance a regular amount which is then topped up depending on the number of arrangements that he has provided. Another scheme has a strict policy against unknown emergency placements.
Shared Lives/ Adult Placement staff

Shared Lives managers and officers hold the following qualifications.*

<table>
<thead>
<tr>
<th>Qualification</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health related (ie. nursing)</td>
<td>2</td>
</tr>
<tr>
<td>Qualified Social Worker</td>
<td>14</td>
</tr>
<tr>
<td>Educational (ie. teacher)</td>
<td>2</td>
</tr>
<tr>
<td>Housing</td>
<td>1</td>
</tr>
<tr>
<td>Other care/ management qualification including NVQ</td>
<td>19</td>
</tr>
</tbody>
</table>

* One scheme did not provide this information whilst some schemes did not account for every member of staff.

One scheme felt that the expectation on the Shared Lives/ Adult Placement carers to be trained is greater than that on officers and there should be an appropriate qualification in Social Work otherwise it will be difficult to raise the profile of the model amongst commissioners.

Currently, there is no established minimum qualification framework for Shared Lives/ Adult Placement staff, which is something that the Shared Lives Plus could explore with the Welsh Government and the social care workforce regulator, Care Council for Wales.
Recommendations

All of the schemes attend the Wales Committee Meetings, schemes in the South West have set up a regional group attended by local schemes whilst there are plan for a similar group to be set up in North Wales.

Schemes provided the following recommendations about the development of Shared Lives/Adult Placement in Wales:

• **Breaking the pattern of care managers doing ‘the same old thing’ when considering care options**

  Two schemes described awareness amongst care managers about the Shared Lives/Adult Placement model of care as poor whilst three schemes talked about a mixed picture that could be improved. One scheme piloted a project working with older people, which had strategic buy-in from the local authority. However, it did not take off the ground because it was lacking the necessary referrals from the older people’s teams.

  Another issue raised was the use of Shared Lives/Adult Placement arrangements as a crisis management tool. A more proactive and planned approach could promote more personalised options of care and prevent the institutionalisation of service users in residential settings.

  In Carmarthenshire Shared Lives/Adult Placement is the default option of care. Care managers will have to consider a Shared Lives/Adult Placement arrangement for service users first and justify the use of other forms of care if a Shared Lives/Adult Placement arrangement is not utilised.

• **Providing expert technical support on complex issues**

  Developing, sharing and mainstreaming good practice guidance in different areas of work. This could also include supporting individual schemes in developing specific procedures, sharing expert knowledge and providing advocacy support.

• **Co-ordinate marketing and promotion of Shared Lives/Adult Placement across the whole of Wales**

  Almost all of the schemes talked about the need to raise the profile of the Shared Lives/Adult Placement model in Wales. Some schemes considered the option of common marketing and advertising material that schemes can personalise with their own logos and contact details. Others went further to suggest joint resourcing and commissioning of advertising. This would require a central point to receive phone calls from potential Shared Lives/Adult Placement carers and signposting interested parties to the most appropriate scheme.
• One unified approach to regulation and inspection

Three schemes identified inspections as one of the main areas of concern for them. Many schemes talked about inspections being geared towards residential settings. This was evident in CSSIW's communication about upcoming inspection visits, forms and paperwork relating to the inspection and, most importantly, the inspectors’ knowledge about how schemes operate. Schemes talked about spending a lot of time with inspectors educating them about the Shared Lives/ Adult Placement model and explaining its nuances.

• Acknowledging and showing the value of the Third Sector as a provider

Both Third Sector providers felt that that Shared Lives/ Adult Placement is often seen as a local authority provision in Wales and that there seems to be a need to raise awareness of Shared Lives/ Adult Placement that includes the third sector.

• Stronger commitment at a national level that acknowledges the Shared Lives/ Adult Placement model as not just an add-on but on equal footing with other forms of care

• Strong engagement and consultation with Shared Lives/ Adult Placement carers

• Other areas identified in the report that should be explored further are:
  - research project to demonstrate the outcomes and savings delivered by Shared Lives/ Adult Placement in Wales
  - the development of a recruitment strategy for Welsh speaking Shared Lives/ Adult Placement carers
  - the development of a qualification framework for Shared Lives/ Adult Placement staff
  - further development and diversification of respite provision by Shared Lives / Adult Placement schemes.
  - better representation of BME groups amongst Shared Lives/ Adult Placement carers and service users
**Shared Lives Plus – Our Commitments for the next three years**

Shared Lives Plus is committed to support local schemes and Shared Lives/Adult Placement carers to achieve the improvements and changes that they wish to see in Wales.

Over the next three years, Shared Lives Plus will:

- Develop strategies to raise the profile of the Shared Lives/Adult Placement model of care amongst commissioners, potential carers (especially amongst Welsh speakers and BME groups) and the general public.
- Provide advice and support to schemes and carers on complex and technical issues.
- Lobby CSSIW for a unified and consistent approach to inspection and regulation.
- Explore the development of a qualification framework for Shared Lives/Adult Placement officers and carers in partnership with the Welsh Government, the Care Council for Wales (CCW) and local schemes.
- Engage and consult with Shared Lives/Adult Placement carers in Wales.
- Ensure that Third Sector providers are equally represented in promotional strategies and developmental plans.
- Develop a business case for Shared Lives in Wales.


