

West Wales  
**Population Assessment**  
March 2017



Partneriaeth Gofal Gorllewin Cymru  
West Wales Care Partnership



West Wales

# Population Assessment

March 2017

# Contents

<b>Foreword</b>	<b>5</b>
<b>1. Executive summary</b>	<b>7</b>
1.1. Overview and Purpose	8
1.2. West Wales Population Profile	8
1.3. How We Undertook the Population Assessment	9
1.4. Recommendations	11
1.5. Thematic Reports	12
<b>2. Introduction</b>	<b>19</b>
2.1. Structure of the Report	20
2.2. Background	21
2.3. Purpose of the Population Assessment	23
2.4. How we Undertook the Population Assessment	24
2.5. Key Relevant Strategies and Plans	26
2.6. Delivering National Outcomes	27
2.7. References	30
<b>3. Consultation and engagement</b>	<b>31</b>
3.1. Approach	32
3.2. Wellbeing Assessment	32
3.3. Highlights from the Findings	33
<b>4. Cross Cutting Themes</b>	<b>37</b>
4.1. Overview	38
4.2. Delivering Services in the Welsh Language	38
4.3. Minority and Marginalised Groups	41
4.4. Prevention	43
4.5. Safeguarding	44
4.6. Promoting Social Enterprises, Cooperatives, User Led Services and the Third Sector	45
4.7. References	46
<b>5. Recommendations</b>	<b>47</b>
Voice and Control	48
Prevention and Early Intervention	48
Wellbeing	48
Co-production	48
Cooperation, Partnership and Integration	49

<b>6.</b>	<b>West Wales Population Profile</b>	<b>51</b>
6.1.	Overview	52
6.2.	All Cause Morality Rates	55
6.3.	Deprivation and Lifestyle Factors	56
6.4.	Further Information	57
6.5.	References	58
<b>7.</b>	<b>Carers</b>	<b>59</b>
7.1.	Overview and Key Messages	60
7.2.	Demographics and Trends	60
7.3.	Current and Future Support Needs	62
7.4.	Current Support Provision	65
7.5.	Gaps and Areas for Improvement	67
7.6.	References	71
<b>8.</b>	<b>Children and Young People</b>	<b>73</b>
8.1.	Overview and Key Messages	74
8.2.	Demographics and Trends	74
8.3.	Current and Future Care and Support Needs	76
8.4.	Current Care and Support Provision	78
8.5.	Gaps and Areas for Improvement	84
8.6.	References	86
<b>9.</b>	<b>Health and Physical Disabilities</b>	<b>87</b>
9.1.	Overview and Key Messages	88
9.2.	Demographics and Trends	88
9.3.	Current and Future Care and Support Needs	91
9.4.	Current Care and Support Provision	93
9.5.	Gaps and Areas for Improvement	95
9.6.	References	99
<b>10.</b>	<b>Learning Disability and Autism</b>	<b>101</b>
10.1.	Overview and Key Messages	102
10.2.	Demographics and Trends	102
10.3.	Current and Future Care and Support Needs	104
10.4.	Current Care and Support Provision	107
10.5.	Gaps and Areas for Improvement	109
10.6.	References	112

<b>11. Mental Health</b>	<b>113</b>
11.1. Overview and Key Messages	114
11.2. Demographics and Trends	114
11.3. Current and Future Care and Support Needs	118
11.4. Current Care and Support Provision	119
11.5. Gaps and Areas for Improvement	123
11.6. References	126
<b>12. Older People</b>	<b>129</b>
12.1. Overview and Key Messages	130
12.2. Demographics and Trends	130
12.3. Current and Future Care and Support Needs	135
12.4. Current Care and Support Provision	138
12.5. Gaps and Areas for Improvement	143
12.6. References	145
<b>13. Sensory Impairment</b>	<b>151</b>
13.1. Overview and Key Messages	152
13.2. Demographics and Trends	152
13.3. Current and Future Care and Support Needs	156
13.4. Current Care and Support Provision	158
13.5. Gaps and Areas for Improvement	160
13.6. References	163
<b>14. Substance Misuse</b>	<b>167</b>
14.1. Overview and Key Messages	168
14.2. Demographics and Trends	168
14.3. Current and Future Care and Support Needs	169
14.4. Current Care and Support Provision	170
14.5. Gaps and Areas for Improvement	170
14.6. References	172
<b>15. Violence Against Women, Domestic Abuse and Sexual Violence</b>	<b>173</b>
15.1. Overview and Key Messages	174
15.2. Demographics and Trends	174
15.3. Current and Future Care and Support Needs	177
15.4. Current Care and Support Provision	179
15.5. Gaps and Areas for Improvement	181
15.6. References	187
<b>16. Appendices</b>	<b>189</b>
16.1. Appendix 1 of List of Figures and Tables	190
16.2. Appendix 2 Group Membership and Acknowledgements	192

# Foreword

The Social Services and Wellbeing (Wales) Act places a strong emphasis on cooperation and partnership working between agencies, and with citizens, to ensure that the very best help is available to those that need care and support within our communities. Two core principles lie at the heart of the West Wales Care Partnership and all that it seeks to achieve: Firstly, that the citizen's voice must be paramount in shaping the way in which care and support is delivered in our region and secondly that by working collaboratively local authorities, the NHS and our partners in the third and independent sectors can become both more efficient and responsive to the needs of the individuals and communities we are all here to serve.

Undertaking our first Population Assessment has been a major priority for the Regional Partnership Board over the past 9 months. We sought from the outset to ensure that the process was inclusive by bringing managers and practitioners from each of the partner agencies together to consider the needs of our population, what these mean in terms of the care and support that should be available, the extent to which current services meet those needs and shared challenges for the future. Equally, we took the opportunity to engage with residents, through the wellbeing survey and follow-up events, and in so doing received some clear messages about what people feel they need and how they want to see these needs addressed.

As a result we have, for the first time, a comprehensive overview of care and support needs across the region, examples of innovation and good practice and numerous pointers in terms of where we still need to improve. We are clear that this is just the start of a much longer process. Not only will the Assessment form the basis for our Area Plan, we will also ensure that it feeds into local improvement plans within individual agencies and is used as a baseline against which the partnership can assess its progress over the coming months and years.

We will also reflect further on how the Assessment was undertaken and look to improve on this, not only for future iterations but in the intervening period as we seek to further develop cooperation across the partnership and ensure that the citizen's voice is taken into account at all stages in the planning and delivery of care and support. In so doing we are confident that we will build strong, resilient communities in which people work together to deliver positive outcomes and all play a part in supporting and protecting those most in need.



## **Sue Darnbrook**

*Strategic Director, Care, Protection and Lifestyle, Ceredigion County Council  
Chair of the West Wales Regional Partnership Board*



## **Councillor Simon Hancock**

*Cabinet Member for Adult Services, Health and Wellbeing and Equalities,  
Pembrokeshire County Council  
Vice Chair of the West Wales Regional Partnership Board*





## Section 1

# Executive Summary

**West Wales Population Assessment** March 2017

## 1.1 Overview and Purpose

This Population Assessment provides a high level strategic analysis of care and support needs of citizens and support needs of carers across West Wales. It assesses the extent to which those needs are currently being met and identifies where further improvement and development is required to ensure that individuals get the right support and are able to live fulfilled lives.

The Assessment has been undertaken to meet new requirements under Part 2 of the Social Services and Wellbeing (Wales) Act 2014 (SSWB Act). Section 14A of the Act requires that local authorities (LAs) and Local Health Boards (LHBs) jointly carry out an assessment of the needs for care and support, and the support needs of carers, in the LA's area. These assessments must then be combined into a single report for the LHB footprint before being signed off by each of the LAs and the LHB.

The Population Assessment will be a key driver for the integration and transformation of care and support in West Wales over the coming period. The Regional Partnership Board (RPB), which has been established under Part 9 of the Act and has responsibility for promoting integration and a partnership approach to service improvement, will use the Assessment to test its existing priorities and identify other areas on which it needs to focus. Over the next few months the RPB will lead on the development of an Area Plan which will set out those areas of change identified within the Assessment which will be addressed collaboratively over the coming three to five years. The Area Plan will link with existing strategic plans of the partner agencies and wider wellbeing goals and actions overseen by the three Public Service Boards (PSBs), thus ensuring a focused, consistent approach to change.

Population Assessments will be undertaken every five years and will be refreshed mid-cycle, allowing unforeseen changes in need to be addressed and progress to be monitored. This will enable us to accelerate the pace of change where necessary and to share examples of success across the region and beyond.

## 1.2 West Wales population profile

The West Wales region covers three LA areas – Carmarthenshire, Ceredigion and Pembrokeshire - and is coterminous with the Hywel Dda University Health Board (HDUHB) footprint. The population of the region is estimated at 384,000. 47.9% of the population live in Carmarthenshire, 20.7% in Ceredigion and 31.4% in Pembrokeshire.

The total population is predicted to rise to 425,000 by 2033, with a rise in those aged over 65 from 88,200 in 2013 to 127,700 by 2033.

There are fewer people aged 25-44 and more people aged over 55 compared with the rest of Wales. Similarly, there is a higher ratio of people aged 75 and over (10.3%

compared with 8.9% in Wales as a whole). Life expectancy for both males and females is broadly in line with the rest of Wales at 78.9 and 82.7 years respectively.

Areas of deprivation centre on parts of Llanelli in Carmarthenshire, Pembroke Dock in Pembrokeshire and Cardigan in Ceredigion.

People living in West Wales have generally healthier lifestyles than is typical across Wales. However there are particular challenges to address, for example higher rates of alcohol consumption in Ceredigion and rates of obesity above the national average in Carmarthenshire and Pembrokeshire.

More information is provided in Chapter 6 of the main report.

### 1.3 How we undertook the Population Assessment

The Assessment was undertaken collaboratively by all partners in the region and has been agreed by the RPB. It has also been endorsed by the three LAs and the UHB, signifying a shared commitment across partner agencies to address its findings.

Cross-agency groups were established to undertake a detailed assessment of care and support needs for different user groups, using a common template to provide consistency and allow full consideration of the characteristics of the group, likely care and support needs, the extent to which these are currently being met and where change is most needed. The results of these individual assessments were collated into thematic reports. The benefits of this process should not be underestimated. The positive impact of bringing people from across the region together to consider shared challenges and learn from current practice has been considerable and provides a firm foundation for collaboration moving forward.

Opportunities were taken to engage with people needing care and support and their carers across West Wales. Questions relating to people's experience of care and support and their thoughts on how things might be improved were included in the Wellbeing Survey conducted across the region during August and September 2016 to inform the Wellbeing Assessment required under the Wellbeing of Future Generations (Wales) Act. Residents were given the chance to discuss relevant issues in a range of consultation events held over the autumn. We also engaged where possible with other stakeholders such as providers in the third and independent sectors. A summary of the outcomes from this engagement is provided in Chapter 3 of the main report (pages 26 – 30). This, combined with the use of information from previous consultation and engagement, provides us with an invaluable insight into the views of our local population but needs to be consolidated through further engagement as we develop our Area Plan and refresh the Assessment in mid-cycle.

A range of quantitative data was used to provide a comprehensive picture of current and future care and support needs and how these are currently being met. To maximise the usability of the Assessment we have included high level, indicative data relating to the region and the constituent LA areas. A comprehensive data repository is being established to retain additional data which will support improvement planning and inform future Assessments.

The Assessment has drawn on a range of existing strategies and plans in place across the region, thus providing an opportunity to review strategic intent at regional and local level. It will be important to ensure that these are reviewed in the light of the Assessment's findings and that the resulting Area Plan aligns with and complements existing plans where appropriate.

In undertaking the Assessment, close reference was made to the National Outcomes Framework for people who need care and support and carers who need support. (Welsh Government, 2016). For example, the principle of people being empowered to understand their own needs, articulate these, take an active part in decisions affecting their lives and having access to the right information to improve their wellbeing, is a consistent theme throughout the thematic reports.

Consideration was also given to a range of cross-cutting issues which need to underpin our journey of improvement and change, namely:

- The need to ensure provision of care and support through the medium of Welsh for those who need it and to ensure that the requirements of the Welsh Language (Wales) Measure 2011 and the 'More than Just Words' strategy are fully met
- The importance of recognising the particular needs of minority and marginalised groups in developing care and support; we undertook a simple Equalities Impact Assessment (EIA) as part of the Assessment and are committed to undertaking further, detailed EIAs as the Area Plan is developed
- The centrality of prevention and the need to ensure that the principles of prevention underpin the range of care and support available, thus improving personal outcomes, promoting independence and reducing or delaying people's need for ongoing care and support
- The vital importance of safeguarding in the provision of care and support, in terms of ensuring people are protected from abuse and neglect and the effective exercise of new powers in relation to adults at risk
- Duties under the Act regarding the promotion of social enterprises, user-led services and the third sector and the need for a focused and strategic approach in growing such provision to ensure greater diversity of public services and empowering people and communities through a co-productive approach

## 1.4. Recommendations

Whilst specific areas for improvement are identified in each of the thematic reports, a number of generic recommendations have been identified for consideration by the RPB and its constituent agencies. These are set out below under the core principles of the Act:

### Voice and control

1. Ensure that maintaining people's dignity and protecting individuals from neglect and abuse must lie at the heart of all services.
2. Ensure all services are available in Welsh for those who require them.

### Prevention and early intervention

3. Build on the considerable foundations in place across the service areas covered in this assessment to ensure appropriate services are available to prevent or delay the need for ongoing care and support and that the prevention ethos underpins all levels and types of care. Specifically, opportunities should be taken to develop consistent preventative frameworks across services, which build on existing good practice, facilitate transition between children and adult's services and demonstrably reduce the need for ongoing care and support.
4. Invest in the development of community-based preventative services, including social enterprise, cooperatives, user-led and third sector provision thus building the resilience of communities and, thereby, of people needing care and support.
5. Align the Intermediate Care Fund (ICF) and Cluster Development Change Programmes to build consistent, whole system change on the ground.

### Wellbeing

6. Prioritise support for carers, enabling them and those they care for to live fulfilled and independent lives for as long as possible.
7. Further improve transition services to facilitate effective planning across services and ensure that young people continue to receive appropriate care and support into early adulthood.

### Co-production

8. Ensure that people needing care and support and carers are involved meaningfully at all stages in the planning, delivery and review of services. This needs to happen at strategic level, engaging with citizens over the future shape of care and support and expectations on individuals to promote their own wellbeing and operationally, ensuring that assessment and care planning allows people to express personal outcomes and influence decisions regarding the support needed to attain them.

### Cooperation, partnership and integration

9. Create an environment which permits radical change and encourages innovation rather than trying to do more of the same with less.
10. Use the population assessment as the basis for the development of integrated commissioning across service areas, based on a common understanding of need.
11. Develop consistent delivery models across service areas and the region, based on a shared strategic vision and the principles within the Act; ensuring common standards to all residents in West Wales.
12. Use this population assessment as a basis for detailed modelling of future scenarios to understand the interdependencies and impact on care and support services of, for example, demographic increases in the older population, and expected increases in known carers and victims of violence against women, domestic abuse and sexual abuse. There is a need to understand how future conditions in the area might impact on social services provision and the extent and diversity of needs for social services over the next 10 -25 years.
13. Pool funds and other resources where appropriate to optimise their impact and support seamless delivery.
14. Engage strategically with providers across all sectors to develop services and build sustainable markets for the future.
15. Work with partners across the public sector and others to embed a preventative approach, promote wellbeing, optimise resources and address specific challenges such as accessibility of services in predominantly rural area.

### 1.5. Thematic Reports

Key messages within the thematic reports are provided below.

#### Carers

- All of us will have our lives touched by caring at some point: 3 in 5 of us will be carers and many of us will also need care in our lifetime (Carers UK, 2001). Carers are the mothers, fathers, sons, daughters, siblings, spouses, friends and neighbours who provide unpaid care, caring at home, picking up prescriptions, changing dressings, providing much needed emotional support and much more, and often neglecting their own health and wellbeing needs. Carers are vital to those they care for and to the foundation of the health and social care system.
- Around 1 in 8 people in West Wales, many of them young people, are providing unpaid care with a significant proportion providing between 20 to 50+ hours of unpaid care per week.

- The provision of unpaid care is becoming increasingly common as the population ages, with an expectation that the demand for care provided by spouses and adult children will more than double over the next thirty years (see for example Personal Social Services Research Unit).
- Based on a national calculation conducted by carers UK and Sheffield University in 2015 (Carers UK, 2015), the cost of replacing unpaid care in West Wales, can be estimated at £924m. This exceeds the NHS annual budget for the region which is almost £727m (Hywel Dda University Health Board 2016).

Gaps and areas for improvement in relation to carers are listed on pages 67 - 70 of the main report.

### Children and Young People

- Children and young people make up approximately 22.2% of the population in the West Wales region. The number of young people is expected to stay relatively stable over the next 15 years
- The region has a lower number of Looked After Children (LAC) than the national average
- Care and support needs span a wide range from universal, through early intervention, multiple needs and remedial intervention
- Partner agencies have adopted a broadly consistent continuum of care and support for children and families with a focus on prevention
- Areas for improvement include further development of preventative and early intervention services, building on established programmes such as Family Information Services, Families First and Team Around the Family; refocusing managed care and support to promote independence and wellbeing; improving multi-agency working and improved collaboration across the region to bring services to a consistent level and standard
- Collaborative action should also be considered to address strategic challenges such as reducing budgets, workforce development and the establishment of user-led preventative services

Gaps and areas for improvement in relation to children and young people are listed on pages 84 - 85 of the main report.

### Health and Physical Disabilities

- A significant proportion of people in the 18-64 age group will not be accessing care and support directly to address specific needs. However, they will benefit from general public health information and programmes aimed at encouraging healthy lifestyles and reducing risks to their health brought about by factors such as smoking and obesity. More generally, adults in Wales will also benefit from combined approaches across sectors and within communities to improve the social, economic and cultural wellbeing of Wales in response to the Wellbeing of Future Generations (Wales) Act 2015.

- Where people within this age range have specific needs because of physical disability or chronic health conditions, proportionate, person-centred and responsive care and support may be required to help them achieve positive personal outcomes and live as independently as possible.
- A range of 'accelerating factors' have been identified within people's environments that might increase the likelihood of them developing an ongoing health condition, or aggravate the effects of existing conditions, and against which mitigating action should be taken. These include unemployment, low wages and poor housing conditions.
- Effective promotion of public health, targeted care and support for those with specific needs and more general support for people particularly at risk should combine to optimise the quality of people's lives and their participation within their communities.
- Supporting people to live active and healthy lives will reduce their needs for care and support and lead to improved outcomes at an individual and community level. The contribution of care and support services must be complemented by a range of collaborative approaches to improve people's social, economic, environmental and cultural wellbeing.
- Public Health has an important role in providing the population with general information and advice on healthy life choices and support in areas such as diet and smoking cessation. This needs to start in the early years but should be sustained where possible across the range of age groups.

Gaps and areas for improvement in relation to health and physical disabilities are listed on pages 95 - 98 of the main report.

### Learning Disability and Autism

Learning Disability can be defined as:

- A significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence)
- A reduced ability to cope independently (impaired social functioning); or
- These are in evidence before adulthood and have a lasting effect on development

The way in which the needs of people with a Learning Disability are met has changed over the last twenty years. People who would historically have been placed in institutional care are increasingly being supported to live in their communities. Health and social care services along with the third sector collaborate to maximise the independence and potential of those who use our services.

Although Autism is not a learning disability it has been included in this section as services for people on the spectrum are generally provided from within learning disability teams or community mental health teams and NICE guidance (2008, 2016) provides standards for provision of services.



Gaps and areas for improvement in relation to learning disability and autism are listed on pages 109 – 111 of the main report.

## Mental Health

- The care and support needs of adults aged 16 + with mental health needs have been considered in this section of the Assessment.
- According to the Mental Health Foundation (2015) in any year one in four of us experience a mental health problem, yet three quarters of people with mental health problems receive no treatment.
- Many of us will require support with respect to our mental health throughout our lives whether this is low intensity support for difficulties such as low level anxiety / depression or longer term support.
- Mental illness can develop from a number of factors including social traumas, illegal drug use and genetic predisposition. Mental health does not discriminate and can affect anyone often leading to debilitating conditions.
- Early intervention is crucial and this can take the form of providing information or referral to community or third sector services. Admissions to inpatient services may occur in extreme situations, where the individual cannot be treated in the community and presents a risk to themselves and/or others.
- It has been estimated that the economic and social costs of mental health problems in Wales is estimated to be £7billion a year (Cyhlarova, 2010).
- In 2015-16, the Welsh Government ring-fenced £587m for mental health services across Wales – up from £389m in 2009-10. Earlier this year, Government announced an additional £15m of new funding is being made available for mental health services in Wales every year.

Gaps and areas for improvement in relation to mental health are listed on pages 123 - 125 of the main report.

## Older People

- According to the Office for National Statistics, the population of West Wales has a higher proportion of older people than the Welsh average, and that already high proportion is predicted to increase significantly in the coming years, as average life expectancy in the region follows the national upwards trend.
- The change in the profile of the population will undoubtedly have an impact on health, as older people are statistically more likely to have a life limiting health condition (Office for National Statistics, 2011) These changes will significantly impact on the health and social care services provided, as demand for hospital and community services by those aged 75 and over is in general more than three times that from those aged between 30 and 40 (Parliamentary Select Committee on Public Service and Demographic Change, 2013).
- A number of 'accelerating factors' add to the challenge of providing effective services to older people in West Wales, from pockets of significant deprivation to

large areas of rurality and high levels of migration of older people to certain areas. (Wales On-line, 2012)

- In 2013-14 an estimated £91 million was spent in West Wales on services specifically for older people including Tier 1 – Community, Universal and Prevention Services, Tier 2 - Early Intervention and enablement and Tier 3 - Specialist and Long Term Services. Across the UK public expenditure related to older people is expected to rise from 20.1% of GDP in 2007-08 to 26.7% in 2057. (Mid and West Wales Health and Social Care Collaborative, 2015) The Office for Budget Responsibility (2011) has noted that 'public finances are likely to come under pressure, primarily as a result of an ageing population.'

Gaps and areas for improvement in relation to older people are listed on pages 143 - 144 of the main report.

### Sensory Impairment

- Sensory impairment can be a significant life limiting condition and its incidence increases with age. This means the challenges associated with the condition are likely to grow over coming decades
- The condition includes sight loss, hearing loss, and dual sensory loss (deafblind).
- Accelerating factors in relation to sight loss include diabetes and obesity
- People with sensory impairment have a range of care and support needs. Early identification is vital, as is prevention, support to reduce loneliness, isolation and promote mental health and wellbeing and measures to support access to employment
- Effective care and support is likely to reduce other risks associated with age and frailty, such as falls
- A range of services are available across West Wales. These provide a foundation for improvement in the future
- Improvements need to focus on further development of generic and specialist services and improving access to other services for people with a sensory impairment. This will require collaborative approaches to ensure consistency and that common challenges are addressed

Gaps and areas for improvement in relation to sensory impairment are listed on pages 160 – 162 of the main report.

### Substance Misuse

- The care and support needs of those affected by alcohol and drug misuse have been considered. The effects of these are far reaching; impacting on children, young people, adults, whole families and communities. Partnership work to address this agenda is taken forward through the Dyfed Area Planning Board for Substance Misuse who are developing their own comprehensive needs assessment to inform their new strategy and action plan.

- A ten year strategy (Welsh Government, 2008) provides the framework for partner organisations in West Wales to tackle the harms associated with drug and alcohol misuse across four key themes;
  - Preventing harm
  - Support for those that misuse drugs and alcohol in order to improve their health and aid and maintain recovery
  - Supporting and protecting families
  - Tackling availability and protecting individuals and communities via enforcement activity
- Those at risk of harm from alcohol misuse come from across the spectrum of society. They include chronic heavy drinkers, adults at home drinking hazardous or harmful levels and children and young adults who suffer from the consequences of parental alcohol misuse. The health impact of misuse of alcohol is considerable; more people die from alcohol related causes than from breast cancer, cervical cancer and MRSA infection combined. Foetal alcohol syndrome is also a risk to the babies of mothers who use alcohol. Most recent data on hospital admissions for Hywel Dda University Health Board show that over 5,000 bed days were taken up by patients with alcohol related conditions at a cost to the Health Board of over £5.2million per year in in-patient treatment alone
- Misuse of drugs, both legal and illegal, and other mind-altering substances such as solvents, can damage health in a variety of ways. These include fatal overdoses, addiction, mental health problems, infections caused by injecting and the toxic effects of the many substances that dealers mix with the active substance. Although the greatest harms are associated with the use of illicit drugs, the misuse of prescription only medicines and over the counter medicines continues to be a problem.

Gaps and areas for improvement in relation to substance misuse are listed on pages 170 - 171 of the main report.

### **Violence Against Women, Domestic Abuse and Sexual Violence**

- Violence against women, domestic abuse and sexual violence (VAWDASV) is a fundamental violation of human rights, a cause and consequence of inequality and has far reaching consequences for families, children and society as a whole (Welsh Government, 2016)
- Domestic Abuse costs Wales £303.5m annually. This includes £202.6m in service costs and £100.9m to lost economic output. If the emotional and human cost is factored in there are added costs of £522.9m (Walby, 2009 cited in Welsh Women's Aid, n.d.)
- The cost, in both human and economic terms, is so significant that marginally effective interventions are cost effective (Welsh Government, 2016)
- New requirements under the Wellbeing of Future Generations (Wales) Act 2015, (SSWB Act), and Violence Against Women, Domestic Violence and Sexual Abuse Act, 2015 impact this area and are likely to increase the number of cases of domestic abuse identified

- Improving partnership responses to survivors could reduce the levels of need for specialist services

Gaps and areas for improvement in relation to violence against women, domestic abuse and sexual violence are listed on pages 181 - 186 of the main report.

A full list of colleagues who contributed to the Population Assessment is provided in Appendix 2.

## Section 2

# Introduction

**West Wales Population Assessment** March 2017

## 2.1 Structure of the report

This report provides a high level summary of the population assessment undertaken for the West Wales region between June and November 2016. It sets out key findings from this intensive piece of regional work.

Whilst illustrating variations and differing challenges in different parts of the region, the report focuses intentionally on shared opportunities and areas for improvement, where it is felt most benefit will be gained in developing collaborative approaches through the forthcoming Area Plan. As well as the Area Plan, the report will also be available to inform future commissioning strategies and other similar activity across the region.

The report is structured around the following chapters:

### Chapter 1: Executive summary

### Chapter 2: Introduction

sets out the background to and purpose of the assessment; our approach to undertaking the assessment, and examples of high level strategies and plans that have informed or will be informed by the assessment.

### Chapter 3: Consultation and engagement

describes our approach to consultation and engagement for the population assessment, areas for further development, and an overview of the feedback from consultation and engagement.

### Chapter 4: Cross cutting themes

discusses a number of these that emerged during the assessment that are common to most or all of the thematic reports including delivering services in the medium of Welsh and key challenges, for example, finances and resources and recruitment and retention.

### Chapter 5: Recommendations

set out against the core principles of the SSWB Act.

### Chapter 6: Demographics and trends

describes the population of West Wales including age and sex profile, life expectancy, all-cause mortality rates and areas of deprivation.

### Chapters 7-15: Thematic reports

for each of the Core Themes at the heart of the population assessment, namely:

- Carers
- Children and Young People (C&YP)
- Health and Physical Disabilities
- Learning Disabilities and Autism
- Mental Health
- Substance Misuse
- Older People
- Sensory Impairment
- Violence Against Women, Domestic Abuse and Sexual Violence (VAWDASV)

Each thematic report contains a demographic profile, a description of care and support needs, current and future care and support provision, and gaps and areas for development.

## Chapter 16: Appendices

containing a list of figures and tables used in the report, membership of the cross-agency groups involved in undertaking the assessment and a glossary.

## 2.2 Background

The SSWB Act provides a new legislative framework for care and support in Wales, aimed at improving the wellbeing of people who need care and support, and carers who need support, and for transforming the way in which services are commissioned and delivered. A number of core principles underpin the Act:

- **Voice and control** putting the individual and their needs, at the centre of their care, and giving them a voice in, and control over reaching the outcomes that help them achieve wellbeing
- **Prevention and early intervention** increasing preventative services within the community to minimise the escalation of critical need
- **Wellbeing** supporting people to achieve their own wellbeing and measuring the success of care and support
- **Co-production** developing ways of working whereby practitioners and people work together as equal partners to plan and deliver care and support
- **Cooperation, partnership and integration** improving the efficiency and effectiveness of service delivery, providing coordinated, person centred care and support and enhancing outcomes and wellbeing

Part 9 of the Act requires local authorities (LAs) and Local Health Boards (LHBs) to establish Regional Partnership Boards (RPBs) to manage and develop services to secure strategic planning and partnership working and to ensure effective services, care and support are in place to best meet the needs of their respective population.

RPBs are required to promote the integration of services, prioritising those for older people with complex needs and long-term conditions, including dementia; people with learning disabilities; carers; families through Integrated Family Support Services; and children with complex needs due to disability or illness. Implicit in this is the requirement to remodel services to meet the needs of the population and to meet the aspirations of the Act. Merely doing more of the same in a more joined up way is unlikely to deliver the wellbeing outcomes which underpin the legislation.

Key to achieving this will be RPBs understanding the needs of their population, assessing the effectiveness of current services and identifying where further change and improvement is needed. Part 2 of the Act requires that local authorities and LHBs must jointly carry out an assessment of the needs for care and support, and the support needs of carers in the local authority's (LA's) area. The assessment must identify:

- The extent to which those needs are not being met
- The range and level of services required to meet those needs
- The range and level of services required to deliver the preventative services required in section 15 of the Act; and
- How these services will be delivered through the medium of Welsh

In common with areas covered by the other six LHBs in Wales, partners in West Wales have established a RPB which brings together senior representatives of the three local authorities (Carmarthenshire, Ceredigion and Pembrokeshire County Councils), Hywel Dda University Health Board, the third and independent sectors and user and carer representatives. The RPB builds on strong foundations of collaborative working across health and social care in West Wales, in relation to areas such as intermediate care, integrated family support, adoption, substance misuse, shared lives for adults and safeguarding. Building on these, it has agreed initially the following strategic priorities, underpinned by a commitment to improving engagement with citizens and developing a workforce equipped to meet future challenges:

- Integrated commissioning of older people's services
- Pooled budgets
- Information, Advice and Assistance/ prevention
- Implementation of the Wales Community Care Information System (WCCIS); and
- Integration of mental health and learning disability services

These priorities complement and support a wider range of activity underway across the region to reshape services and improve the way in which they are commissioned and delivered. The Population Assessment has provided an invaluable further 'test' of both the Board's priorities and the wider activity and these will be refined as necessary in light of its findings. During 2017 the RPB will oversee the development of a comprehensive combined Area Plan linked to internal agency plans and setting out



those areas of change identified within the Assessment that will be addressed collaboratively over the coming 3 to 5 years.

## 2.3 Purpose of the Population Assessment

The Population Assessment provides a high level strategic analysis of care and support needs, and support needs of carers across West Wales. It assesses the extent to which those needs are currently being met and identifies where further improvement and development is needed to ensure that individuals get the services they need and are supported in living fulfilled lives.

The Assessment draws on existing strategies in place across West Wales and for the first time brings together the views of citizens, service data and research evidence in a single, regional document. In highlighting shared issues and challenges, as well as successful approaches already in place, it provides an invaluable basis for the RPB in taking forward transformational change. Such change is all the more important in view of the projections within the Assessment, which point towards increased volume and complexity of care and support needs in the region over the next two decades.

Completing the Assessment is only the first step in a much longer process. We are required under Section 14A of the SSWB Act to respond to the Population Assessment by developing an Area Plan for our region. This will contain actions designed specifically to address the challenges we have identified. Linking with the UHB's Integrated Medium Term Plan (IMTP), LA plans and those of other partners, the Area Plan will be a key driver for change over the coming period and delivery will be overseen by the RPB. We will look to pool resources wherever possible across agencies to support delivery of the Area Plan and will ensure that additional funding such as the Intermediate Care Fund (ICF) is focused on those areas where most change is needed and the greatest benefit can be gained for people who need care and support.

We recognise the contribution of other services to the wellbeing of people who need care and support and will work with the three Public Service Boards (PSBs) in the region to ensure that the needs we have identified are reflected in wider wellbeing goals and actions across West Wales.

The RPB will undertake new population assessments every five years and will ensure that existing assessments are refreshed mid-cycle. This will provide an opportunity not only for identifying unforeseen changes in the level and type of need for care and support within the region but also for assessing the extent to which the required improvements are happening on the ground. This will enable us to accelerate the pace of change where necessary and to share examples of success across the region and beyond.

## 2.4 How we undertook the Population Assessment

The Assessment was undertaken collaboratively by all partners in the region and has been agreed by the RPB. It has also been ratified by the three local authorities and the Local Health Board, signifying a shared commitment across partner agencies to address its findings.

To ensure a genuinely collaborative approach, our existing regional Integrated Programme Delivery Board (IPDB), comprising senior representatives from all partner agencies, took on the role of Joint Committee for the purposes of the Assessment. All partners committed to engaging fully and providing time and resources to ensure the Assessment was completed on time and contained relevant information from all parts of the region. Carmarthenshire County Council took a lead agency role, coordinating the process and securing external project management capacity to steer the assessment process and ensure legislative requirements were met.

Key partners in the Assessment, alongside Carmarthenshire County Council, were:

- Ceredigion County Council
- Hywel Dda University Health Board
- Pembrokeshire County Council
- Public Health Wales

Cross-agency thematic groups were established to undertake a detailed assessment for each user group, each focusing on one or more sections of the population. A common template was followed to help partners fully consider the characteristics of the user group, likely care and support needs, the extent to which these are currently being met, where change is most needed and how this needs to be taken forward over the coming period. The thematic groups also identified specific issues in relation to areas such as market sustainability and workforce and these are aggregated in the Chapter 4.

The IPDB received regular updates on progress and contributed directly to the drafting of the report before recommending to the RPB that it be approved.

In undertaking the Assessment opportunities were taken to engage with people needing care and support and their carers across West Wales. Questions relating to people's experience of care and support and their thoughts on how things might be improved were included in the Wellbeing Survey conducted across the region during August and September to inform the Wellbeing Assessment required under the Wellbeing of Future Generations (Wales) Act 2015. Residents were given the chance to discuss relevant issues in a range of consultation events over the autumn.

Where possible we also used recent consultation findings and intelligence gained from individual service users and user and stakeholder groups to inform the detailed assessments contained within the thematic reports. Further detail on our approach to consultation is provided in the Consultation and Engagement chapter.

We also sought to speak with other stakeholders such as providers within the third and independent sector in the course of our assessment, thereby looking to obtain as wide a perspective as possible on need, current provision and priorities for change. In addition, specific research undertaken by academic institutions and organisations representing users and carers has been referenced where appropriate.

Whilst this engagement activity played a key role in our assessment, it has been less extensive in some cases than we had hoped, largely due to the challenging timescales in which we were required to complete our work. We are confident, however, that we have established firm foundations for ongoing engagement as we develop our Area Plan and work towards the refresh of the Assessment by 2020. The RPB has made specific commitments to improve regional arrangements for citizen and provider engagement over the coming period, providing potential opportunities for a rich ongoing dialogue with all stakeholders as we take forward change in West Wales.

Robust quantitative data on our current and projected population and how services are currently provided has been another key element of our Assessment. We have extracted this from a range of sources, including among others a comprehensive data catalogue compiled on our behalf by the Local Government Data Unit, Daffodil Cymru, 2011 census data and statutory performance returns submitted by partner agencies. In analysing the data we have adopted an epidemiological approach, looking at the size and composition of different groups within our region currently and how this is predicted to change in the future, resulting levels of need and the ability of current services to meet those needs. Where appropriate we have also used comparative data to illustrate prevalence in West Wales compared with other parts of the country and, in some cases, significant variances across different parts of our region. Although some data is available at NHS locality and cluster levels, this is not the case for all services. For this reason the majority of data is presented at regional and LA level. In developing the Area Plan, it will be important for partners to examine more local data to ensure responsiveness to local need and the right focus for investment.

We took the decision not to include detailed data on current performance of services within our Assessment. We considered it more important to consider the extent to which current service models and approaches met current need, rather than to assess how well we were providing those services. Of course, performance data is and will continue to be important in assisting managers to identify problems in services and areas for improvement and it will continue to be used in this way to ensure that those needing care and support at the current time get the best possible services.

An exception to this was our decision to incorporate early findings from the user surveys circulated by local authorities during the summer of 2016 to assess the extent to which nationally identified outcomes are being achieved for individuals. Details are provided in the Consultation and Engagement chapter.

To keep the report manageable, we have had to select the most pertinent data to each of the user groups; however a comprehensive data repository has been established to retain data not cited directly within the report but which nevertheless will have a role in supporting service planning and informing future assessments.

## 2.5 Key relevant strategies and plans

The Population Assessment has intentionally drawn on a range of existing strategies and plans in place across the region and provided an opportunity to review strategic intent at regional and local level in the light of identified and projected needs.

Partners have already articulated shared strategic intentions in a number of service areas, for example for older people in the Statement of Intent for the Integration of Services for Older People with Complex Needs (Mid and West Wales Health and Social Care Collaborative, January 2014a), and subsequent Market Position Statement for older people's services (Mid and West Wales Health and Social Care Collaborative, November 2015) and for learning disabilities in the regional Statement of Intent (Mid and West Wales Health and Social Care Collaborative, October 2014b). These intentions have been tested and in most cases reaffirmed in the Population Assessment. Equally, partners have committed to revising existing plans where necessary to ensure they fully address the findings of the Assessment.

Similarly, there is significant alignment between the themes emerging from the Population Assessment and those that underpin local plans such as the UHB's Integrated Medium Term Plan (IMTP), LA improvement plans and a range of service strategies developed on the LA footprints.

When work begins on the development of the Area Plan it will be important to maintain this alignment, ensuring its commitments reflect those within existing plans (adjusted and refocused where necessary) and vice versa. This will help ensure a consistent focus across agencies on the priorities and challenges that have been identified.

Each of the thematic reports includes further details of existing strategies and plans that are relevant to that particular user group.

## 2.6 Delivering national outcomes

The need to achieve improved wellbeing for people in need of care and support lies at the core of our Population Assessment and will underpin our resulting Area Plan. Services across the statutory, third and independent sectors need to continue to work in partnership to build on people's strengths and abilities and enable them to maintain an appropriate level of independence and realise their personal goals.

To support services in achieving this, the Welsh Government has developed a National Outcomes Framework for people who need care and support and carers who need support. This framework sets out a series of national wellbeing outcomes which people who need care and support and carers should expect in order to lead fulfilled lives. A series of national outcome indicators are identified for each of the outcomes and the framework will be a key driver in identifying evidence-based national priorities for improvement. The national wellbeing outcomes are listed in the following table.

Figure 2:1: National Wellbeing Outcomes

What wellbeing means	National wellbeing outcomes
Securing rights and entitlements Also for adults: Control over day-to-day life	<ul style="list-style-type: none"> <li>I know and understand what care, support and opportunities are available and use these to help me achieve my wellbeing.</li> <li>I can access the right information, when I need it, in the way I want it and use this to manage and improve my wellbeing.</li> <li>I am treated with dignity and respect and treat others the same.</li> <li>My voice is heard and listened to.</li> <li>My individual circumstances are considered.</li> <li>I speak for myself and contribute to the decisions that affect my life, or have someone who can do it for me.</li> </ul>
Physical and mental health and emotional wellbeing Also for children: Physical, intellectual, emotional, social and behavioural development	<ul style="list-style-type: none"> <li>I am healthy and active and do things to keep myself healthy.</li> <li>I am happy and do the things that make me happy.</li> <li>I get the right care and support, as early as possible.</li> </ul>
Protection from abuse and neglect	<ul style="list-style-type: none"> <li>I am safe and protected from abuse and neglect.</li> <li>I am supported to protect the people that matter to me from abuse and neglect.</li> <li>I am informed about how to make my concerns known.</li> </ul>
Education, training and recreation	<ul style="list-style-type: none"> <li>I can learn and develop to my full potential.</li> <li>I do the things that matter to me.</li> </ul>
Domestic, family and personal relationships	<ul style="list-style-type: none"> <li>I belong.</li> <li>I contribute to and enjoy safe and healthy relationships.</li> </ul>
Contribution made to society	<ul style="list-style-type: none"> <li>I engage and make a contribution to my community.</li> <li>I feel valued in society.</li> </ul>
Social and economic wellbeing Also for adults: Participation in work	<ul style="list-style-type: none"> <li>I contribute towards my social life and can be with the people that I choose.</li> <li>I do not live in poverty.</li> <li>I am supported to work.</li> <li>I get the help I need to grow up and be independent.</li> <li>I get care and support through the Welsh language if I want it.</li> </ul>
Suitability of living accommodation	<ul style="list-style-type: none"> <li>I live in a home that best supports me to achieve my wellbeing.</li> </ul>

Source: Welsh Government, 2016

The Population Assessment has taken the National Outcomes Framework into account in considering the care and support needs of different user groups, the extent to which these are being met and areas for improvement. For example, the principle of people being empowered to understand their own needs, articulate these, take an active part in decisions affecting their lives and having access to the right information to improve their wellbeing is a consistent theme throughout the thematic reports. Similarly, physical health, mental health and emotional wellbeing, protection from abuse and neglect, access to appropriate educational and recreational opportunities and support in developing strong personal and community relationships have been important considerations in assessing support needs of particular groups and the type of care and support that should be available.

## 2.7 References

*Mid and West Wales Health and Social Care Collaborative (2014a). Statement of Intent for the Integration of Services for Older People with Complex Needs [online].*

<http://www.wwcp.org.uk/documents/>

*Mid and West Wales Health and Social Care Collaborative (2014b). Statement of Intent for Learning Disability Services [online].*

<http://www.wwcp.org.uk/documents/>

*Mid and West Wales Health and Social Care Collaborative (2015). Market Position Statement for older people's services [online].*

<http://www.wwcp.org.uk/documents/>

*Welsh Government (2016).*

*National outcomes framework for people who need care and support and carers who need support [online].*

<http://gov.wales/docs/dhss/publications/160610frameworken.pdf>



## Section 3

# Consultation and engagement

**West Wales Population Assessment** March 2017

### 3.1. Approach

Our approach to consultation and engagement to support the Population Assessment was underpinned by the principle to identify gaps and avoid duplication and engagement fatigue by:

- Linking in with the Wellbeing Assessment undertaken regionally by the three PSBs in the region to meet the requirements of the Wellbeing of Future Generations (Wales) Act 2015, thus utilising consultation and engagement opportunities for mutual benefit
- Identifying existing provider, service user and carer forums that could contribute to and support the assessment
- Using intelligence from relevant international, national, regional and sub-regional consultation and engagement activities and events undertaken in the recent past
- Undertaking additional engagement where it was agreed that there was a significant gap in our understanding of needs to support the development of the Population Assessment

### 3.2. Wellbeing Assessment

We worked with the PSBs of Carmarthenshire, Ceredigion and Pembrokeshire to co-ordinate public engagement activities on the Population Assessment and Wellbeing Assessment (WBA). This provided a framework for a consistent, regional approach and promoted the interconnectedness of the two key pieces of legislation, using shared engagement activities for mutual benefit.

The key components of the regional engagement approach were:

- A survey directed at residents
- An agreed toolkit for undertaking direct engagement work through focus groups or in less formal settings across the region
- Media campaign activities including social media posts, press releases, newsletters articles, staff briefings

A survey was developed and a series of questions were formulated under the Wellbeing themes of economic, environmental, social and cultural wellbeing respectively. A further section was developed which explored the importance of health to individuals in order to ascertain the views of respondents to the care and support needs that they have and how these are currently met. For the purposes of the Population Assessment our engagement activities were focused on developing our understanding of:

- The extent to which people need care and support or carers need support
- The extent to which needs are not being met

- The range and level of services required to meet the care and support needs of people including the support needs of carers
- The range and level of preventative services required
- The actions required to provide the range and level of services needed to be provided through the medium of Welsh

Alternative versions of the survey were produced in order to ensure accessibility across a wide range of age groups and abilities, namely a younger person's version and an easy read version. In total 7,006 surveys were completed across the region which has provided a wealth of information about the views and needs of residents.

A regional engagement toolkit was also developed and included a series of documents to help organisers in running events and focus groups. A wealth of qualitative data has been gathered as a result of engagement with members of the public or specific patient/service user groups. This activity included:

- Attendance at community events, for example county shows and over 50s forums
- Drop-in sessions on hospital sites and schools
- 7 'Let's Talk Health' events
- 3 Siarad Iechyd events; and
- A number of focus groups, including with Youth Forums, Equality Carmarthenshire and Disability Coalition

Taking a regional and collaborative approach to engagement with our communities in the development of the Wellbeing and Population Assessments has resulted in an excellent survey response rate providing both quantitative and qualitative data. It is acknowledged that some specific population groups may be under-represented both within the survey respondents and the qualitative data gathered through focus groups/community activities. However, we believe that engagement and participation is a fundamental underlying principle of service development and delivery and whilst specific activities have taken place to support this Population Assessment it is important to ensure an ongoing dialogue with service users, families and carers as this represents the ethos of co-production.

### 3.3. Highlights from the findings

Whilst the response rate was good, the findings from the Wellbeing Assessment and engagement events will only provide a snapshot in time of residents' perceptions and identified need. However, combined with recent consultation data and ongoing engagement activity, they make an invaluable contribution to our understanding of needs and views across our communities.

Key messages emerging from the resident's survey align with the issues highlighted in our population assessment and, particularly, the areas identified as priorities for future development and improvement. A sample of these messages is provided below.

**A significant number of respondents identify themselves as having caring responsibilities:** 34% of respondents in Carmarthenshire, 35% in Ceredigion and 36% in Pembrokeshire stated this to be the case. Given that 78% of Carmarthenshire respondents, 62% of Ceredigion respondents and 67% of Pembrokeshire respondents had no dependent children (reflecting the high age profile generally of those that responded), it would appear that the majority of those identifying as carers are caring for other adults. It is particularly important to note that these figures significantly exceed the number of carers formally known to partner agencies, as set out in Chapter 7 of this assessment. There are clear implications in terms of ensuring appropriate support to those carers to ensure wellbeing and prevent future demand on core services.

**Around a third of respondents claimed to have a health issue that affected their wellbeing (32% in Carmarthenshire, 24% in Ceredigion and 32% in Pembrokeshire).** Possibly, the variation across the region reflects the existence of pockets of deprivation within Carmarthenshire and Pembrokeshire which are not present in Ceredigion. However, across the three counties, the incidence of such health issues increases markedly with age. In the 75-84 age group, 49% of respondents in Carmarthenshire, 47% in Ceredigion and 53% in Pembrokeshire said they had a health issue affecting their wellbeing. Corresponding figures for the over 85s were 72%, 67% and 67%. These figures underscore the messages within Chapter 12 relating to the implications of an ageing population and the need for effective preventative services to help people maintain a good quality of life and prevent or delay their need for intensive support.

**Many people needing care and support are receiving this from their families.** The proportion of respondents claiming this to be the case was 81% in Carmarthenshire, 71% in Ceredigion and 85% in Pembrokeshire. This contrasted strongly with the numbers reporting to be in receipt of LA care, the corresponding figures being 6%, 8% and 11%. Interestingly, 76% of respondents in Carmarthenshire receiving support from their families felt this was adequate, suggesting a significant proportion who might need more formal care support now and in the future. This reinforces the need to build low level capacity at community level to supplement the care and support provided by families, support carers themselves and keep people as independent as possible.

**A range of responses were received in relation to care not meeting needs.**

These included:

- Care visits at unsuitable times and at infrequent intervals
- Long waiting lists for LA care
- Changes in benefits reducing individuals' capacity to purchase support privately
- Unmet need for emotional support and for practical help following slips and falls
- Lack of training and support for family members, for example in relation to mental health

Once again these comments provide a clear indication of the need for and value of low level support to keep people independent and maintain their wellbeing within their communities, as well as the need to manage demand for more formal care to ensure that those in need of this receive timely and responsive support.

**People go to a variety of places for information and advice in relation to care and support.** In Carmarthenshire, most people said their preference would be to go to their GP, followed by family and then the Internet; in both Ceredigion and Pembrokeshire the Internet was the preferred route, followed by GP then family member. Implications from this include:

- The need to ensure information contained on the Internet is accessible and accurate (the implementation of the Dewis Cymru database across the region in 2017 will play a key role in this)
- The need to ensure access to the Internet is adequate across the region and to promote digital inclusion
- The need to partner with primary care and GPs to ensure consistent and appropriate information and advice on wider care and support is provided at this point of entry into the system

Discussions at the engagement events which followed circulation of the Wellbeing Survey provided useful insight into the thoughts and perceptions of those residents that participated. Once again a number of these reflect the core premise of this population assessment. A selection of comments made during discussions is provided below:

### **What does wellbeing look like?**

- Support from friends, family and professionals
- Freedom to make choices
- Mental health and wellbeing – especially children
- Connectedness
- Information/ support to make decisions
- Confidence, knowing you are not alone
- Maintaining social links in later life
- Local services that you can reach easily

### **What are the cultural and social factors that are important to the wellbeing of your community?**

- Supporting communities to help themselves
- Everyone has something to offer
- Valuing carers
- Sound information in a variety of media

- Access to someone who can give information on preventative measures to avoid ill health and helping to make healthy lifestyle choices – pharmacist, advisers at the gym etc
- Opportunities for befriending and intergenerational links, e.g. schools 'adopting' care homes
- Community hubs
- Welsh language and culture
- Getting services in the language we want to speak
- A community that works together

### **What improvements are needed to care and support?**

- Put patient at the heart of things
- Specialist clinics in the community and closer to people's homes
- Proactive care events
- Transport and access to services

Full reports have been produced on the findings of the Wellbeing Assessment, including those questions included specifically relating to health and wellbeing in the resident survey, and qualitative feedback from the consultation events. These reports will be made available when this assessment is published.

## Section 4

# Cross Cutting Themes

**West Wales Population Assessment** March 2017

## 4.1. Overview

Whilst each of the thematic reports identifies issues and challenges relevant to that user group, some of these are common across all parts of the population and require a generic response from the RPB and its constituent partners. These common issues and challenges are set out below.

## 4.2. Delivering Services in the Welsh Language

Being able to access Welsh language services is a desire for some people whilst for others it is a necessity and can play a key role in securing positive wellbeing outcomes. Particularly when they find themselves at a vulnerable point in their lives and potentially in need of care and support services, some people will find expressing and communicating needs in Welsh more natural than they would in English, particularly where Welsh is their first language and that through which they think and live their lives. Therefore, maximising the availability of services in Welsh needs to be a priority for local authorities, LHBs and other partners across health and social care and the wider public service. Failure to do so can mean that the basic needs of some of the population cannot be met.

Under the Welsh Language (Wales) Measure 2011 the language has official status in Wales and as such should not be treated less favourably than the English language. The Measure establishes a legal framework placing a duty on organisations providing services to the public in Wales to meet specified standards in relation to:

- Delivery of services
- Policy making
- Internal operations
- Promotion of the Welsh Language; and
- Record keeping

Each LA in Wales has been issued with a compliance notice by the Welsh Language Commissioner setting out the Standards introduced by the measure that they are expected to meet. Councils are required to submit annual progress reports on how these standards are being met. Regulations creating the Standards for NHS Wales are likely to be passed by the National Assembly for Wales in late 2016/early 2017. From that point, the Welsh Language Commissioner will also have the right to serve compliance notices to NHS agencies.

The Wellbeing of Future Generations (Wales) Act 2015 contains seven goals for the wellbeing of Wales, one of which is to ensure 'A Wales of vibrant culture and thriving Welsh language'. The SSWB Act includes in its definition of wellbeing 'securing rights and entitlements'. For Welsh speakers, this will mean being able to use their own language to communicate and participate in their care as equal partners.



The Welsh Government's 'Mwy na geiriau' or 'More than Just Words' initiative was launched in 2012 and provides a strategic framework for Welsh language services in health, social services and social care (Welsh Government, 2012). Since its inception the framework has driven a number of important improvements, achieved by optimising existing skills and resources across social services and the NHS.

A follow-on Strategy was launched in 2016 (Welsh Government, 2016a), reflecting the developing legislative context and aimed at building momentum in the development of Welsh language services, in recognition of the importance of care and support delivered through the medium of Welsh for vulnerable people.

Examples might include those suffering from dementia or stroke, or very young children who may only speak Welsh. A key principle of the original Framework – that of the 'active offer' remains central in the new strategy. This means providing a service in Welsh without someone having to ask for it, placing the onus on service commissioners and providers rather than the individual needing care and support. The new strategy covers the following areas: National and local leadership; mapping, auditing, data collection and research; service planning, commissioning, contracting and workforce planning; promotion and engagement; professional education, Welsh in the workplace and regulation and inspection.

Effective delivery of statutory requirements and the requirements within 'More than Just Words' is particularly important in West Wales, where a significant proportion of the population is Welsh speaking. The following table provides a break-down of the proportion of Welsh speakers by age in each county within the region, compared with Wales as a whole.

Figure 4:1 Proportion of Welsh speakers in each County

Age group	Carmarthenshire	Ceredigion	Pembrokeshire	West Wales	Wales
3-4	46%	58%	22%	40%	23%
5-9	60%	82%	41%	57%	38%
10-14	60%	83%	46%	59%	42%
15-19	53%	45%	35%	46%	29%
20-24	42%	31%	18%	32%	18%
25-29	39%	49%	16%	34%	16%
30-34	36%	47%	13%	31%	15%
35-39	36%	48%	13%	31%	15%
40-44	36%	45%	13%	30%	14%
45-49	35%	44%	13%	29%	13%
50-54	38%	44%	13%	31%	13%
55-59	39%	42%	14%	32%	13%
60-64	40%	39%	14%	31%	13%
65-69	45%	42%	15%	34%	15%
70-74	46%	45%	15%	35%	15%
75-79	50%	49%	15%	38%	16%
80-84	53%	51%	17%	41%	18%
85+	57%	51%	17%	43%	19%
All aged 3+	44%	47%	19%	37%	19%

Source: Office for National Statistics, 2011

The above table illustrates that the proportion of the population over 3 years of age who are Welsh speakers in West Wales is significantly higher – at 37% than in Wales as a whole, for which the corresponding figure is 19%. Also of note is the variation in the number of Welsh speakers in each county area; whilst Carmarthenshire and Ceredigion both exceed the proportion across Wales as a whole by a considerable margin, the proportion in Pembrokeshire is the same, at 19%. There are also variations within county areas. 55% of people in the Gwendraeth Valley in Carmarthenshire speak Welsh, compared with just 25% in Llanelli town. There is a wide variation between the numbers of Welsh speakers in North and South Pembrokeshire, the proportions being 40% and 12% respectively. In Ceredigion the variations are less marked, although 52% of the population speak Welsh in the south of the county, compared with 44% in the north.

These figures highlight the importance of promoting the Welsh language and taking all available measures to strengthen the breadth of Welsh language services across the region. All statutory partners are signed up to the 'More than Just Words' strategy, and a number of local initiatives are in place across the region. A particular challenge in meeting needs in relation to the Welsh language will be in ensuring that a sufficient number of those providing services on the front line are able to converse with users and carers in Welsh where individuals have expressed this preference.

### 4.3. Minority and marginalised groups

The Regional Community Cohesion Steering Group, comprising Carmarthenshire, Ceredigion, Powys and Pembrokeshire County Councils, is focusing on mainstreaming the seven outcomes (set out below) of the Community Cohesion National Delivery Plan 2016-17 (Welsh Government, 2016b) into policies, strategies, partnerships and service delivery.

The seven outcomes are to ensure:

- Departments, organisations and people understand hate crime, victims make reports and get appropriate support
- Departments, organisations and people understand modern slavery, victims make reports and get appropriate support
- Increased awareness and engagement across Gypsy and Traveller communities.
- Increased evidence and awareness on immigration and supporting the inclusion of asylum seekers, refugees and migrants
- Increased understanding regarding the impacts of poverty on people with Protected Characteristics across key service and policy delivery
- Key policies and programmes are supporting and evidencing delivery against the national goal on more cohesive communities through the Wellbeing of Future Generations (Wales) Act 2015
- Policies and services are responsive to community tensions

There are also a range of partnerships in each county that are supporting this work including:

- Pembrokeshire Voices for Equality
- Pembrokeshire County Council Corporate Equality Strategy Working Group
- Safer Pembrokeshire, Community Safety Partnership
- Ceredigion Voices for Equality
- Ceredigion Corporate Equality Strategy Working Group
- Ceredigion Community Safety Partnership
- Equality Carmarthenshire
- Fair and Safe Communities Thematic Group

However, in order to deliver these outcomes and to fully understand the care and support needs of minority and marginalised groups there is a need to obtain and analyse more robust demographic data than that currently available.

For example, 2011 Census data shows that the Black and Minority Ethnic population in West Wales made up less than 2% of the overall population (compared to 4.4% in Wales) and that there were 335, 74, and 454 persons in Carmarthenshire, Ceredigion and Pembrokeshire, respectively described as White Gypsy or Irish Traveler. However, we also know that since 2011 there has been inward migration of people from other parts of the EU and of refugees and asylum seekers from other parts of the world.

The total number of asylum seekers and refugees living in Wales is estimated to be between 7,500 and 11,500). The top five countries of origin of asylum seekers living in Wales at the end of March 2013 were People's Republic of China, Pakistan, Iran, Nigeria and Afghanistan. The most common age group of asylum seekers is 30-34 years. Just under half of all asylum seekers living in Wales are female. More work is needed to engage with such groups, identify specific needs and ensure that services are responsive to them.

There is also a lack of consistent data to inform our understanding of these groups and other minority and marginalised groups including:

- Offenders, ex-offenders, and their families
- Homeless
- The lesbian, gay, bisexual and transgender (LGBT) community
- Black and Minority Ethnic (BME) groups
- Military veterans

For example, in relation to homelessness, local authorities collect data on the numbers of people who present as homeless and who after advice and / or mediation are assessed as 'final duty' homeless. However, there are less consistent approaches in relation to identifying rough sleepers across the region.

Where possible, we have highlighted specific needs of minority and marginalised groups into the thematic reports; for example, the carers Report notes that the proportion of carers in the BME population is less than the proportion in the population as a whole and the VAWDASV report makes specific reference to the care and support needs of migrant, refugee and asylum seeking women in the region.

A high level Equalities Impact Assessment (EIA) was undertaken to support this population assessment and ensure that it reflects the requirements of the Public Sector Equality Duty and properly considers the needs of protected groups. Moreover, it will be vitally important to ensure, when planning future services and addressing the issues and

challenges raised in this report, that partners take all opportunities to engage with minority and marginalised groups and ensure their needs are properly understood and addressed. This work will need to be supported as appropriate by further EIAs.

#### 4.4. Prevention

Prevention lies at the heart of the new arrangements for care and support envisaged within the SSWB Act. Specifically, Section 15 of the Act requires local authorities to provide or arrange for the provision of preventative services to prevent, delay or reduce need for care and support. They also have an important role to play in:

- Promoting the upbringing of children by their families, where that is consistent with the wellbeing of children
- Minimising the effect on disabled people of their disabilities
- Contributing towards preventing people from suffering abuse or neglect
- Reducing the need for proceedings for care or supervision orders under the Children Act 1989;
- Criminal proceedings against children
- Any family or other proceedings in relation to children which might lead to them being placed in LA care, or proceedings under the inherent jurisdiction of the High Court in relation to children
- Encouraging children not to commit criminal offences
- Avoiding the need for children to be placed in secure accommodation; and
- Enabling people to live their lives as independently as possible

Not surprisingly, partners across West Wales have for some time been working to develop and enhance the range of preventative services available to people who either need care and support or who are likely to in the future. Some of this activity has been supported through national initiatives such as Families First, Flying Start and Integrated Family Support Services in relation to children and families. A range of initiatives are underway in West Wales to build resilience within communities through local provision of low level support services including Information, Advice and Assistance and befriending services which help people remain independent without having to seek formalised care. Programmes targeted at reducing unnecessary hospital admissions, especially among older people, and accelerating discharge back home have been funded through the Welsh Government's ICF. These include third sector-led partnerships such as the Pembrokeshire Intermediate Voluntary Organisations Team (PIVOT) which provides a home to hospital service for older people and is now being replicated across all parts of the region.

Meanwhile many new initiatives are being developed across GP clusters to improve the integration of primary and community services and develop approaches such as social prescribing, which encourage the referral of people to wellbeing services within their

communities rather than on to specialist health services. Initiatives such as time banking are being developed to encourage members of the community to contribute to such services; optimising community assets and driving genuinely user-led approaches to prevention.

Current achievements in relation to prevention are set out in more detail in the thematic reports, with a consistent call for further development to ensure the delivery of efficient and effective wellbeing for the local population. The identification of prevention as one of its strategic priorities demonstrates the commitment of the RPB to further improvement in this area.

## 4.5. Safeguarding

Safeguarding is a central theme in the SSWB Act. In the Act, one of the identified elements of wellbeing is protection from abuse and neglect. For children and young people this includes their physical, intellectual, emotional, social and behavioural development; and their welfare (ensuring they are kept safe from harm).

Part 7 of the Act introduces a new duty on local authorities to make enquiries if they have reasonable cause to suspect that an adult within their area is at risk, and on all relevant partners to report an adult at risk. Councils may grant adult protection and support orders (APSOs) where there is reasonable cause to suspect that a person is an adult at risk and the order is needed to enable them to be assessed.

Under the Act all relevant partners of a LA also have a duty to report a child at risk. Local authorities then have a duty to make enquiries (linking into section 47 of the Children Act 1989) if they are informed that a child may be at risk; and to take steps to ensure that the child is safe.

Regional safeguarding boards for children and adults are required under the Act, representing a range of partners and with responsibility for identifying and disseminating effective practice in relation to safeguarding. These are in place in the Mid and West Wales region, complementing local safeguarding arrangements and spanning the West Wales and Powys areas. A review of the regional safeguarding board – CYSUR - was undertaken in late 2015 and informed the structure and operation of the adult safeguarding board which was established in early 2016. Both boards come together on a regular basis to share approaches and consider common issues.

Arrangements are in place in each LA to ensure compliance with the other safeguarding duties introduced by the Act and outlined above.

## 4.6. Promoting social enterprises, cooperatives, user led services and the third sector

The SSWB Act also places a strong emphasis on the role of social enterprises, cooperatives, user-led services and the third sector in providing care and support services. This will be key in delivering the Welsh Government's policy for greater diversity in the delivery of public services and in empowering people and communities through a co-productive approach.

Once again, a number of the thematic reports identify existing good practice in this area, citing specific examples of social enterprises that are providing a range of services across client groups. However, without exception the reports conclude that these foundations need to be built upon and the development of such new service models accelerated, both to achieve sustainability of care and support within communities and to drive a genuinely community-based approach to wellbeing. In delivering this, expert support will be sought from recognised experts such as the Wales Cooperative Centre and Social Firms Wales to ensure that new models are appropriate and sustainable within the region. Regional forums will be established to support social value based providers to develop a shared understanding of this agenda, and to share and develop good practice.

## 4.7. References

*Children Act 1989, chapter 41.*

<http://www.legislation.gov.uk/ukpga/1989/41/section/47>

*Office for National Statistics. (2011). Welsh Language Skills (QS207WA). [online].*

<http://www.neighbourhood.statistics.gov.uk/dissemination/Download1.do>

*Welsh Government (2012). More than just words: Strategic Framework for Welsh Language Services in Health, Social Services and Social Care.*

[http://www.wales.nhs.uk/sites3/Documents/415/WEB%20-%2016184\\_Narrative\\_e\\_WEB.pdf](http://www.wales.nhs.uk/sites3/Documents/415/WEB%20-%2016184_Narrative_e_WEB.pdf)

*Welsh Government (2016a). More than just words: Follow-on Strategic Framework for Welsh Language Services in Health, Social Services and Social Care 2016 – 2019.*

<http://gov.wales/docs/dhss/publications/160317morethanjustwordsen.pdf>

*Welsh Government (2016b). Community Cohesion National Delivery Plan 2016-17.*

<http://gov.wales/docs/dsjlg/publications/equality/160310-community-cohesion-plan-en.pdf>



## Section 5

# Recommendations

**West Wales Population Assessment** March 2017

Whilst specific areas for improvement are identified in each of the thematic reports, there are a number of generic recommendations which need to be considered by the RPB if it is to drive sustainable change to services on the ground. These are set out below under the core principles of the Act:

### Voice and control

1. Ensure that maintaining people's dignity and protecting individuals from neglect and abuse must lie at the heart of all services.
2. Ensure all services are available in Welsh for those who require them.

### Prevention and early intervention

3. Build on the considerable foundations in place across the service areas covered in this assessment to ensure appropriate services are available to prevent or delay the need for ongoing care and support and that the prevention ethos underpins all levels and types of care. Specifically, opportunities should be taken to develop consistent preventative frameworks across services, which build on existing good practice, facilitate transition between children and adult's services and demonstrably reduce the need for ongoing care and support.
4. Invest in the development of community-based preventative services, including social enterprise, cooperatives, user-led and third sector provision thus building the resilience of communities and, thereby, of people needing care and support.
5. Align the Intermediate Care Fund (ICF) and Cluster Development Change Programmes to build consistent, whole system change on the ground.

### Wellbeing

6. Prioritise support for carers, enabling them and those they care for to live fulfilled and independent lives for as long as possible.
7. Further improve transition services to facilitate effective planning across services and ensure that young people continue to receive appropriate care and support into early adulthood.

### Co-production

8. Ensure that people needing care and support and carers are involved meaningfully at all stages in the planning, delivery and review of services. This needs to happen at strategic level, engaging with citizens over the future shape of care and support and expectations on individuals to promote their own wellbeing and operationally, ensuring that assessment and care planning allows people to express personal outcomes and influence decisions regarding the support needed to attain them.

## Cooperation, partnership and integration

9. Create an environment which permits radical change and encourages innovation rather than trying to do more of the same with less.
10. Use the population assessment as the basis for the development of integrated commissioning across service areas, based on a common understanding of need.
11. Develop consistent delivery models across service areas and the region, based on a shared strategic vision and the principles within the Act; ensuring common standards to all residents in West Wales.
12. Use this population assessment as a basis for detailed modelling of future scenarios to understand the interdependencies and impact on care and support services of, for example, demographic increases in the older population, and expected increases in known carers and victims of violence against women, domestic abuse and sexual abuse. There is a need to understand how future conditions in the area might impact on social services provision and the extent and diversity of needs for social services over the next 10 -25 years.
13. Pool funds and other resources where appropriate to optimise their impact and support seamless delivery.
14. Engage strategically with providers across all sectors to develop services and build sustainable markets for the future.
15. Work with partners across the public sector and others to embed a preventative approach, promote wellbeing, optimise resources and address specific challenges such as accessibility of services in a predominantly rural area.

The process of undertaking this assessment has brought professionals from across the region together to consider objectives, contemplate solutions and agree on where change is most needed. This in itself provides another firm foundation across partner organisations for the RPB in discharging its primary duty – to drive the strategic change that is still needed through cooperation, partnership and integration. This will go long way in ensuring that care and support in West Wales supports the wellbeing and promotes the independence of those in need within our communities.



## Section 6

# West Wales Population Profile

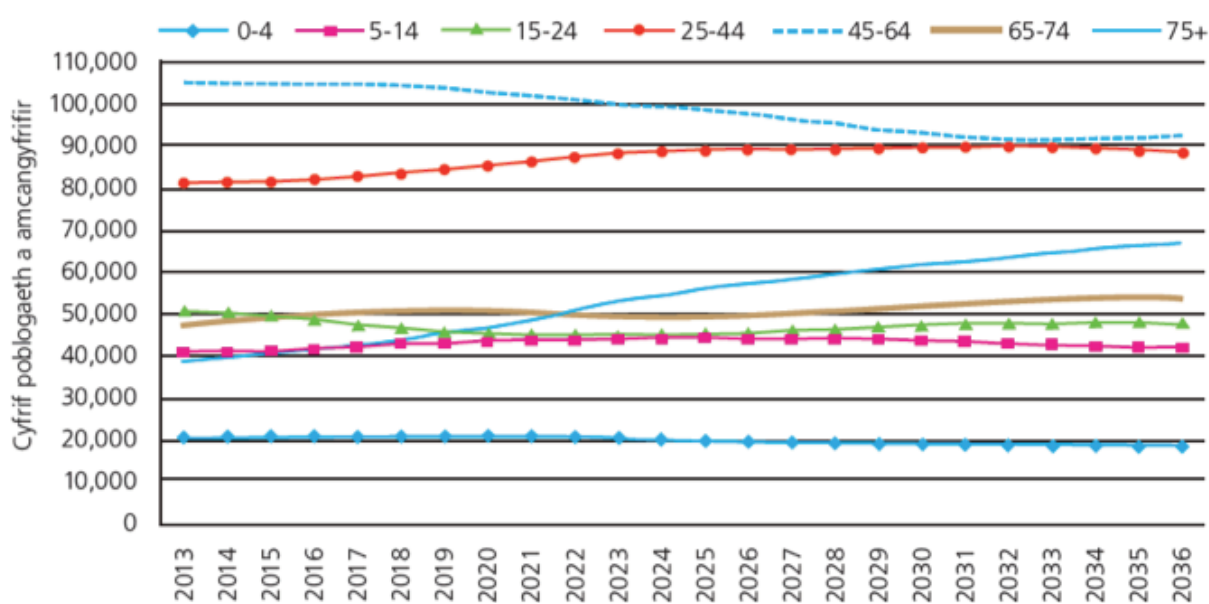
**West Wales Population Assessment** March 2017

## 6.1. Overview

The West Wales region covers three LA areas - Carmarthenshire; Ceredigion and Pembrokeshire - and is coterminous with the Hywel Dda University Health Board (HDUHB) footprint. Estimated population of the region is 384,000 (Hywel Dda University health Board, 2016). Covering a quarter of the landmass of Wales, it is the second most sparsely populated health board area in Wales. 47.9 per cent of the population in the region live in Carmarthenshire, 20.7 per cent in Ceredigion and 31.4 per cent in Pembrokeshire.

Current population projections suggest that the total population of West Wales will rise to 425,400 by 2033, with a rise in those aged over 65 years from 88,200 in 2013 to 127,700 by 2033. These estimates are based on assumptions about births, deaths and migration. The increase in the number of older people is likely to cause a rise in chronic conditions such as circulatory and respiratory diseases and cancers. Meeting the needs of these individuals will be a key challenge for the UHB. In the current economic climate, the relative (and absolute) increase in economically dependent and in some cases, care-dependent populations will pose particular challenges to communities

**Figure 6:1 Projected population counts by age group, Hywel Dda UHB, 2013-2036**

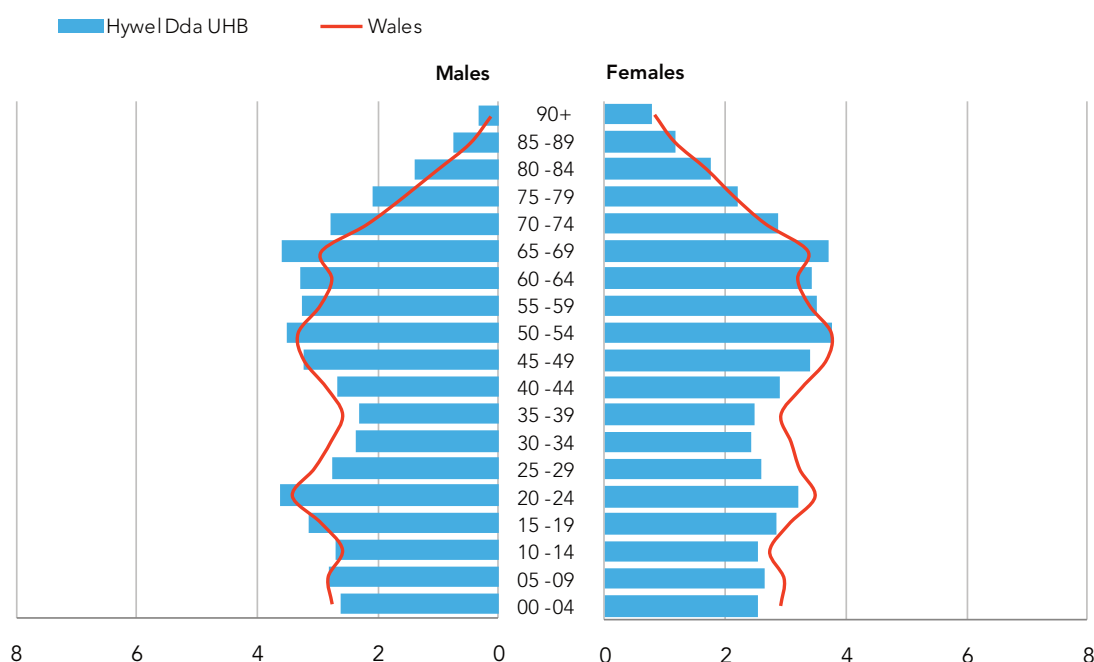


Source: Hywel Dda University Health Board

With 12.4% of Wales' population the area's age and sex profile is similar to that of Wales as a whole.

The following Figure provides detail of how the West Wales region compares to the rest of Wales in relation to the age and sex distribution of its population. It shows how in West Wales the age composition of the population is higher than in Wales generally with fewer people aged between 25 and 44 and more people aged 55 and over.

**Figure 6:2 Population pyramid percentage by age and sex in Hywel Dda UHB and Wales, 2014**



Source: Hywel Dda University Health Board

Figure 6.3 sets out further key population statistics for West Wales compared with the rest of Wales. This shows that West Wales has a higher proportion of people aged 75+ than Wales; slightly higher life expectancy for both males and females than Wales; slightly higher rates of people who are obese or overweight, and lower proportions of people who smoke and who drink alcohol above guidelines. West Wales also has a lower take up of MMR immunization and a lower birth rate than Wales. Emergency admissions per 1000 population are also lower in West Wales.

**Figure 6:3 Key Population Statistics**

Key Statistics	Wales	West Wales
Total population	3,092,000	384,000
Population aged 75 and over (%)	8.9	10.3
Life expectancy at birth – males (years)	78.1	78.9
Life expectancy at birth – females (years)	82.2	82.7
Adults who are overweight or obese (%)	58.1	58.5
Adults who smoke (%)	20.9	19.7
Adults who drink above guidelines (%)	41.1	39.1
MMR uptake (%)	95.8	94.9
Live birth per 1,000 women aged 15-44	59.1	56.8
Emergency hospital admissions (European age standardised rate per 1,000 population)	112.4	105.3

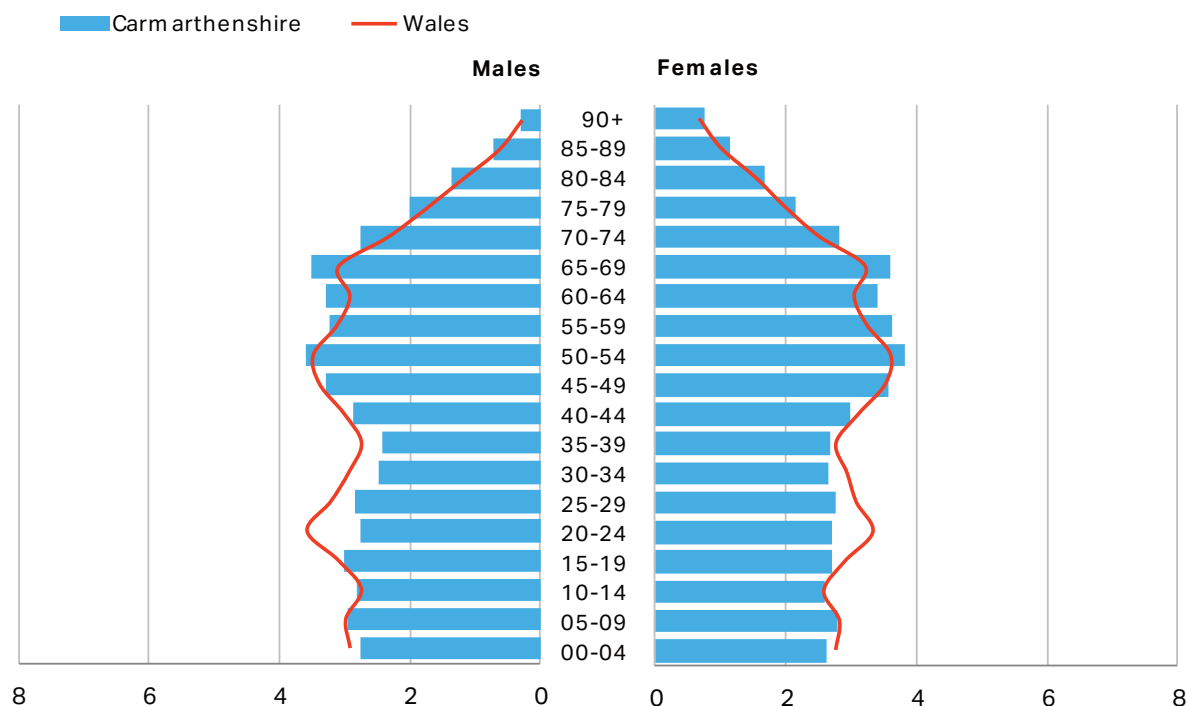
Source: Hywel Dda University Health Board

Within the region there are notable differences in the composition of the population as illustrated below:

### Figure 6:4 Population Pyramids

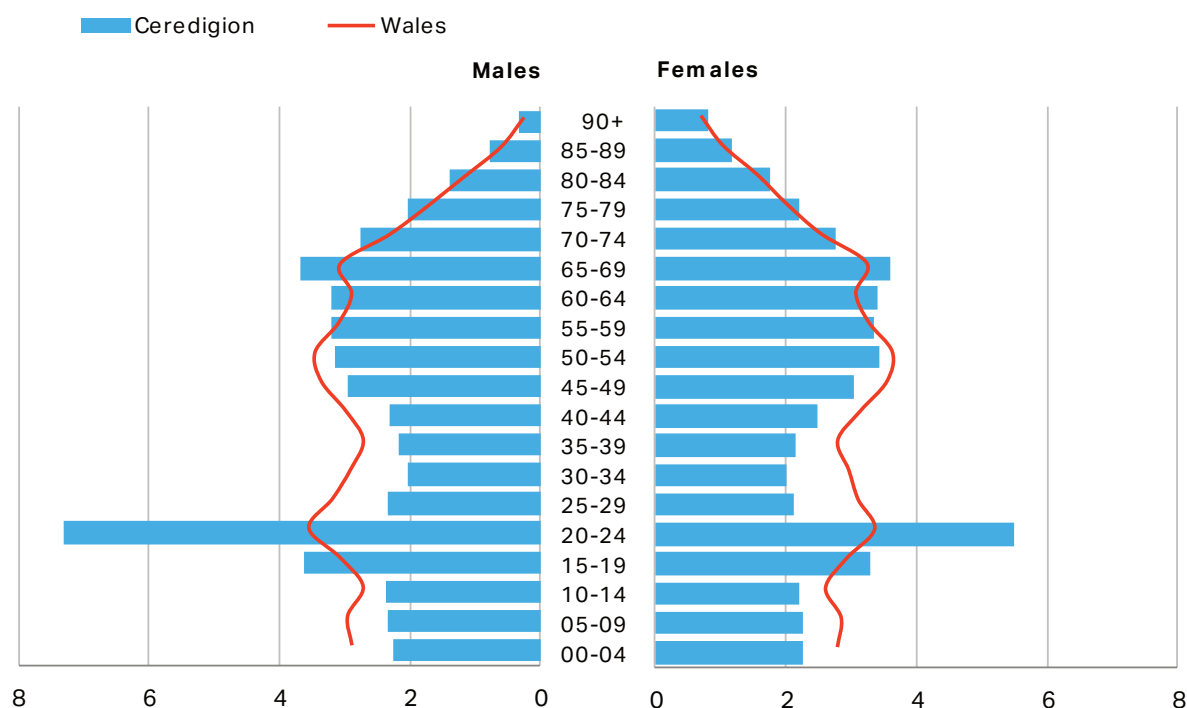
#### Percentage of population by age and sex, Carmarthenshire and Wales, 2015

Produced by Public Health Wales Observatory, using MYE (ONS)



#### Percentage of population by age and sex, Ceredigion and Wales, 2015

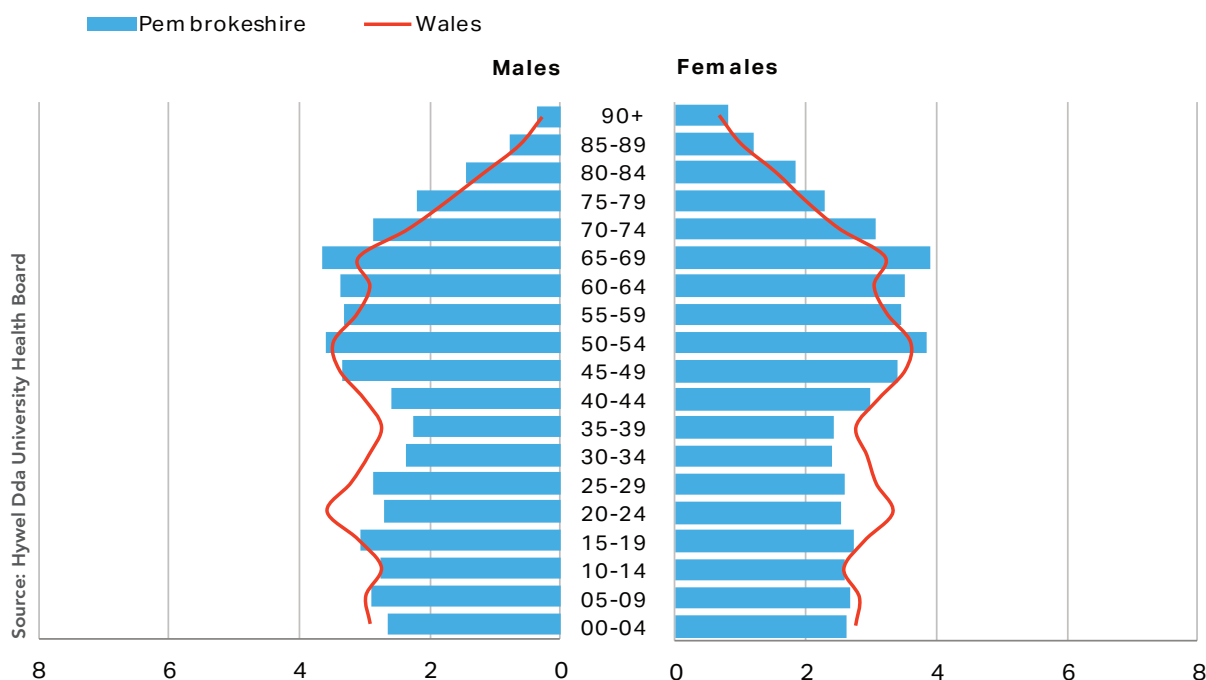
Produced by Public Health Wales Observatory, using MYE (ONS)





## Percentage of population by age and sex, Pembrokeshire and Wales, 2015

Produced by Public Health Wales Observatory, using MYE (ONS)

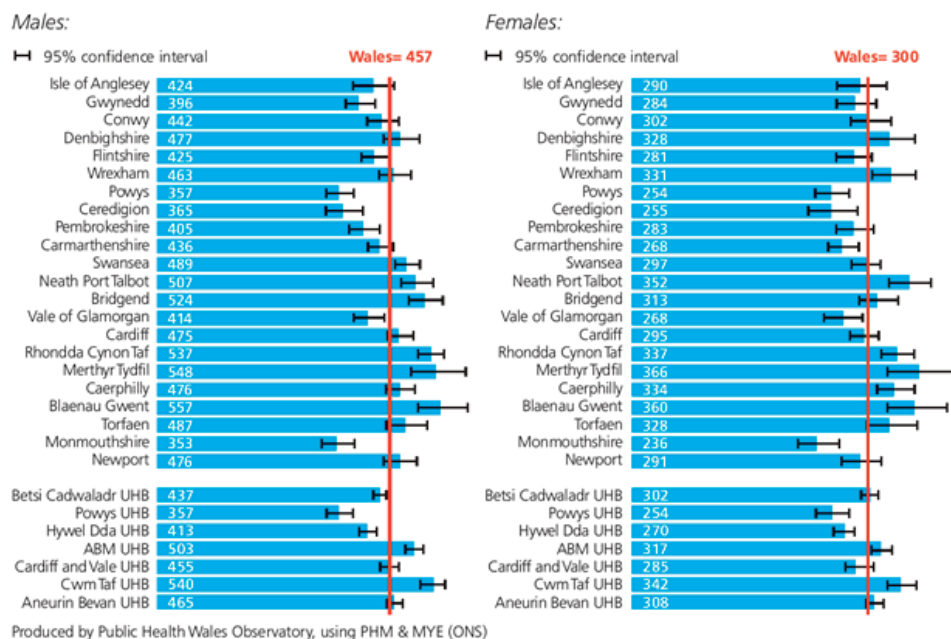


Ceredigion has a large proportion of young adults aged 20-24 years in its population due to its large University town compared to Carmarthenshire and Pembrokeshire.

## 6.2. All cause mortality rates

Figure 6.5 shows that in West Wales the under 75 age-standardised mortality rate for males and females is statistically lower than the Wales rate. However, at LA level there seems to be no statistical difference between Wales and Carmarthenshire for males and Pembrokeshire for females.

**Figure 6:5 All cause mortality, EASR per 100,000, count and crude rate, under 75, Wales local authorities, health boards, 2012-14.**

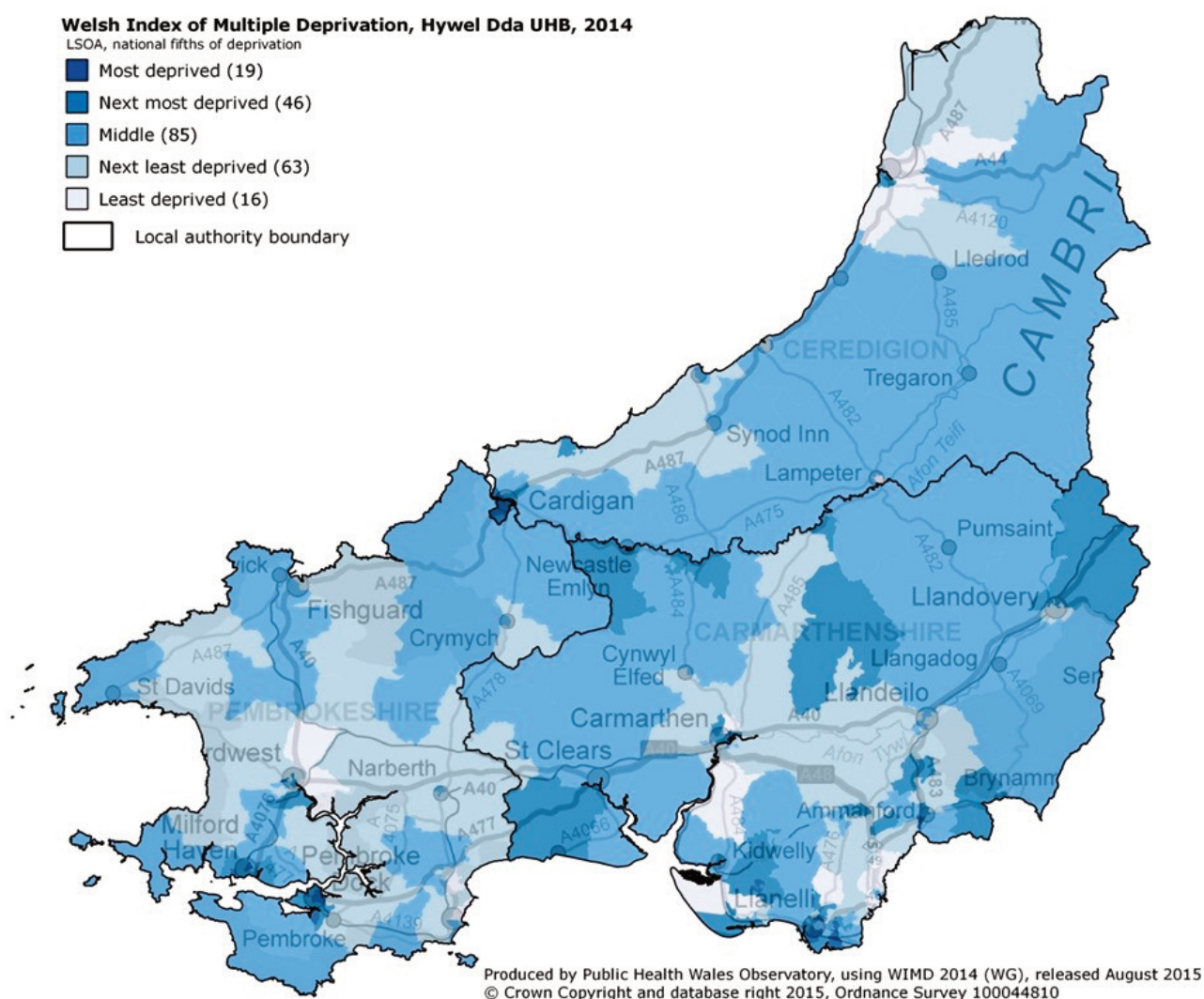


Source: Hywel Dda University Health Board

### 6.3. Deprivation and lifestyle factors

Geographically based deprivation measures can be used to show inequalities in health and suggest areas likely to most need measures to improve health and manage ill-health. The Welsh Index of Multiple Deprivation 2014 is produced at Lower Super Output Area (LSOA) level and is derived from a broad range of factors. The following figure shows that in West Wales there are areas of deprivation including parts of Llanelli, Pembroke Dock and Cardigan.

**Figure 6:6 Welsh Index of Multiple Deprivation, Hywel Dda UHB 2014**



Source: Hywel Dda University Health Board

Figure 6.6 shows that people living in the West Wales region have generally healthier lifestyles than is typical across Wales. Yet there are still challenges to be addressed. For example, Ceredigion has a slightly higher rate of adults reporting to drink alcohol above the guidelines and binge drink, whereas Pembrokeshire and Carmarthenshire are reporting higher than the Welsh average in rates of obesity. This is despite better rates than Wales for levels of physical activity and fruit and vegetable consumption.

**Figure 6:7 Observed percentage of adults who reported key health-related lifestyles, by LA, Health Board and Wales, 2013/14**

		Wales	Hywel Dda UHB	Ceredigion	Pembrokeshire	Carmarthenshire
Daily alcohol consumption	Smoker	21	19	18	18	19
	Above guidelines	41	39	42	35	39
	Binge	25	22	26	18	24
Consumption of fruit & veg	Meets guidelines	32	37	39	38	35
Exercise or physical activity	Active on 5 or more days per week	30	33	35	32	33
	0 Active days	34	31	27	34	31
Body mass index	Overweight or obese	58	58	52	59	60
	Obese	22	22	17	23	24
*Unweighted base		29,177	3,703	1,295	1,122	1,266

\*Bases vary, those shown are for the whole sample

Source: Hywel Dda University Health Board

## 6.4. Further information

More information on the West Wales population is available in the Public Health Needs Assessment Report (Hywel Dda University Health Board, 2016). This document provides further details on the demographic profile, prevalence and incidence of various chronic conditions, lifestyle risk factors and some of the wider determinants that impact upon health. There is also reference to the local Single Integrated Plans for Carmarthenshire, Ceredigion and Pembrokeshire.

Further reference is made to lifestyle and environmental factors where appropriate in each of the thematic reports that follow.

## 6.5. References

*Hywel Dda University Health Board (2016).  
Health Needs Assessment Report 2016.*

<http://www.wales.nhs.uk/sitesplus/862/page/85702>

## Section 7

# Carers

**West Wales Population Assessment** March 2017

## 7.1. Overview and Key Messages

All of us will have our lives touched by caring at some point: 3 in 5 of us will be carers and many of us will also need care in our lifetime (George, 2001). Carers are the mothers, fathers, sons, daughters, siblings, spouses, friends and neighbours who provide unpaid care, caring at home, picking up prescriptions, changing dressings, providing much needed emotional support and much more, and often neglecting their own health and wellbeing needs. Carers are vital to those they care for and to the foundation of the health and social care system.

Around 1 in 8 people in West Wales, many of them young people, are providing unpaid care with a significant proportion providing between 20 to 50+ hours of unpaid care per week.

The provision of unpaid care is becoming increasingly common as the population ages, with an expectation that the demand for care provided by spouses and adult children will more than double over the next thirty years (See for example Pickard, 2008).

Based on a national calculation conducted by carers UK and Sheffield University in 2015 (Buckner and Yeandle, 2015), the cost of replacing unpaid care in West Wales, can be estimated at £924m. This exceeds the NHS annual budget for the region which is almost £727m (Hywel Dda University Health Board 2016a).

## 7.2. Demographics and Trends

Census data suggests that within West Wales there are more than 47,000 unpaid carers representing 12.5% of residents (ONS, 2011):

- Carmarthenshire has the highest proportion (13.2%) of unpaid carers in West Wales, the 3rd highest in Wales
- Pembrokeshire has the second highest proportion (12.4%) in West Wales, the 11th highest in Wales
- Ceredigion has the lowest proportion in West Wales (8,603), the 4th lowest in Wales. In comparison with the other 21 authorities across Wales however, the percentage change (8.7%) between 2001 and 2011 of carers in Ceredigion was the second highest across all of Wales (joint second with Powys)
- The age range that provided the greatest share of care were women aged 50-64, with more than a quarter of all women in this age group providing some level of unpaid care
- The percentage of people providing over 50 hours of care per week rises with age, for both males and females
- The Black and Minority Ethnic (BME) population of West Wales is 2.12% of our total population or 8,105 people, considerably lower than the Welsh average of 4.4%. The rates of caring amongst the BME population are significantly lower than the

population as a whole, around half that of the general population. This is partly explained by the lower age profile found in BME groups

Figures from Carers UK (2013a) indicate that over one third of eligible carers do not claim the carers Allowance benefit.

The 2011 Census further suggests that:

- 7.2% of the population provide 1-19 hours unpaid care per week
- 1.7% provide 20-49 hours unpaid care per week
- 3.5% provide more than 50 hours of unpaid care per week
- The age range that provided the greatest share of care were women aged 50-64, with 25.7% of all women in this age group providing some level of unpaid care. A total of 10% of this age group are providing over 20 hours care p/w
- The total number of people in the area providing over 50 hours of care p/w is 13,373 of whom 5,485 (41%) are male and 7,888 (59%) are female
- The percentage of people providing over 50 hours of care p/w rises with age, for both males and females
- In the 25-49 years age group, 2.3% (1,215) of all males and 4.1% (2,297) of all females provide over 50 hours of care p/w
- In the 50-64 years age group, 4.2% (1,629) of all males and 6.3% (2,564) of all females provide over 50 hours of care p/w

The percentage of carers identified to health and social care organisations in West Wales increased from 10.2% in June 2013 to 20.6% in June 2016 (Hywel Dda University Health Board, 2016b).

Census data suggest that there are 3,436 young carers (defined as 5-17 year olds) in West Wales.

Of those:

- 48% are male and 52% are female (compared to 43% and 57%, respectively in the overall carer population)
- 858 (25%) of young carers are providing more than 20 hours unpaid care per week
- 385 (11%) are providing more than 50 hours of unpaid care per week

Figures published by the BBC suggest there are four times more young carers in the UK than are officially recognised (Howard, 2010).



### 7.3. Current and Future Support Needs

It is worth noting that not all carers want or need support all of the time. For example, 51% of 1,020 carers who were offered a carers assessment by Ceredigion Social Services in 15/16 declined the offer. Just over a third (35%) of those that declined the offer reported that they were managing in their caring role so did not require any additional support.

However, the Carers Trust (2016) estimate that by 2030 the number of unpaid carers will grow by around 60% as more people live longer but with more complex needs.

The role of an unpaid carer can negatively impact a carer's physical and mental health and their career and financial security. Carers can also experience social isolation, a lack of recognition of their caring role and their knowledge of the cared for person. Life after caring can also bring its own challenges.

Evidence suggests that:

- Providing more than 50 hours of unpaid care can increase the likelihood of self-reported poor health (Census data)
- The short and long-term impact of carer collapse can be devastating. Carers can end up in a double admission alongside their ill or disabled loved one, (Carers UK, 2014)
- Caring for someone with dementia or mental health needs can have an even greater impact leading to stress and frustration and a detrimental impact on carers' physical and mental health
- Carers frequently report that their involvement in care is not adequately recognised and their expert knowledge of the 'cared for person' is not taken into account. A disconnected model of involvement like this can lead to carers being excluded at important points (Worthington et al, 2013); and this issue contributed to readmission of the cared for person into hospital in 62% of cases (Carers Trust Wales, 2016)
- It can be difficult for working-age carers to combine paid work with caring duties and carers may choose to quit paid work or reduce their work hours (OECD, 2011)
- Around 5% or 1 in 20 people of working age combine paid work with their role as an unpaid carer (Carers UK, 2013b) and yet across the region the percentage of working age people claiming Carer's Allowance is around 2.0%. Whilst this is comparable to the Wales percentage (2.1%) in Ceredigion the uptake is lower (1.4%) (Data Unit Wales, 2015). Direct Payments to carers in their own right is also low which could be linked to the take up of assessment offers. More than a third of carers miss out on state benefits because they didn't know they could claim for them (Carers Trust, 2016).



*"A carer confided in the GP surgery receptionist that she was not coping at home due to the stress of being a carer to her husband who had been diagnosed with Dementia. She was alone, and nobody understood how her husband could be a handful as his friends and family knew him as this kind caring man".*

Source: Hywel Dda Regional IiC (2016)

It is important to recognise that carers' wellbeing can be significantly improved by addressing low level issues such as not being able to carry out maintenance or DIY, tidy up the garden or clean the windows.

Carers are not a static population. Every year around a third of carers find their caring role has come to end as the person they care for recovers, moves into residential care or passes away (Carers UK, 2015). Life after caring can bring new challenges. Loss of role and function compound normal grieving and can lead to isolation and depression. Many carers will have depended on the welfare benefits of those that they cared for to jointly live on but when the caring role comes to an end welfare benefits can stop too leaving carers having to apply for benefits themselves. As one carer put it:

*"Why doesn't anyone pick up on this and help the carer to be able to move on?"*

Source: Carers UK

Carers also face a number of other challenges including transport and finding suitable and affordable housing, and inadequate and inaccessible service provision for carers and for the cared for person.

- Looking after someone with a disability or illness can make it difficult to get out of the house. This could be due to mobility, travel and fuel costs or poor transport links within large rural areas
- Carers and their families often face problems in relation to suitable and affordable housing. Carers are not being prioritised for housing, can suffer overcrowding or other types of inappropriate housing, sometimes without a separate bedroom for the carer or cared for person
- Inadequate service provision for the carer and cared for person is also an issue across the region. Lack of services can have a knock on effect on carers, for example a lack of inpatient, day services, clinics, and respite care, and specialist services for example for older people, people with mental health issues, veterans and their families and younger adults with physical disability. The north of the region is particularly poorly served in terms of mental health and dementia service

Health and care services need to be better tailored to the carer's individual needs rather than the organisations providing them. Mixed consistency of support from local services means that carers are facing barriers to maintaining their health, balancing work and

care, and balancing education and care which is having a markedly negative impact on their life chances: Carers who are supported by their communities are more than three times as likely to always be able to maintain a healthy lifestyle (Carers UK, 2016).

Local carer feedback supports this:

*"As a carer attempting to get understanding, advice, support and emergency care from the 'community' – such as GP, public transport, social services, dentist pharmacies and hospitals – can be very challenging, exhausting and beyond stressful".*

*"Although a commissioned service is "marvellous", what is needed, is someone to take the cared for person out so that the carer can have time at home on their own".*

Source: Hywel Dda Regional IiC (2016)

Young Adult Carers (YACs) (18 -25 year olds) face many of the same challenges as adult carers including having their own physical or mental health problems. In addition, they are four times more likely to drop out of college or university than a student without caring responsibilities. Only 36% of YACs feel able to balance their commitments with their caring role compared to 53% without a caring role. Many YACs in West Wales live in rural and remote communities and financial hardship can make it difficult to access services because of travel costs and time restraints. YACs need advice and information about education, health, employment, benefits, relationships, respite and support around their caring role and transition to an independent adult life.

Young carers (5 -17 year olds) face additional challenges of problems at school, with completing homework and in getting qualifications, isolation from other children and other family members, being stigmatised or bullied, lack of time for play, sport or leisure activities, feeling that there is nobody there for them, and that professionals do not listen to them. Young carers can also experience problems moving into adulthood, including with finding work, their own home and establishing relationships.

One Young carer said:

*"I've gone from 12 to 30 and it's hard. I want to live a normal life. I want to be understood".*

Source: Children's Society, 2012

## 7.4. Current Support Provision

Carers' needs are currently met in the region through a range of services that are delivered by or commissioned by the local authorities, health, the third sector and other local community groups. These can be broadly broken down in to services that support:

- Identification and recognition
- Advice and information
- Assessment of carers needs
- Practical support (for example replacement care, help around the home, shopping)
- Advocacy
- Condition specific support for the carer and the person they care for

Services that directly support carers include:

- Carers needs assessments and support plans
- Commissioned support services  
(i.e. services providing practical and emotional support for the carer)
- Breaks from caring (from a few hours to extended periods depending on assessed need)
- Comprehensive information in a range of formats including social media
- Direct payments for carers
- Carers Emergency Card schemes
- Programme of events including carers week and carers rights day
- Carers Forums and support groups (engaging, informing, consulting and peer support)
- Advocacy
- Grants

Services that indirectly support carers include:

- Replacement care for cared for person (day opportunities, replacement care and respite)
- Direct payments for cared for person
- Expanded care plans
- Workforce development and training / eLearning. The value of workforce training is highlighted by the following feedback

*"This course gave me insight into who can be carers, what defines them for being a carer and their entitlements under law. The course has also provided me with access to links which can help me direct carers to the support they can get whilst carrying out their caring role".*

Source: Carer Aware e-Learner Feedback Survey, 15/16 Hywel Dda University Health Board. Carers' Measure Strategy Annual Report, 2016.

Significant progress has been made in the region particularly through the Investors in Carers (IiC) scheme. IiC is an accredited award initiative for GP practices, secondary care settings, pharmacies and schools aimed at improving the help and support given to carers. The scheme delivers a number of cultural changes including;

- Mainstreaming of areas of good practice within the partner organisations
- Increased communication between professionals and voluntary organisations
- Recognition of the caring role and the identification of 'hidden' carers
- Targeted health checks for carers
- Engaging carers in the design, development and delivery of the services they receive, for example; the new Information Advice and Assistance (IAA) 'Pre-Front Door' operating Model and the development of a digital inclusion project in rural Tregaron, Ceredigion, to help overcome social isolation
- Partnership working between Mid Wales Healthcare Collaborative, Ceredigion County Council's Carers Unit and the IiC Scheme to develop a training programme to build resilience and improve the wellbeing of carers across the region - the first time the training programme has been adapted and trialled with carers in the whole of the UK
- Roll out of the Carer Aware training scheme and Young Carer Aware E-learning package
- Ensuring that HR policies include support for employees to remain in work, fulfil their career potential and meet their caring responsibilities

Evidence of improvements include:

- An increase in the percentage of carers identified from 10.2% in 2013 to 20.6% in 2016
- An increase in the number of carers registered with GP surgeries in the region from 5,871 in 2015 to over 6,138 in June 2016. GP Surgeries also made 635 carer referrals for further help and support (almost a 40% increase since 2015)
- Positive feedback for example

*"I realised that I was a carer and could register with my GP after seeing the notices on the board in my Surgery".*

*"Carer and cared for have used some of the information leaflets available in the GP surgery to access support/advice".*

Source: Hywel Dda Regional IiC (2016)

Social enterprises and voluntary groups also provide a wide range of services to support carers including:

- Crossroads Care
- Action for Children – supporting Young Carers
- Mind – Mental health services and support for Carers
- Carers Provider Forum
- Carers' Networks

In addition, there are numerous voluntary and community groups offering services in the community, such as luncheon clubs, learning circles, exercise classes, shopping services, book clubs, and so on which can help improve the wellbeing of carers.

Some work has been done to stimulate social enterprise in the region. County Voluntary Councils (CVCs) have facilitated development workshops alongside local agencies with respect to social enterprise but there are resource implications to progressing this further.

CVCs also support a wide range of social enterprises and voluntary and community groups, which collectively make up the third sector. Experienced staff provide information and support on setting up new groups (including legal structures and governing documents); organisational development; good governance; sustainable funding and fundraising and quality assurance.

Communities offer significant assets and social capital that could be utilised to improve the physical and mental wellbeing of carers including:

- Carers themselves (experts through experience)
- A network of community buildings offering local access to services, events and activities
- A vibrant third sector
- Active volunteer network – including formal and informal volunteers
- A beautiful natural environment, including a national coastal path
- Community based groups
- Community connectors/community champions being developed under the SSWBA implementation
- Arts, educational, cultural, and spiritual resources

## 7.5. Gaps and Areas for Improvement

There are challenges to improving experience and outcomes for carers including:

- Recruitment and retention of staff to many health and social care providers and lack of capacity to recruit and support volunteers
- Stretched budgets, reductions in grants, or reduced access to grants to third sector providers, and short term funding

- Lack of market competition in the private sector in rural areas
- National variations in the age ranges used in relation to YACs which has a bearing on how research data can be compared. For example, Carers Trust considers YACs to be 14-25. The Census and other research consider the age range to be 18-25 years

However, the Population Assessment will inform partners' future plans including:

- Investors in Carers development plan (2017 onwards)
- Regional Carers Strategy
- Hywel Dda Transition Carers Action Plan 2016-2018
- Ceredigion Carers Unit Business Plan
- Carmarthenshire Carers Action Plan
- Pembrokeshire Carers Strategy – Supporting the Health and Wellbeing of Carers

Headline intentions will be overseen through the RPB and through local governance structures including the Regional Carers Strategy Implementation Group and Regional Carers Programme Board, Ceredigion Carers Alliance, Carmarthenshire Strategic Partnership Board for Carers and Pembrokeshire Joint Carers Strategy Board.

Partners including the third sector will continue to work together to address gaps and areas for improvement which are set out below against the core principles of the SSWB Act.

### Voice and Control

There are challenges to improving outcomes for carers. Caring responsibilities can grow over time so that individuals do not immediately recognise they have become a 'carer' or that support may be available. There is a need to:

- Further embed good practices around identification, information and consultation. This includes maintaining Carers Information Services to include information about health and care services and key stages in the caring journey from being a new carer, to changes in needs, transition points in life stages, preparing for the end of caring, bereavement and when the caring role ends
- Raise the profile and public understanding of caring
- Ensuring carers are involved in decisions about the cared for person including discharge planning

### Prevention and Early Intervention

There is a need to design and develop preventative services and review commissioned service specifications to meet the prevention model.

## Wellbeing

There is a need to improve carer assessments and to do more to ensure services that support the cared for person are accessible and available (for example rapid response services to support people with night care during acute episodes and emergencies, respite services, support for people in a crisis and transitional services for children and young people).

Programmes aimed at maintaining general wellbeing of carers should also be considered. One such programme was piloted by the Mid Wales Healthcare Collaborative in partnership with Ceredigion County Council's Carers Unit and HDUHB's liC Scheme over an eight week period in autumn 2016. A training programme entitled 'Caring for the Third Workforce: The Resilience and Wellbeing of Carers' was developed aimed at building resilience and improving the wellbeing of Carers across Ceredigion. This was the first time this exciting and well trusted training programme has been adapted and trialled with Carers in the whole of the UK; Ceredigion was specifically chosen as an area with a rural dispersed population. Carers had the opportunity to be one of the first in the UK to take part. The resilience pathway considered the effects of isolation, stress and identity. The methodology enabled the Carers to develop a situational analysis process regarding stress levels, as a means of always finding a way back to their "best self" as the core resilience pathway. The outcomes of the robustly evaluated pilot with the participants indicated significant and sustainable improvements in a positive mind set and self-help, identified by the carers through their own analysis and that of the researcher as to their improved resilience. The participants have continued to meet into 2017 since course completion as a support group with their own identity 'Caring Friends'. There is significant ongoing interest and commitment to further trials for the model of delivery to support further roll out, both from Carers and professionals, it has potential for Carers in the Workforce and Young Carers. The Report will be shared with the Mid Wales Collaborative and the West Wales RPB. The research is to be discussed at the BMJ International Conference in July 2017, and with the Welsh Government. It is also a training programme under discussion with Academi Wales as a tool to support the resilience of the workforce and the Carers within that environment in Spring 2017 for further development.

## Co-production

Support the role of user-led services including:

- Create local carer co-operatives that can commission services that best meet their needs
- Work with carers through Carer Forums on the co-production of services

## Co-operation, Partnership and Integration

- Strengthen the role of social enterprises and user-led services including
- Developing commissioning and procurement processes that pro-actively build social enterprise supply chains
  - Promote new models of service delivery by sharing examples of what works elsewhere and encourage collaboration
  - Develop a programme of training courses and workshops for carers delivered by third sector organisations and social enterprises
- Develop a much more joined up approach between partners and other agencies to ensure the issues facing carers are taken into account when planning community programmes such as transport, housing, and technology developments and other community programmes. For example whilst technology developments have significant potential many carers need paper based and face to face advice because they cannot access online information or require the emotional support from personal contacts
- Support carers with housing problems for example through
  - Advice services for carers including specialist housing advice services for carers of older people or people with learning disabilities
  - Local authorities and housing associations taking carers' needs into account in housing lettings policies
  - Support with adaptations; equipment, repairs and improvements, alarms and telecare technologies
  - Support to move home from an inappropriate property (The Princess Royal Trust for Carers, 2010)
- Address the challenges of transport in the region through for example, integrating carers impact assessments within transport planning for the community and more consistent Community Transport Schemes across the region. For example 'Cars for Carers' is no longer resourced in all counties and needs to be considered on a regional footprint. And address carer transport needs using Direct Payments, Voucher schemes and other community schemes
- Address the low up take of benefits and increase claims and to ensure:
  - Older carers over the age of 65 take up entitlement that could passport them onto other benefits or carer addition to Pension Credit
  - Coordinated local concessions across the regional footprint e.g. free bus passes for carers, free parking, and other concessions that can make a big difference to the lives of carers and their families, and help to build a more carer friendly community



## 7.6. References

**Buckner, L. and Yeandle, S. (2015). *Valuing Carers 2015: The rising value of carers' support*. London: Carers UK.**

[https://www.sheffield.ac.uk/polopoly\\_fs/1.546409!/file/Valuing-Carers-2015.pdf](https://www.sheffield.ac.uk/polopoly_fs/1.546409!/file/Valuing-Carers-2015.pdf)

**Carmarthenshire County Council (2016) *Carers population assessment briefing – Officers summary to Regional Carers Implementation Group citing Depression in carers of patients with dementia*.**

<http://priory.com/psych/carerde.htm>

**Carer Aware e-Learner Feedback Survey, 15/16 Hywel Dda University Health Board Carers' Measure Strategy Annual Report, 2016.**

<http://www.wales.nhs.uk/sitesplus/862/page/71869>

**Carers Trust (2016). *Key fact about carers and the people they care for*. [online].**

<https://carers.org/key-facts-about-carers-and-people-they-care>

**Carers Trust Wales (2016). *Investing in Carers, Investing to Save: Key Principles for Health and Social Care Commissioners*. Cardiff: Carers Trust Wales.**

[https://carers.org/sites/files/carustrust/media/commissioning\\_wales\\_finallo.pdf](https://carers.org/sites/files/carustrust/media/commissioning_wales_finallo.pdf)

**Carers UK (2014). *Carers UK Forum* [Online]**

<https://www.carersuk.org/forum/support-and-advice/all-about-caring/life-after-caring-21451>

**Carers UK (2013a) *Policy Report Estimating the Take up of Carers Allowance (November 2013)***

<https://www.carersuk.org/for-professionals/policy/policy-library/carers-allowance-takeup>

**Carers UK (2013b). *Supporting Working Carers: The Benefits to Families, Business and the Economy*. London: Carers UK.**

<https://www.carersuk.org/for-professionals/policy/policy-library/supporting-working-carers>

**Carers UK (2014). *Carers at Breaking Point*. London: Carers UK.**

<https://www.carersuk.org/for-professionals/policy/policy-library/carers-at-breaking-point-report>

**Carers UK (2015). *Making life better for Carers*.**

<https://www.carersuk.org/>

**Carers UK (2016). *Building Carer Friendly Communities: Research report for Carers Week 2016*.**

<https://www.carersuk.org/for-professionals/policy/policy-library/building-carer-friendly-communities-research-report-for-carers-week-2016>

**Census 2011 data, reported in Carers UK Policy Briefing Nov 2015.**

[https://www.carersuk.org/images/Facts\\_about\\_Carers\\_2015.pdf](https://www.carersuk.org/images/Facts_about_Carers_2015.pdf)

**Data Unit Wales (2015). *Percentage uptake of carers allowance*.**

<http://www.infobase.cymru.net/IAS/themes/employmentandbusiness/benefits/view?viewId=88>

George, M. (2001). *It could be you: a report on the chances of becoming a carer*. London: Carers UK.

Howard, D. (2010). "Number of child carers 'four times previous estimate'". BBC, [online], 16 November.

<http://www.bbc.co.uk/news/education-11757907>

Hywel Dda University Health Board (2016a). *Annual Report and Accounts 2015-16 Summary* [online].

<http://www.wales.nhs.uk/sitesplus/documents/862/AnnualReportSummary2016WEB.pdf>

Hywel Dda University Health Board (2016b). *Carers' Measure Strategy Annual Report, 2016*.

<http://www.wales.nhs.uk/sitesplus/862/page/71869>

Hywel Dda University Health Board (2016c). *Carers' Measure Strategy Annual Report*

Available at: Hywel Dda Regional IiC (2016). Thematic analysis of Carers in Ceredigion and Pembrokeshire between 2013 – 2015 for HDUHB Carers Measure Programme Board, Analysis of Carers' Stories Gathered by the IiC Team 2013-2015. Report and presentation to Hywel Dda Regional Partnership Carers Programme Board

OECD (2011). *Help Wanted? Providing And Paying For Long-Term Care*. [online].

<http://www.oecd.org/els/health-systems/47836116.pdf>

Office for National Statistics (2011). *Health and Provision of Unpaid Care (KS301EW)*.

<http://www.neighbourhood.statistics.gov.uk/dissemination/datasetList.do?JSAllowed=true&Function=%24ph=60&CurrentPageld=60&step=1&CurrentTreeIndex=1&searchString=&datasetFamilyId=2480&Next.x=29&Next.y=13>

Pickard, L. (2008). *Informal Care for Older People Provided by Their Adult Children: Projections of Supply and Demand to 2041 in England*. London: Personal Social Services Research Unit

The Children's Society (2012). *Supporting young carers and their families: Information for health care professionals*.

[http://www.youngcarer.com/sites/default/files/health\\_care\\_pros\\_booklet\\_2012\\_low\\_res.pdf](http://www.youngcarer.com/sites/default/files/health_care_pros_booklet_2012_low_res.pdf)

The Princess Royal Trust for Carers (2010). *Carers and Housing: Addressing their needs*.

<http://static.carers.org/files/2446-carers-and-housing-en-4965.pdf>

*Thematic analysis of Carers in Ceredigion and Pembrokeshire between 2013 – 2015 for HDUHB Carers Measure Programme Board, Analysis of Carers' Stories Gathered by the IiC Team 2013-2015*

Worthington, A., Rooney, P. and Hannan, R. (2013). *Triangle of Care*, 2nd edition. London: Carers Trust.

[https://professionals.carers.org/sites/default/files/triangle\\_of\\_care\\_2016\\_latest\\_version\\_0.pdf](https://professionals.carers.org/sites/default/files/triangle_of_care_2016_latest_version_0.pdf)

## Section 8

# Children and Young People

**West Wales Population Assessment** March 2017

## 8.1. Overview and key messages

- Children and young people make up approximately 22.2% of the population in the West Wales region. The number of young people is expected to stay relatively stable over the next 15 years
- The region has a lower number of looked After Children (LAC) than the national average
- Care and support needs span a wide range from universal, through early intervention, multiple needs and remedial intervention
- Partner agencies have adopted a broadly consistent continuum of care and support for children and families with a focus on prevention
- Areas for improvement include further development of preventative and early intervention services, building on established programmes such as Family Information Services, Families First and Team Around the Family; refocusing managed care and support to promote independence and wellbeing; improving multi-agency working and improved collaboration across the region to bring services to a consistent level and standard
- Collaborative action should also be considered to address strategic challenges such as reducing budgets, workforce development and the establishment of user-led preventative services

## 8.2. Demographics and trends

In 2015 there were 85,170 children and young people (aged between 0 and 19) in the West Wales region, of which 41,920 reside in Carmarthenshire, 15,890 in Ceredigion and 27,360 in Pembrokeshire. Across the region this represents 22.2% of the total population.

Projections suggest these figures will remain relatively stable at regional level between now and 2030, the estimated number of children and young people standing at 84,430. Slight increases are predicted in Carmarthenshire (projection of 43,220) and Ceredigion (17,210) to 43,220 with a slight drop to 26,230 predicted in Pembrokeshire (Daffodil Cymru).

LA data indicates that there are currently 144 children and young people with a disability (including Autism Spectrum Disorder or ASD) in Carmarthenshire, with corresponding figures for Ceredigion and Pembrokeshire standing at 184 and 136, respectively. Available figures for children with ASD and disability project a relatively stable incidence of these conditions over the period to 2030.

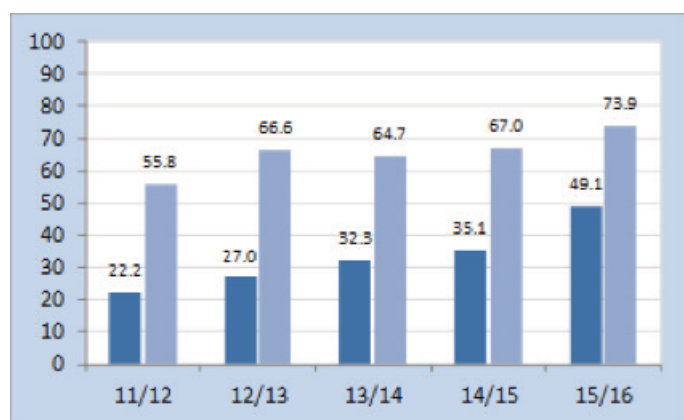
A study undertaken across the region in 2015-16 indicated that the number of children and young people identified with complex needs stood at 64 (16 in Carmarthenshire, 21 in Ceredigion and 27 in Pembrokeshire). 23 children and young people were identified as having complex needs by Hywel Dda University Health Board (People and Work Unit, 2016).

These numbers should be seen as indicative definitions of complexity and nature of conditions vary across local authorities, and anonymised records mean that there could be overlap between those children and young people identified by social services and those identified by the NHS.

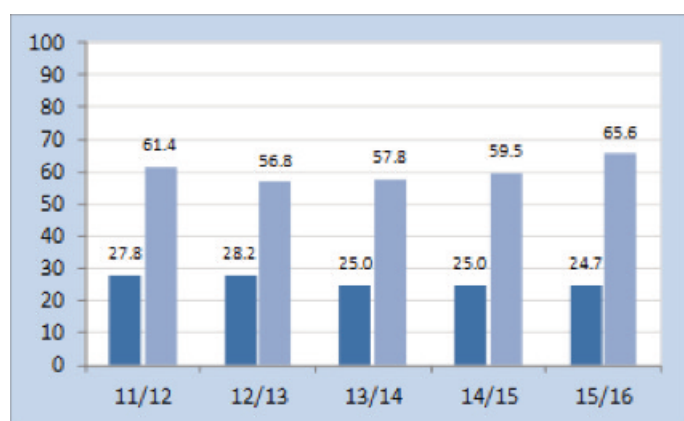
Figure 8.1 shows the comparison, between pupils receiving free school meals (FSM) and those not receiving free school meals (Non FSM) in the key attainment measure below, between 2011 -2016. There is clearly a significant difference in attainment between these two groups.

**Figure 8:1 Level 2 threshold including English/Welsh and Mathematics (L2+):  
Qualifications achieved equivalent to 5 GCSE grades A\*C, including  
one in English/Welsh and one in Mathematics**

### Ceredigion

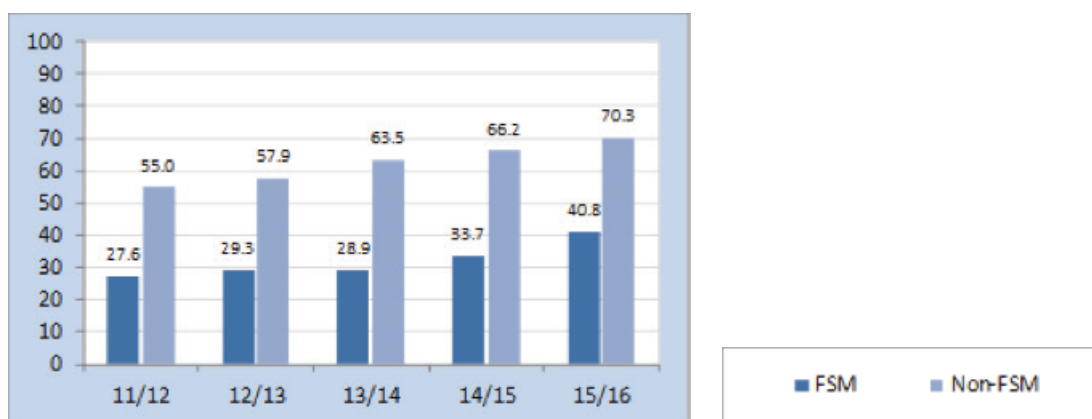


### Pembrokeshire



Source: Welsh Government

## Carmarthenshire



Source: Welsh Government

The following table shows the percentage of children and young people not in education, employment or training in 2015 in each county in years 11, 12 and 13. Whilst the data shows similarities between the counties for year 12, there are some notable differences between Ceredigion and the other two counties in year 11, and between all counties in year 13.

**Figure 8:2 Percentage of children and young people not in education, employment or training (NEET) 2015**

### Not in Education, Employment or Training 2015

	Carmarthenshire	Ceredigion	Pembrokeshire
% known to be NEET in year 11	3.5	1.4	3.8
% known to be NEET in year 12	1.1	1.3	1.3
% known to be NEET in year 13	2.8	3.3	4.0

Source: Careers Wales

## 8.3. Current and future care and support needs

Children and young people will have a range of care and support needs depending on their personal circumstances. Broadly speaking, this range will encompass:

- **Universal needs**, for example information and advice, low level family support, preventative services such as health visiting, early ante-natal provision, dietetic support and advice, childcare and careers advice
- **Additional needs and early intervention**, such as improvement support for families, youth engagement, supporting young people into education and training, education inclusion and welfare

- **Multiple needs**, requiring coordinated multi-agency support to support children and families to address complex and/ or entrenched needs
- **Need for remedial intervention** to support children at risk

Effective transition into adult services for children and young people who need ongoing care and support, and providing the right support for young people leaving care are also important factors when planning and delivering services.

Regardless of the specific nature of their need, care and support for children and young people should contribute to the ten aspects of wellbeing set out in Part 2 of the SSWB Act. In particular, partners share a strategic commitment to:

- Promote physical and mental health and emotional wellbeing
- Support welfare and development of children and families by working collaboratively with parents, family networks and community services including education, training and recreation providers
- Keeping children safe and protecting them from abuse and neglect

All planning for care and support for children and young people is guided by the United Nations Children Rights Convention and we will work together for children to *ensure they are not harmed, are looked after and are kept safe (Article 19)* and achieve their wellbeing outcomes (United Nations, 1989).

Wellbeing Outcomes that are particularly important to this group are:

### **Physical and mental health and emotional wellbeing**

- I am healthy and active and do things to keep myself healthy
- I am happy and do the things that make me happy
- I get the right care and support, as early as possible

### **Protection from abuse and neglect**

- I am safe and protected from abuse and neglect
- I am supported to protect the people that matter to me from abuse and neglect
- I am informed about how to make my concerns known

### **Education, training and recreation**

- I can learn and develop to my full potential
- I do the things that matter to me

### **Domestic, family and personal relationships**

- I belong
- I contribute to and enjoy safe and healthy relationships

Children will want to achieve wellbeing outcomes that are personal to them and they may need care and support from many different areas in helping them to achieve these. Children with disability or additional needs will require enhanced or targeted support to assist them.

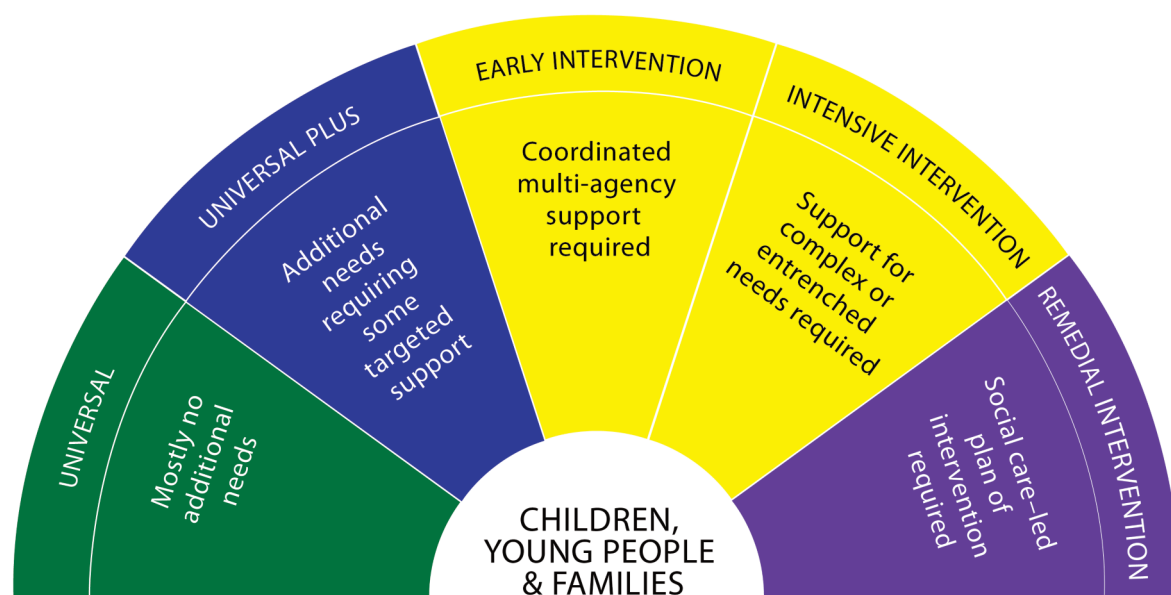
Exposure to Adverse Childhood Experiences (ACEs) such as parental separation, domestic violence or individuals with alcohol or substance misuse problems have a long term harmful effect. Preventing ACEs can improve health across the whole life course and enhance an individual's wellbeing while supporting families with parenting and child development plays a central role by promoting resilience, positive self-esteem and has a positive impact on wellbeing outcomes (Public Health Wales, 2015).

Workers across health, social services and associated preventative services gather the views of children, young people and their families through their day to day practice. In addition to this a range of consultation and engagement activity is undertaken to ensure that the experience and voice of children, young people and their families shapes service improvement and planning. For example, in Ceredigion the views of the wider children and young people population are gathered through the School Wellbeing Survey.

#### 8.4. Current care and support provision

In response to the needs identified in the previous section, partners across the region have adopted a service continuum as a basis for planning and delivering care and support as shown in the following diagram.

**Figure 8:3 Service continuum**



Source: Institute of Public Care



Whilst the continuum is articulated differently in each county area and the precise categorisation of services varies slightly, there are common core principles which include:

- A recognition of the importance of physical, mental and emotional wellbeing of children and the key role of universal services in achieving this
- The importance of partnership working, for example between social services, youth services, youth prevention services and other organisations to ensure that young people have access to social activities
- The view that resilience and wellbeing are rooted in families and communities and therefore that support should be focused wherever possible on promoting family life and enabling children and young people to remain within their families and/ or communities so long as it is safe for them to do so
- A multi-agency and individualised approach to supporting children with complex needs
- Effective transition for children and young people into adult services where appropriate

Similarly, service provision varies in detail across the region, but they are predicated on this continuum of services. A summary of services currently in place is provided below.

- Family Information Services (FIS) are in place in each LA area which provide members of the public, professionals and other agencies with access to a broad range of information about local relevant services and support available to families including those who may have a need for advice with specific issues
- Advocacy services are provided through a newly commissioned regional contract spanning Mid and West Wales (including Powys)
- A range of services are commissioned through the Families First programme, which has a clear emphasis on early intervention for families, especially those living in poverty, through a multi-agency approach and coordinated working with other programmes and services across the region. These include Flying Start, which provides enhanced services for children age 0-4 living in particular geographical areas as well as third sector providers which cover the whole region such as Action for Children, Plant Dewi and Homestart.

More information on Families First can be found at

<http://gov.wales/topics/people-and-communities/people/children-and-young-people/parenting-support-guidance/help/families-first/?lang=en>

and on Flying Start at:

<http://gov.wales/topics/people-and-communities/people/children-and-young-people/parenting-support-guidance/help/flyingstart/?lang=en>

- There is an increasing focus on reducing adverse childhood experiences such as drug use, domestic violence, mental illness alcohol and drug use as well as continuing to address child maltreatment verbal, physical and sexual abuse. Those families who may have more complex or entrenched difficulties require assessment and coordination by a specialist worker to develop and deliver plans which will incorporate a range of specialist responses from dedicated services such as the Integrated Family Support Service (IFSS) and Looked After Children (LAC) teams. <http://gov.wales/topics/health/socialcare/working/ifst/?lang=en>
- Education welfare services in each area work with partners in education to reduce persistent non-attenders and ensure educational entitlement
- Specialist provision for children and young people with complex physical and mental health needs, including residential care (fostering, in-house placements, children's homes, care homes and secure accommodation), community care packages enabling people to live at home and a range of health and education services such as Speech and Language Therapy, Occupational Therapy, sensory, educational psychology (EP), physiotherapy, child psychology, and children and adolescent mental health services (CAMHS)
- A range of 'looked after' solutions including child protection reviews, adoption, fostering and residential care. A regional adoption service is in place across Mid Wales, including Powys, which has enabled a standardisation of approach and collaborative working in areas such as promotion, recruitment, assessment, training and ongoing support
- Regional safeguarding arrangements through the CYSUR Children's Safeguarding Board, which has the aim of 'protecting children who are experiencing, or are at risk of abuse, neglect or other kinds of harm, and prevent children from becoming at risk of abuse, neglect or other kinds of harm'. The regional arrangements have facilitated the development of consistent policies and procedures, including a regional action plan in relation to Child Sexual Exploitation, and are being aligned closely with arrangements for adult safeguarding to address cross-over issues such as domestic abuse and violence
- Transition services and enhanced 'leaving care' provision to meet the requirements of the SSWB Act
- A comprehensive range of sexual health services including:
  - Sexually Transmitted Infections (STI) testing and treatment
  - Complex contraception including provision of all LARC methods
  - Basic contraception

- Cervical screening
- Community gynaecology
- Psychosexual counselling
- Rapid access for vulnerable groups
- Child Sexual Exploitation (CSE) risk assessment for all patients under 18
- Assessment for domestic abuse
- Post-Exposure Prophylaxis (PEP) and Hepatitis B vaccinations

The sexual health service sees approximately 25,000 patients a year with the highest levels of attendance falling within the 15-24 age range.

Within each authority there are individual examples of co-producing creative solutions to support future services such as the Intergenerational Community Centre in Aberaeron. This is spearheaded by the third sector (Ray Ceredigion & Age Cymru), and the introduction of the 'Signs of Safety' outcome measurement framework when working with families which is a strengths-based and safety-focused approach to child protection work grounded in partnership and collaboration.

The following table provides a breakdown of the numbers of children supported through a range of statutory and non-statutory services across the region.

**Figure 8:4 Numbers of children supported through a range of statutory and non-statutory services**

Statutory Children's Services	Carmarthenshire	Ceredigion	Pembrokeshire
Referrals to Social Services (2015/16)	1,473	531	1262
Rate of Looked After Children (LAC) per 10,000 child population as at 31/3/16	58 (n=215)	62 (n=80)	46 (n=126)
Number of LAC placed by other LAs as at 31/3/16	166	24	59
Rate on Child Protection Register (CPR) per 10,000 child population as at 31/3/16	24 (n=88)	46 (n=55)	24 (n=60)
Rate of Children In Need (CIN) per 10,000 child population as at 31/3/15 (2016 comparative data not yet available)	250 (n=930)	360 (n=450)	205 (n=505)

Adoption activity 2015/16	Carmarthenshire	Ceredigion	Pembrokeshire
Number of adoption orders granted	25	4	3
Placed ready for adoption	12	1	6
Number of approved Adopters	8	6	5
Post adoption support	45	26	27
Adoption breakdowns	0	0	0
Foster placements 2015/16	Carmarthenshire	Ceredigion	Pembrokeshire
Within LA boundary	163	50	88
Outside LA boundary	12	12	5
Other community placements 2015/16	Carmarthenshire	Ceredigion	Pembrokeshire
Independent living	6	0	1
Residential employment	0	0	0
Residential placements 2015/16	Carmarthenshire	Ceredigion	Pembrokeshire
Looked after and placed in secure unit	0	0	0
Placements in homes and hostels subject to Children's Homes Regulations	2	1	8
Placements in other hostels and supportive residential settings	0	1	0
Placements in residential care homes	0	0	0
NHS/ Health Trust or other medical establishment providing medical or nursing care	0	1	1
Family centre or mother and baby unit	0	0	0
Youth offender institution or prison	0	0	0
School placements 2015/16	Carmarthenshire	Ceredigion	Pembrokeshire
Residential schools, except where dual registered as a school and children's home	1	0	2

Non-statutory/ preventative services			
Family Information Service 2015/16	Carmarthenshire	Ceredigion	Pembrokeshire
Contacts – Telephone/email enquiries	641	600	300
FIS Website visits	15,098	54,725	47,787
Flying Start 2015-16	Carmarthenshire	Ceredigion	Pembrokeshire
Numbers of children worked with	1570	525	1226
% assessed as medium and high need	41%	37%	41%
Families First 2015-16	Carmarthenshire	Ceredigion	Pembrokeshire
Individuals accessing FF funded projects	8626	1732	2500
Numbers of JAFFs completed	1162	399	205
TAF requests for support	476	163	463
TAF cases (closed during the year)	285	122	203
Youth Justice Service – Preventions	Carmarthenshire	Ceredigion	Pembrokeshire
Number of NEW prevention cases	30	148	33
Number of ACTIVE prevention cases	35	66	22
Elective Home Education (EHE)	Carmarthenshire	Ceredigion	Pembrokeshire
Numbers known to be in EHE	196	123	119
Children with a disability	Carmarthenshire	Ceredigion	Pembrokeshire
Children receiving continuing care funding	11	6	12
Children receiving a service from Children's Community Nursing Service	135	29	105

Source: Local Data

## 8.5. Gaps and Areas for Improvement

As outlined above, the range and level of care and support currently being provided aims to address identified need and offers a range of interventions at varying levels of intensity, with the aim of preventing escalation and delivering positive outcomes to children and young people. There is room for confidence that the required statutory services are in place to meet the needs of the most vulnerable children and young people and to keep them from harm.

The development of fit for purpose services right across the range is, however, an ongoing journey and there are a number of areas in which further improvement can be made. These are set out below against the core principles of the SSWB Act.

### Voice and control

- Enhancing assessment and care planning processes to ensure that citizens have a genuine voice over outcomes and support needed to achieve them
- Ensuring that children, young people and their families are able to access services through their language of choice and that the 'active offer' of services through the medium of Welsh is always available

### Prevention and early intervention

- Further development of information, advice and assistance to meet the requirements of the SSWB Act and direct children and young people to appropriate care and support within communities
- Continuing to strengthen the focus on prevention across the range of services, to build resilience of children, young people and families, reduce reliance on statutory services and facilitate de-escalation from intensive support where appropriate. It will also be important to have robust mechanisms in place to assess the impact of these new approaches
- Improved working with community-based organisations to support children and young people in the development of life skills
- Refocusing social work practice and resources towards early, direct interventions that strengthen the resilience and functionality of families

### Wellbeing

- Reducing the number of placement moves for LAC and reducing reliance on residential care
- Improving access to mental health services at an early stage, thus preventing the need for referral to CAMHS services. There continue to be significant numbers of young people who require psychological support (intensive or remedial intervention) although there remains very limited provision. It will also be important to improve joint planning between CAMHS and learning disability services to ensure equitable service provision for children with neuro-developmental conditions. The 'Together for Children' programme provides a mechanism for this

- Enhancing accommodation and meeting accommodation support needs of young people who are care leavers (including those leaving residential care) and following custodial sentences. Local initiatives in place to improve arrangements need to be consolidated moving forward
- Improving the support offered for family relationships, particularly for new parents or parents who are experiencing stress due to other factors such as imprisonment or disability. This will be instrumental in reducing the risk of domestic abuse or other offending behaviours (Welsh Government, 2016)
- Increasing the level of support available for child victims of sexual abuse; a recent study also suggested gaps in capacity in this area across Wales (Allnock et al, 2015)
- Achieving better integration between children's services, mental health and learning disability to address specialist needs of specific children and young people
- Improving access to child sexual health services

### Co-production

- Developing community-based, user-led services

### Cooperation, partnership and integration

- Developing consistent methodology such as Signs of Safety to underpin care and support across the region
- Developing a consistent, outcomes-based performance framework for children and young people's services across the region
- Developing links between Integrated Family Support Services (IFSS) and other council services such as adult care and housing as well as community-based services, to help families back to independence and enable them to function effectively within their communities
- Reconfiguring commissioning processes for high cost, low volume care and support packages for children with complex needs are needed to ensure best outcomes for service users and improve financial efficiency. The possibility of developing new services on a regional basis should also be explored

Opportunities should be taken to take these areas forward in partnership across the region; thereby ensuring consistency of provision and enabling a 'once for West Wales' approach wherever possible. The regional partnership arrangements provide a mechanism for this and for sharing of effective practice and approaches as they are developed. Shared strategic challenges such as improving services while budgets are being reduced, workforce development and delivering effective services in a highly rural area will also benefit from a consistent approach across the region. These should be considered as the regional Area Plan is developed in response to this assessment.

Existing strategies such as the 'Together for Children and Young People' strategy for child and adolescent mental health in Wales and Child Poverty Strategy for Wales (Welsh Government, 2015) will be reviewed and refocused as appropriate to ensure delivery of the identified areas for improvement.

## 8.6. References

Allnock, D., Sneddon, H. and Ackerley, E. (2015). *Mapping therapeutic services for sexual abuse in the UK in 2015*. Luton: The International Centre: Researching Child Sexual Exploitation, Trafficking and Violence, the University of Bedfordshire

Careers Wales. (2015). *Destinations – by Local Authority* [online].

<http://www.careerswales.com/prof/server.php?show=nav.3850>

Daffodil Cymru (2014). *Population by age: population aged 0-25, by age, projected to 2035* [online].

<http://www.daffodilcymru.org.uk/index.php?pageNo=1002&PHPSESSID=2b7me5n714paqi0683jjuuup840&at=y&sc=1&loc=1>

Mid and West Wales Health and Social Care Collaborative (2016). *Complex Needs, Transition and Vulnerable Persons Project – Market Position Statement*.

<http://www.wwcp.org.uk/documents/>

Public Health Wales (2015). *Adverse Childhood Experiences and their impact on health-harming behaviours in the Welsh adult population*.

<http://www.cph.org.uk/wp-content/uploads/2016/01/ACE-Report-FINAL-E.pdf>

United Nations (1989). *Convention on the Rights of the Child. Treaty Series, 1577, 3*.

<https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>

Welsh Government (2015). *Child Poverty Strategy for Wales*.

<http://gov.wales/docs/dsjlg/publications/150327-child-poverty-strategy-walesv2-en.pdf>

Welsh Government (2015).

*Together for Children and Young People: Framework for Action*.

<http://www.wales.nhs.uk/documents/Framework%20For%20Action.pdf>



## Section 9

# Health and Physical Disabilities

**West Wales Population Assessment** March 2017

## 9.1. Overview and Key Messages

This report considers the needs of the population aged between 18 and 64 who live in West Wales. A significant proportion of people in this age group will not be accessing care and support directly to address specific needs. However, they will benefit from general public health information and programmes aimed at encouraging healthy lifestyles and reducing risks to their health brought about by factors such as smoking and obesity. More generally, adults in Wales will also benefit from combined approaches across sectors and within communities to improve the social, economic and cultural wellbeing of Wales in response to the Wellbeing of Future Generations (Wales) Act 2015.

Where people within this age range have specific needs because of physical disability or chronic health conditions, proportionate, person-centred and responsive care and support may be required to help them achieve positive personal outcomes and live as independently as possible.

The report identifies a range of 'accelerating factors' within people's environments that might increase the likelihood of them developing an ongoing health condition, or aggravate the effects of existing conditions, and against which mitigating action should be taken. These include unemployment, low wages and poor housing conditions.

Effective promotion of public health, targeted care and support for those with specific needs and more general support for people particularly at risk should combine to optimise the quality of people's lives and their participation within their communities.

Supporting people to live active and healthy lives will reduce their needs for care and support and lead to improved outcomes at an individual and community level. The contribution of care and support services must be complemented by a range of collaborative approaches to improve people's social, economic, environmental and cultural wellbeing.

Public Health has an important role in providing the population with general information and advice on healthy life choices and support in areas such as diet and smoking cessation. This needs to start in the early years but should be sustained where possible across the range of age groups.

## 9.2. Demographics and Trends

There are currently 219,606 people aged between 18 and 64 in West Wales. This equates to around 70% of the adult population across the region, with the proportion being slightly lower in Pembrokeshire at 68% and that in Carmarthenshire and Ceredigion standing at 70% and 71%, respectively.

Of those adults aged between 18 and 64, 1,679 people are registered with a physical disability and a further 1,744 are registered as having physical and sensory disabilities. Together this represents around 1.1% of the total 18-64 population, which is in keeping broadly with the Welsh average of 1.02.

Proxy figures suggest that significant numbers of people within this cohort of the West Wales population experience one or more 'accelerating' factors which could result in increased need for care and support.

For example:

- 1,010 adults are in receipt of Incapacity Benefit or Severe Disability Allowance, 10.3% of the Wales total
- 16,740 adults are entitled to Disability Living Allowance or PIP (personal independence payment), representing 12% of the all-Wales figure
- 3.14% of people between 18 and 64 do not have central heating (1.97% in Carmarthenshire, 3.47% in Pembrokeshire and 5.5% in Ceredigion), compared with a Welsh average of 1.84%
- Among people living with severe health conditions 9,480 are in receipt of Employment Support Allowance (which is 0.4% of the Wales 18+ population). (Daffodil Cymru)

Neurological conditions are the most common cause of serious disability and have a major, but often unrecognised, impact on health, social services and on people's lives (Hywel Dda University Health Board, 2015).

- 25% of people aged between 16 and 64 with chronic disability have a neurological condition
- 33% of disabled people living in residential care have a neurological condition
- 10% of visits to Accident and Emergency Departments and 19% of hospital admissions are for a neurological problem
- 7% of GP consultations are for neurological symptoms
- In West Wales there are:
  - 727 people living with Muscular Sclerosis
  - 723 living with Parkinson's disease. 80% of people with Parkinson's disease will develop dementia or experience cognitive decline
  - 2,934 adults with Epilepsy on GP registers
  - 223 admissions for headaches for people under 65
  - 31 people known to have Motor Neurone Disease
  - 247 people attended Rookwood Welsh Spinal Cord Injury Rehabilitation Centre in Cardiff with spinal injury in the last 10yrs
- Approximately 130 people admitted to hospital with head injury every year. Of these on average, 30 people per year require admission to a regional centre due to the

significance of the presentation. In addition 10 people have anoxic brain damage every year in HD

- Approximately 710 people living with cerebral palsy. For many this includes not only physical disability but also a learning disability and may result in significant care needs

Of those adults in West Wales living with a limiting long term illness, only 7.5% fall within the 18-64 age range. The total figure of those with a life limiting illness in West Wales is 23,656 and is predicted to decrease by 4% by 2030, with the most significant drop of 9.9% predicted in Ceredigion. This is reflective of general population trends, which predict a fall in the numbers of adults aged between 18 and 64 in general. However, the expected decrease in West Wales is significantly greater than in Wales as a whole, which stands at 0.7% (Daffodil Cymru).

The following tables provide further details of health related lifestyle factors in the 18+ population.

**Figure 9:1 Adults who reported health related lifestyles**

**Observed percentage of adults who reported being overweight or obese, persons aged 16-44 and 45-64, Hywel Dda UHB and local authorities, 2013-2015**

	Aged 16-44		Aged 45-64	
	Percentage	Estimated count*	Percentage	Estimated count*
<b>Wales</b>	49.2	544,900	67.7	550,200
<b>Hywel Dda UHB</b>	48.1	60,200	68.9	72,400
Ceredigion	42.5	11,900	63.3	12,200
Pembrokeshire	49.2	18,700	67.9	23,300
Carmarthenshire	50.1	29,800	71.5	36,800

Produced by Public Health Wales Observatory, using MYE (ONS) & WHS (WG)

\* Rounded to nearest 100

**Observed percentage of adults who reported smoking, persons aged 16-44 and 45-64, Hywel Dda UHB and local authorities, 2013-2015**

	Aged 16-44		Aged 45-64	
	Percentage	Estimated count*	Percentage	Estimated count*
<b>Wales</b>	25.1	279,000	21.0	170,800
<b>Hywel Dda UHB</b>	23.3	29,200	18.5	19,500
Ceredigion	22.6	6,300	17.3	3,300
Pembrokeshire	21.3	8,100	19.1	6,600
Carmarthenshire	24.8	14,800	18.6	9,600

Produced by Public Health Wales Observatory, using MYE (ONS) & WHS (WG)

\* Rounded to nearest 100

**Observed percentage of adults who reported not meeting guidelines for fruit and vegetable consumption, persons aged 16-44 and 45-64, Hywel Dda UHB and local authorities, 2013-2015**

	Aged 16-44		Aged 45-64	
	Percentage	Estimated count*	Percentage	Estimated count*
<b>Wales</b>	69.1	766,300	66.9	544,000
<b>Hywel Dda UHB</b>	65.4	81,900	63.1	66,300
Ceredigion	60.8	17,000	64.0	12,400
Pembrokeshire	66.6	25,300	61.2	21,100
Carmarthenshire	66.9	39,800	63.9	32,800

Produced by Public Health Wales Observatory, using MYE (ONS) & WHS (WG)

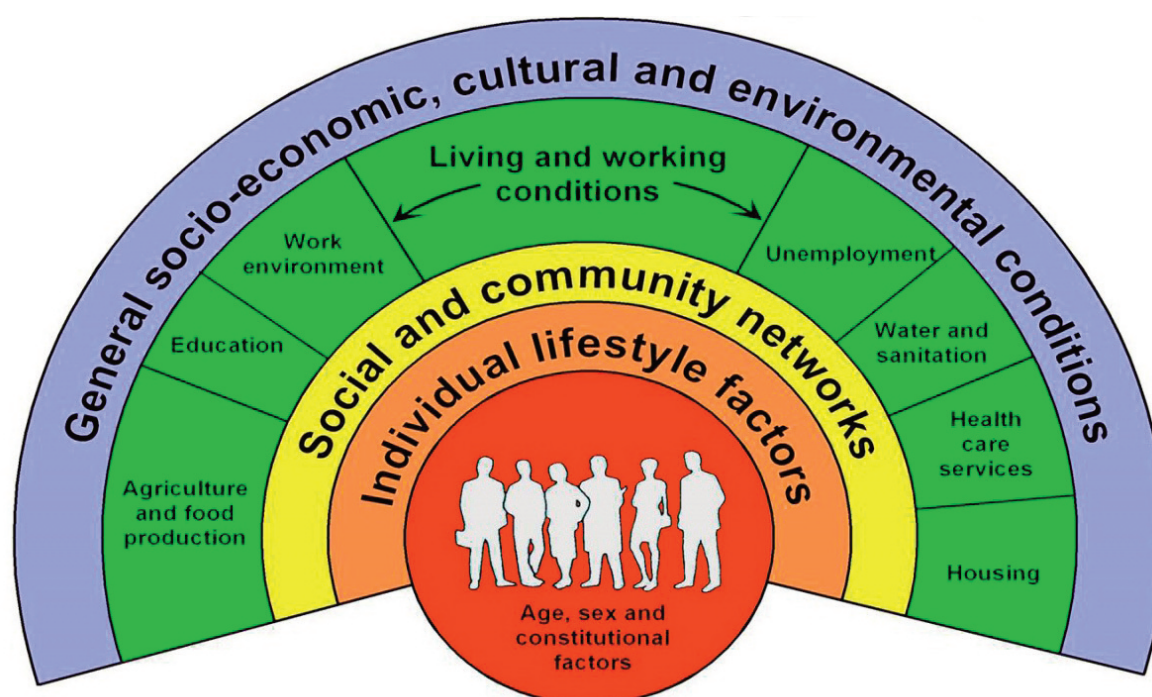
\* Rounded to nearest 100

Source: Hywel Dda University Health Board

### 9.3. Current and Future Care and Support Needs

Supporting people to live active and healthy lives will reduce their needs for care and support and lead to improved outcomes at an individual and community level. The following chart sets out a range of factors which can affect an individual's wellbeing, of which formalised care and support represents a small proportion.

**Figure 9:2 The Determinants of Health.**



The contribution of care and support services must be complemented by a range of collaborative approaches to improve people's social, economic, environmental and cultural wellbeing as required by the Wellbeing of Future Generations (Wales) Act 2015.

Public Health has an important role in providing the population with general information and advice on healthy life choices and support in areas such as diet and

smoking cessation. This needs to start in the early years but should be sustained where possible across the range of age groups.

More generally, a range of preventative measures within communities will help ensure that individuals can take care of themselves, access low level support when needed and remain independent for as long as possible. Examples of this include:

- Information, advice and assistance about universal and prevention services, including how to access these services, must be available in formats and venues that are appropriate to this cohort's communication needs and preferences
- Effective information, advice and assistance to maximise income and access employment opportunities and benefits
- Training and further education to improve probability of successfully entering employment
- Access to a range of sport and exercise facilities/programmes that are tailored to meet specific needs to support good health and wellbeing
- Support to access activities and services within communities that counteract socio-economic deprivation and maximise engagement (including volunteering);
- Appropriate transport provision, especially in rural areas
- Where appropriate, access to mental health services to improve wellbeing through diagnosis, assessment and care planning

People with chronic, long term health conditions and physical disabilities will have specific care and support needs. Given the greater preponderance of these conditions in older age groups, it is important that services are available to younger adults and responsive to meet their particular needs. In keeping with the requirements of the Social SSWB Act and the expressed need of individuals, these services need to retain a preventative approach, helping people to support themselves without the need for long term care and support. Sometimes this will be about signposting people to 'low level' services run within their communities, others may need an intensive intervention in the short term to prevent escalation and the need for longer term care. In all instances it is vital that people are supported in achieving their desired personal outcomes in a proportionate and dignified way. Early identification of conditions and anticipatory care is vital to improve people's health and wellbeing.

Examples of support needs for this section of the population include:

- Support at home to maintain independence, including assistive technology such as telecare and telehealth (including those that link individuals with clinicians), adaptations, equipment and aids and assistance with personal care
- Links to groups within the community providing support for people with particular conditions; and
- Step up and down beds and other intermediate care options such as occupational therapy and reablement, to avoid admission and support safe discharge from hospital to provide support when needed

In many cases of complicated health conditions or physical disabilities, specialist acute provision will be required, although again where possible short-term care and support should be provided to help people optimise their self care. For others, residential support in independent/ supported living environments (including extra care) might be appropriate. In all such cases health, social care and other professionals should work together and with individuals to ensure service users have a genuine voice in relation to both their desired outcomes and their choice of service provision.

## 9.4. Current Care and Support Provision

There are a range of services and support available to the adult population to help them lead healthy and fulfilled lives; although a significant degree of responsibility for this falls on the individual and responsibility for services and support extends well beyond health and social care.

The following table gives an indication of the numbers of people aged 18-64 in receipt of care and support services.

**Figure 9:3 Numbers of people aged 18-64 in receipt of care and support services.**

18-64 In Receipt of Support 2014-15	18-64 Receiving Services	18-64 Supported in the community	18-64 Receiving residential services	18-64 Equipment	18-64 Adaptations	18-64 Direct payments	18-64 Home care
Wales	8509	8139	370	4742	2031	1471	2275
West Wales Region	959	925	34	493	133	287	219
Carmarthenshire	454	437	17	295	..	135	112
Ceredigion	134	128	6	19	20	49	21
Pembrokeshire	371	360	11	179	113	103	86
18-64 In Receipt of Support as a % of 18+ In Receipt of Support	Receiving Services	Supported in the community	Receiving residential services	Equipment	Adaptations	Direct payments	Home care
Wales	17%	19%	5%	21%	29%	55%	13%
West Wales Region	14%	17%	3%	17%	30%	64%	10%
Carmarthenshire	12%	15%	2%	17%	..	71%	9%
Ceredigion	24%	29%	6%	26%	34%	72%	14%
Pembrokeshire	15%	17%	3%	16%	29%	54%	10%

Source: Stats Wales



General services available to promote self-care and wellbeing include:

- Universal services and amenities within the community
- Prevention and early intervention services including information, advice and assistance
- Third sector provision including a wide range of facilities including transport, social activities, help at home with domestic tasks such as finance management gardening and cleaning and various targeted support groups such as carers' support; and
- Leisure services, which can where appropriate be accessed via the National Exercise Referral Scheme (NERS) which is in place across the region

For those with chronic and long term conditions and physical disability, a range of services are provided:

- Chronic conditions management through district and specialist nurses
- Social services support in residential settings and in the community
- Community-based support to reduce risk of deterioration and promote independence
- High level support through the provision of assistive technology, equipment, adaptations, direct payments and home care; and
- Advocacy services to help people make informed decisions about how their needs can be met and to support or improve independence

People with neurological conditions can receive a range of specialist neurological services within community settings or hospital. Acute medical inpatient care and generic rehabilitation services are provided from four District General Hospitals with support of community hospitals, with a neurological service provided by Abertawe Bro Morgannwg University Health Board.

Health and LA Leisure services work together to provide targeted intervention for those who are referred by GPs onto the National Exercise referral scheme. This produces good outcomes and many of these participants go on to regular exercise programmes. For example, Ceredigion had 386 referrals in 15/16 of which 65% were aged 17-65, and in Pembrokeshire there were 608 referrals of which 66% were aged 17-65. Leisure centres also provided support to those with: Stroke, Cardiac, Falls, Back Care, Pulmonary, Cancer, Weight management, Mental Health and Antenatal Care.

People with health and physical disabilities are provided with a range of services to improve or help maintain their independence levels and quality of life. This support includes: occupational therapy support with assessments, equipment and aids and referrals for disabled facilities grants and adaptations. Leisure services also provide exercise and sports programs designed to benefit those with health and physical disabilities through provision at leisure and sports centres.



General and universal services such as information, advice and assistance and advocacy, third sector support groups, supported employment, education and training opportunities are also on offer. Day care provision at day centres and where required in other settings provide opportunities for this cohort and support carers so they can benefit from a break from caring duties.

The range of services available include:

- Stop Smoking Wales
- NERS
- Provision of equipment from the Joint Equipment Store
- Disabled Facility Grants
- Reablement including Occupational Therapy and Physiotherapy Services
- Telecare
- Meals on wheels
- Daycare
- Respite care
- Minor adaptation provision
- Falls prevention/fall clinic
- Disabilities sport wales development officer
- 50+ Network
- Blue Badge Scheme
- Disability Forum
- Rally Round App which is being piloted and is a free online service which makes it easy for friends and family to come together and help a loved one stay safe and well at home

## 9.5. Gaps and Areas for Improvement

Although a drop in the number of people falling within this thematic group is predicted in the medium term, and the current number of people with specific care and support needs is small, it is vital that appropriate provision is in place to promote wellbeing and independence and prevent escalation of need. The following gaps and areas for improvement have been identified and are set out below against the core principles of the SSWB Act.

### Voice and control

Areas for improvement include information, advice and assistance to ensure that people are signposted to relevant support within their community, advocacy, and improved choice in the format and range of services available.

### Prevention and Early Intervention

Enhancing community based support to prevent isolation and promote independence is common to all themes including this one. In addition, HDUHB has identified a

number of areas for improvement to help people adopt healthy lifestyles and prevent ill health:

- High population awareness of the health harms of smoking and alcohol consumption above recommended guidelines, the benefits of physical activity and healthy eating and of sources of help for lifestyle change
- Increased numbers of people who stop smoking
- Increased numbers of people who achieve a healthy weight or, by losing a clinically significant amount of weight (5-10% body weight), move in that direction
- Increased numbers of people undertaking sufficient physical activity to benefit their health
- Reduction in alcohol consumption above recommended guidelines; and
- Effective identification and treatment of risk factors associated with health inequality and heart disease

To achieve this, resources are being targeted at the following priorities:

Reducing smoking prevalence and inequality can be achieved through

- Developing a clear understanding of the social and economic pressures in communities, e.g. deprived communities and age groups where smoking rates are highest
- Supporting intensive targeted interventions to specifically address smoking cessation uptake with target groups
- Advocating increased action at the population level including plain packaging and reducing second-hand smoke exposure in children; and
- Ensuring that every contact with health services is used to both prevent smoking uptake and encourage cessation

Reducing the proportion of the population who are overweight and obese through

- A better understanding of why individuals are likely to become overweight or obese in early adulthood and how this can be prevented
- Ensuring effective interventions and pathways for prevention, treatment and management of childhood obesity are routinely available and systematically implemented
- Supporting intensive targeted interventions to specifically address weight and diet issues within the deprived communities; and
- Advocating increased action at the population level to ensure healthy food is available to all

Increasing physical activity levels especially in older population groups through

- Better understanding of why individuals stop exercising as they get older and how this can be prevented
- Supporting interventions within targeted age groups to increase participation in physical activity

- Better understanding the motivations and barriers for undertaking physical activity; and
- Considering interventions within a settings approach

Reducing alcohol consumption and binge drinking through

- Better understanding the social changes that cause a demographic shift in alcohol prevalence
- Advocating increased action to reduce the marketing and promotion of alcohol for home consumption, e.g. multi-buy deals, minimum unit price of alcohol; and
- Increasing awareness of harmful alcohol consumption in less deprived areas

Further health related objectives are

- To increase survival rates for cancer through prevention, screening, earlier diagnosis, faster access to treatment and improved survivorship programmes
- To improve the early identification and management of patients with diabetes, improve long term wellbeing and reduce complications
- To improve the support for people with established respiratory illness, reduce acute exacerbations and the need for hospital based care
- To improve the mental health and wellbeing of our local population through improved promotion, prevention and timely access to appropriate interventions
- The measurement of risk factors for the development of cardiovascular disease and lifestyle improvement programmes are also critical to improve the prevention, detection and management of the disease
- Establishing structured community Neuro Rehabilitation in Hywel Dda to compliment commissioned neurological as well as local generic services

## Wellbeing

- Raising awareness of the wellbeing impact of leisure and cultural activities and what's available especially from the third sector by having a directory or database of services and support
- Domiciliary care and supported living services will have to evolve to support increased use of assistive technology, such as telecare
- Day opportunities that support people with specific health and physical needs
- Greater flexibility to deliver step up and down provision to respond to changing needs and a greater focus on mental health provision
- Building community resilience by encouraging a culture of ownership and responsibility for individuals' and the community's own health and wellbeing and support for example through local support groups for people with chronic conditions
- Support for and improved awareness of those with mental health conditions
- Improved internet/ broadband access and public and community transport
- Help with low level tasks around the house

To promote a culture of care for patients, carers and the public and a culture of care for all staff, NHS Wales developed and adopted a Health and Wellbeing Charter in May 2013. The charter encourages the health and wellbeing of all its staff and recognises that staff act as role models to the community they serve in promoting and preventing ill health.

### **Co-production**

A number of the services that people between 18 and 64 with specific needs require tend to be available to, and shaped around the needs of, older people. It is vital that they are co-developed further to ensure that younger adults have access to the care and support needed for them to lead fulfilled lives and have a greater say in the development of services.

The HDUHB Together for Health Neurological Delivery Plan 2013 – 2017 priorities for 2014 – 17 include reviewing and revising clinical/care pathways in order to deliver well co-ordinated care that feels integrated from a user perspective (Hwyl Dda University Health Board, 2015).

### **Co-operation, partnership and integration**

- Strengthening partnership working for Neurological services between Regional and local services, Statutory and third sector organisations, and Clinical and user groups
- Strengthening transition arrangements between children and young people's services and adult services

## 9.6. References

*Daffodil Cymru (2014a). Population aged 18 and over, receiving ESA, Incapacity Benefit, or Severe Disablement Allowance, as at May 2015. [Online].*

<http://www.daffodilcymru.org.uk/index.php?pageNo=1098&PHPSESSID=tkcbe3j5tj20n9hp3b6v3qt8c2&at=a&sc=1&loc=1&np=1>

*Daffodil Cymru (2014b). Population aged 18 and over predicted to have a limiting long-term illness, by age and gender, projected to 2035. [Online].*

<http://www.daffodilcymru.org.uk/index.php?pageNo=1046&PHPSESSID=86j1afe7vbmhmhuud06laf7u91&at=a&sc=1&loc=1&np=1>

*Dahlgren, G. and Whitehead, M. (1992). Policies and strategies to promote equity in health. Copenhagen: World Health Organisation*

*Hywel Dda University Health Board (2015). Together for Health Neurological Delivery Plan 2013 – 2017. Version 2.*

<http://www.wales.nhs.uk/sitesplus/862/document/266052>

*Hywel Dda University Health Board (2016). Health Needs Assessment Report 2016.*

<http://www.wales.nhs.uk/sitesplus/862/page/85702>

*Stats Wales. (2016). Adults receiving services by local authority, client category and age group. [Online].*

<https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Social-Services/Adult-Services/Service-Provision/adultsreceivingservices-by-localauthority-clientcategory-age>



## Section 10

# Learning Disability and Autism

**West Wales Population Assessment** March 2017

### 10.1. Overview and Key Messages

There are several ways in which the term ‘learning disability’ can be defined, however for the purposes of this assessment, Learning Disability is defined as:

- A significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence)
- A reduced ability to cope independently (impaired social functioning); or
- These are in evidence before adulthood and have a lasting effect on development

The way in which the needs of people with a Learning Disability are met has changed over the last twenty years. People who would historically have been placed in institutional care are increasingly being supported to live in their communities. Health and social care services along with the third sector collaborate to maximise the independence and potential of those who use our services.

Although Autism is not a learning disability it has been included in this section as services for people on the spectrum are generally provided from within learning disability teams or community mental health teams and NICE guidance (2008, 2012) provides standards for provision of services.

### 10.2. Demographics and Trends

In 2015 there were an estimated 1,483 people over the age of 18 with a moderate or severe learning disability in the West Wales region. This represents just under 0.5% of the total adult population, which is comparable with the picture across Wales.

The breakdown across the constituent parts of the region is as follows:

<b>Carmarthenshire:</b>	<b>713</b>
<b>Ceredigion:</b>	<b>305</b>
<b>Pembrokeshire:</b>	<b>465</b>

The rate of incidence within the adult population stands at approximately 0.5% in each of the county areas, in line with the regional average.

This regional total is predicted to rise to 1,571 by 2030, although as a percentage of the total population the position is expected to remain largely the same.

An increase of 35 in the total number of adults with a moderate or severe learning disability in Carmarthenshire is predicted over the same period, whilst in Pembrokeshire and Ceredigion numbers are expected to remain the same. This means the proportion of adults with a learning disability will decline slightly in those 2 areas (although the change will be negligible), whilst in Carmarthenshire it will remain about the same.



Of note is the expected significant rise in the numbers of people aged 75 and over with a moderate or severe learning disability, estimated to increase by 33% by 2030. Current numbers and projections for each part of the region are as follows:

**Figure 10:1 Numbers (current and predicted) of people aged 75 and over with a moderate or severe learning disability**

	2015	2030
Carmarthenshire	38	57
Ceredigion	16	23
Pembrokeshire	27	40
Region	81	122

Source: Daffodil Cymru

Whilst the predicted rise is less than that for Wales as a whole over this period, there are clear implications for care and support services as older people with learning disabilities encounter other age-related conditions, are less likely to receive support from family and friends and are therefore more likely to present with more complex needs than they would at a younger age.

Autism is a pervasive developmental disorder that is thought to affect 1 in 100 people in the population (Baird et al, 2006). The research shows that there is a high rate of co morbidity between Neuro-developmental disorders (ND) e.g. Autistic Spectrum Disorders (ASD)/Attention Deficit Hyperactivity Disorder (ADHD), and also of other mental health disorders. Research suggests that based on the population of Hywel Dda UHB:

- 1% ASD, 2-4 % ADHD
- 70% ADHD/ASD co-morbidity
- 40% ASD anxiety disorder
- 90 % prisoners mental disorder including ND
- 30% IP eating disorders have ASD
- 40% specialist substance misuse ND

The current demand for the ASD diagnostic service is based on a pattern of referral which is likely to be an underestimation of the actual population's need. Local data on referrals for ASD diagnostic services shows that for the period January 2013 – end of November 2015 there were 265 referrals. However, since April 2016, the service has received 99 referrals.

Data relating to the incidence of autism is not collected routinely by all local authorities. However, open cases for people with autism in Ceredigion and Pembrokeshire in November 2016 are as follows:

**Figure 10:2 Open cases for people with autism in Ceredigion and Pembrokeshire 2016**

	Caseload numbers (18 years +)	Caseload numbers (open to transition)
Ceredigion County Council	22	18
Pembrokeshire County Council	91	22

Source: Local data

Data is not available for Carmarthenshire.

### 10.3. Current and Future Care and Support Needs

People with learning disabilities are likely to require a range of care and support, depending on the nature and complexity of their individual needs. Depending on individual circumstances, needs will include support to help people participate fully in their local communities (for example through education, training, volunteering and access to employment), day opportunities, (for example access to social activity centres and programmes), general health care, residential care and supported accommodation to enable people to remain living independently within their communities.

There is a growing recognition that, in common with other groups needing care and support, delivery models for learning disability need to move away from traditional, risk-averse approaches which result in an over-reliance on options such as residential care. Such approaches tend to ‘lock’ people into expensive, passive forms of care which do little to promote independence and are not suited to helping them build skills and capacity for more active participation in society and, thereby, achieve more positive personal outcomes. The concept of the ‘progression model’ of care and support for people with learning disabilities has emerged, described by the Social Services Improvement Agency (SSIA) (2014) as

*“the ability to promote independence through strength-based assessment, clear development plans, positive risk taking and outcome based review to transform services”.*

Across the region, numerous mechanisms are in place for engagement with users and carers to obtain their perspective on the care and support they would like to receive. Examples include:

- Engagement events facilitated by Carmarthenshire People First in October 2015 to inform the development of Carmarthenshire County Council and Ceredigion County Council's Equality Strategies, focusing specifically on the needs of people with a learning disability
- Consultation in support of the development of Pembrokeshire County Council's Strategy for People with Learning Disabilities in May 2016
- Ongoing dialogue between service commissioners, providers and users and carers through local stakeholder groups in each county area

A clear message is coming from service users and carers; they want support to help them optimise their independence, access employment and benefit from volunteering opportunities. People also say they want greater opportunities for training and development and to be able to make new friends and participate in social activities. These clearly reflect the principles underpinning the progression model of care and support.

In Pembrokeshire a set of wellbeing outcomes has been co-produced with users and carers. These send clear messages in terms of the kinds of care and support which should be provided now and in the future and are set out below:

- Improved Health – 'I am as healthy as I can be and can easily visit doctors, dentists, hospitals and other health services'
- Productive and independent lives - 'I am able to live a fulfilled life'
- Freedom from discrimination and harassment - 'I have an equal right to live free from fear, discrimination and prejudice'
- Personal Dignity – 'I feel valued by others'
- Exercise choice and control – 'I have the same life chances as other adults.'
- Part of the Community – 'I can participate as a full and equal member of my community.' 'I can live in a home of my choice by having the right support in place'
- Maintain and develop social and family ties – 'I have the same opportunities to maintain relationships as other adults'

These outcomes are forming the basis of a Learning Disability Charter, which is currently in draft. Pembrokeshire County Council's Learning Disabilities Strategy (2016) is based on a 'Circle of Support' shown below, which articulates the types of support which are needed, and which should equally apply across other parts of the region:

Figure 10:3 Circle of support for learning disability



Source: Pembrokeshire County Council

Broad aims under each of the segments in the Circle of Support are as follows:

**Community connections/ Creative solutions**

Growth of local community solutions such as social enterprises, cooperatives, user-led and third sector services to provide opportunities for people with a learning disability to contribute to society and develop skills.

**Communication and information**

Provision of Information, Advice and Assistance as required under the SSWB Act, with particular regard to the specific communication needs of this service user group.

**Social care and support**

Acknowledging the need for ongoing support for some people with a learning disability, provision of supported living models which enable as many of them as possible to live within and contribute to their local communities.

**General health care and treatment**

Improved access for people with a learning disability to generic health care services, acknowledging that there is an above-average incidence among this service user group of conditions such as epilepsy, diabetes and cardiac disease. Encouraging take-up of annual health checks.

### **Transitions and family support**

Ensuring that children and young people who have received care and support, and those that have not, are known to social services and that appropriate measures are in place to arrange appropriate support once they reach adulthood.

### **Support for Carers**

Ensuring that those caring for people with a learning disability receive appropriate information, advice and support on options available and entitlements, etc.

### **Voice, choice and advocacy**

Ensuring people with a learning disability have access to high quality advocacy services so that they can make informed choices and be supported appropriately in achieving personal outcomes.

### **Personal growth, including education, training, employment and volunteering**

Providing equitable access to further education and appropriate support in accessing training and volunteering opportunities.

### **Environment, including transport and housing**

Availability of transport links to enable access to care, support and other services and appropriate housing to facilitate independent and supported living.

### **Autistic Spectrum Disorder Diagnostic and Pre/post Counselling Service**

Improved recognition and diagnosis of people with Autistic Spectrum Disorder (ASD).

### **Housing**

There are still significant numbers of people particularly in Carmarthenshire under the age of 65 in residential care. A priority for the LA and Health Board is to reverse this trend and develop housing options to prevent admission to hospital and residential settings, facilitate discharge from hospital. There is need to jointly commission a range of community accommodation options and services that offers more choice and control for individuals using learning disability services.

## **10.4. Current Care and Support Provision**

A range of care and support services are in place across the region to support adults with a learning disability to live fulfilled lives within the community. Whilst specific care and support options vary across counties, current provision includes:

- **Universal services** For example leisure centres, community centres, libraries, adult education opportunities although it is recognised that these services do not yet provide consistent equal access to people with LD

- **Preventative services** Council grant funding supports the growth of alternative community services that are co-produced with members of communities enabling people to build upon their own individual strengths and resources. These include good neighbour schemes, luncheon clubs, community enterprises, community/voluntary services
- **Specialist Health interventions** Consultant psychiatry, psychology, community nursing, Speech and Language Therapy, Occupational Therapy and Physiotherapy provide specialist interventions to adults with a diagnosed learning disability both within in-patient and community setting
- **Specialist Health Autistic Spectrum Disorder Diagnostic and Pre/post Counselling Service** The current service consists of allocated sessions from a locum consultant and a specialist practitioner
- **Day Opportunities** Providing social contact and stimulation, reducing isolation and loneliness, maintaining and / or restoring independence, offering activities which provide mental and physical stimulation, providing care services, offering low-level support for people at risk
- **Pathways to employment** A range of local initiatives including FRAME, Workways Plus, Stackpole Estate and ESTEAM in Pembrokeshire and Opportunities Team and 'Steps' in Carmarthenshire. In addition national programmes such as 'Work choice', run by the Department for Work and Pensions, support those with lower level LD
- **Respite provision** Short breaks/respite is a key commitment in recognition that planned breaks are an essential part of supporting families
- **Commissioned Services** Individually commissioned supported living arrangements which enable people with learning disabilities to live in their own tenancies with support at varying levels, and residential services which include both the provision of accommodation and care on site, with care being available 24 hours per day. These include a regional **Shared Lives** service, managed for the region by Carmarthenshire County Council and providing a route for people to return to their communities and is an example of an alternative to traditional residential services. Advocacy services are commissioned across the region; and
- **Direct Payments** These provide another way for individuals to access a range of opportunities by being able to choose who provides the services they need

Assessment and care planning for people with a learning disability is managed through multi-disciplinary Community Teams for Learning Disability (CTLDDs), in place across the region and staffed by health and social care professionals. The teams also work jointly with Disabled Children's Teams and Transition Teams with occasional involvement from age 14 upwards and undertaking assessment when a young person in receipt of services reaches 17. Transition teams play a key role in supporting the transfer of care needs between one service and another, and typically between adult and children's services.

Data held by the Welsh Data Unit indicates that the reliance on residential care in each of the three counties is above the Welsh average. Pembrokeshire currently ranks

third, Ceredigion sixth and Carmarthenshire eighth in Wales in relation to the proportion of people with a learning disability receiving care and support that are supported in this way.

## 10.5. Gaps and Areas for Improvement

As evidenced by the summary of current provision in the preceding section, whilst there is a clear direction of travel towards a range of care and support for people with learning disabilities based on progression principles, there is more to do in rebalancing the current emphasis on traditional solutions such as residential care.

A number of foundations are in place to drive further change. Key among these is a regional Statement of Intent for Learning Disability Services (Mid & West Wales Health and Social Care Collaborative, 2014) and Model of Care and Support (Mid & West Wales Health and Social Care Collaborative, 2015), which have subsequently been endorsed by all statutory partners in the region. The purpose of the Statement of Intent is to provide a clear, shared strategic vision for learning disability services and to articulate an integrated, regional approach to the transformation of services. Predicated on the 'progression model', it identifies four regional aims as follows:

- To improve community resilience and enablement through choice, self-direction and control for people with learning disabilities over decisions affecting their lives
- To commission services that strengthen quality and value for money across the range of services provided for people with a learning disability
- To reduce health inequalities by increasing access to and uptake of universal health, social care and wellbeing services for people with learning disabilities
- To build community resilience and capacity across a range of services that support people with a learning disability

The development of fit for purpose services is, however, an ongoing journey and there are a number of areas in which further improvement can be made. These are set out below against the core principles of the SSWB Act.

### Voice and control

- Empowering people with a learning disability to decide who provides their support and what form that support takes
- Development of an identifiable framework for service delivery that reflects individual personalised care and local need

### Prevention and early intervention

- Giving people access to low level support which they require to remain independent for as long as possible, which may delay or reduce any further support requirements
- Improving the recognition, diagnosis and the treatment and management of people with Neurodevelopmental disorders including Autistic Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD)



## Wellbeing

- Improve services for Adults with Neurodevelopmental disorders in order to provide a high quality integrated model which includes availability of input from highly specialist expertise and an ability to contribute to the evidence base for service delivery
- Development of a defined model of care and support based on the principles of the progression model
- Reduction in the number of children and young adults transitioning into residential care
- Reducing health inequalities across a continuum of care (from accessing mainstream health and social care services to specialist care, and prevention of crisis and ill health)
- Reducing reliance on residential care and promoting opportunities for independent living
- A continued shift from traditional day services to a model that offers choice and variety, that is outcome and community based, supports access to employment and volunteering, helps people realise individual aspirations and promotes social inclusion

## Co-production

- Increased access and availability of local housing and accommodation to enable people with a learning disability to live as independently as possible, in a place of their choice
- Strengthening pathways back to local communities following education, and developing local education and work opportunities in communities and making the necessary adjustments for people with a learning disability
- Placing an emphasis on building strong communities, in which people with a learning disability have a sense of belonging and can contribute to the wellbeing of fellow citizens. The development of social enterprise, cooperatives, user-led and third sector services will be a key factor in this

## Co-operation, partnership and integration

- 'Right-sizing' existing packages of care to ensure they meet current needs and facilitate personal development and increased independence, and that they are cost-effective
- Maximising opportunities from regional collaboration, partnership and integrated working to deliver high quality, cost effective services
- Regional collection and use of data to support future planning and commissioning

Strategic leadership from the RPB will be instrumental in building on existing foundations and taking this agenda forward. Mechanisms such as the *Learning Disability Service Redesign* programme recently launched by Hywel Dda University Health Board will be key drivers in achieving the change required.



*“Together we are committed to support people with individual needs live the life they choose. By providing a range of flexible care and support services we will ensure people with learning disabilities are as independent as possible and connected with their local communities”.*

From Model of Care and Support, Mid and West Wales Health and Social Care Collaborative (2015)

## 10.6. References

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. and Charman, T. (2006). "Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)". *The Lancet*, 368 (9531), pp. 210-215.

Daffodil Cymru, 2014. People aged 18-64 estimated to have a moderate or severe learning disability, projected to 2035. [Online].

<http://www.daffodilcymru.org.uk/index.php?pageNo=1065&areaID=18&loc=18>

Mid & West Wales Health and Social Care Collaborative (2014). *Statement of Intent for Learning Disability Services*.

<http://www.wwcp.org.uk/documents>

Mid and West Wales Health and Social Care Collaborative (2015). *Model of Care and Support*.

<http://www.wwcp.org.uk/documents/>

NICE (2008). *Attention deficit hyperactivity disorder: diagnosis and management, clinical guidance 72*.

<https://www.nice.org.uk/guidance/cg72>

NICE (2012). *Autism spectrum disorder in adults: diagnosis and management, clinical guidance 142*.

<https://www.nice.org.uk/guidance/cg142>

Pembrokeshire County Council (2016). *Learning Disability Strategy 2016-2021*.

[http://www.pembrokeshire.gov.uk/objview.asp?object\\_id=13659&language=](http://www.pembrokeshire.gov.uk/objview.asp?object_id=13659&language=)

Social Services Improvement Agency (2014). *Transforming Learning Disability Services in Wales [online]*.

[http://www.ssiacymru.org.uk/home.php?page\\_id=7049](http://www.ssiacymru.org.uk/home.php?page_id=7049)

## Section 11

# Mental Health

**West Wales Population Assessment** March 2017

## 11.1. Overview and Key Messages

This chapter considers the care and support needs of Adults aged 16 + with mental health needs. The care and support needs of older people (aged 65+) with dementia are addressed in the Older People's thematic report.

According to the Mental Health Foundation (2015) in any year one in four of us experience a mental health problem, yet three quarters of people with mental health problems receive no treatment.

Many of us will require support with respect to our mental health throughout our lives whether this is low intensity support for difficulties such as low level anxiety / depression or longer term support.

Mental illness can develop from a number of factors including social traumas, illegal drug use and genetic predisposition. Mental health does not discriminate and can affect anyone often leading to debilitating conditions.

Early intervention is crucial and this can take the form of providing information or referral to community or third sector services. Admissions to inpatient services may occur in extreme situations, where the individual cannot be treated in the community and presents a risk to themselves and / or others.

It has been estimated that the economic and social costs of mental health problems in Wales is estimated to be £7billion a year (Cyhlarova, 2010).

In 2015-16, the Welsh Government ring-fenced £587m for mental health services across Wales – up from £389m in 2009-10. Earlier this year, Government announced an additional £15m of new funding is being made available for mental health services in Wales every year.

## 11.2. Demographics and Trends

In Wales, according to the Welsh Government Mental Health Strategy (Welsh Government, 2012):

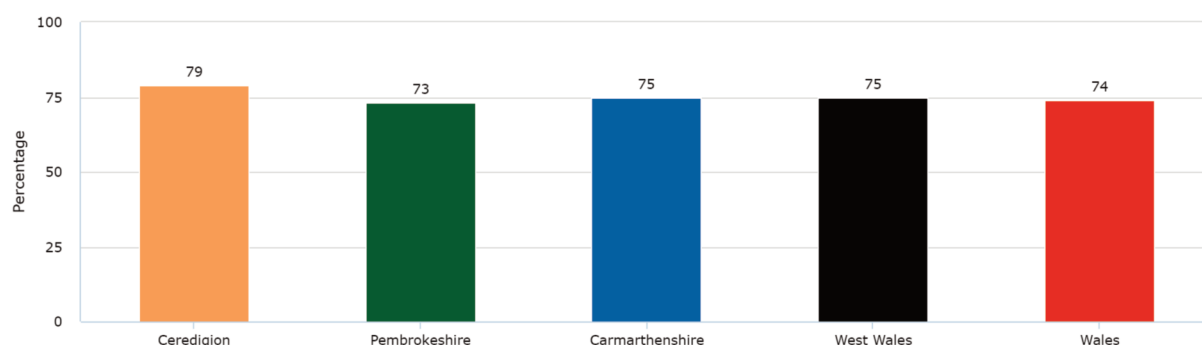
- 1 in 4 adults experiences mental health problems or illness at some point during their lifetime
- 1 in 6 of us will be experiencing symptoms at any one time
- 2 in 100 people will have a severe mental illness such as schizophrenia or bipolar disorder at any one time
- Approximately 50% of people with enduring mental health problems will have symptoms by the time they are 14 and many at a much younger age
- Between 1 in 10 and 1 in 15 new mothers experience post-natal depression

- 9 in 10 prisoners have a diagnosable mental health and / or substance misuse problem
- In Wales the number of people detained in police custody as a place of safety under section 136 of the Mental Health Act 1983 decreased from 8,667 in 2011-12 to 6,028 2013-14. 2014-15 saw this figure decrease further (Mental Health Foundation, 2016)

According to Rethink Mental Illness (2016) individuals with a severe mental illness die on average 20 years younger than the rest of the population, predominately due to health related issues such as coronary heart disease, diabetes and some cancers. This in part may be due to a poor diet, side effects of medication, poor monitoring of physical health and life style factors. People with mental health needs are more at risk of social exclusion and poverty and have poorer employment / education prospects.

The following graph shows the percentage of people in the 3 counties aged 16 + who are free from experiencing a common mental health disorder (2013-14) when compared to West Wales and Wales. There are some small variations when compared to the Wales percentage (74%).

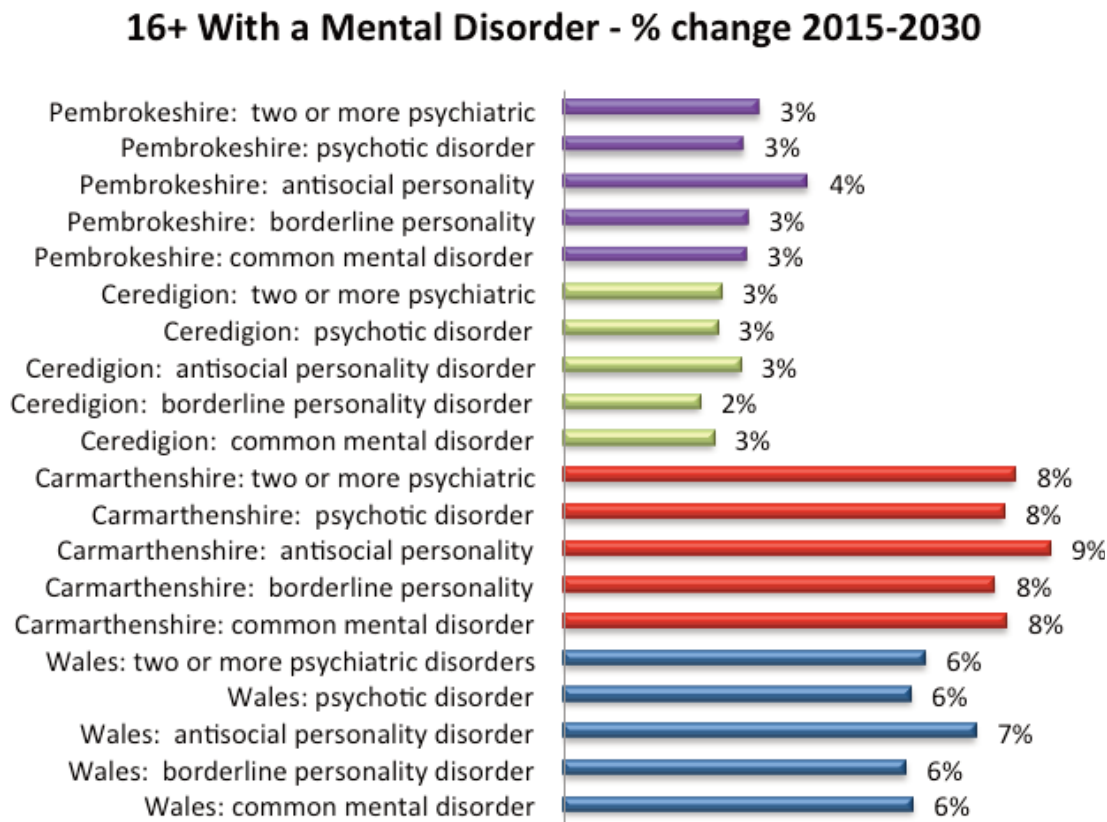
**Figure 11:1 % of people aged 16+ years free from common mental disorder - 2013-2014**



Source: Welsh Government

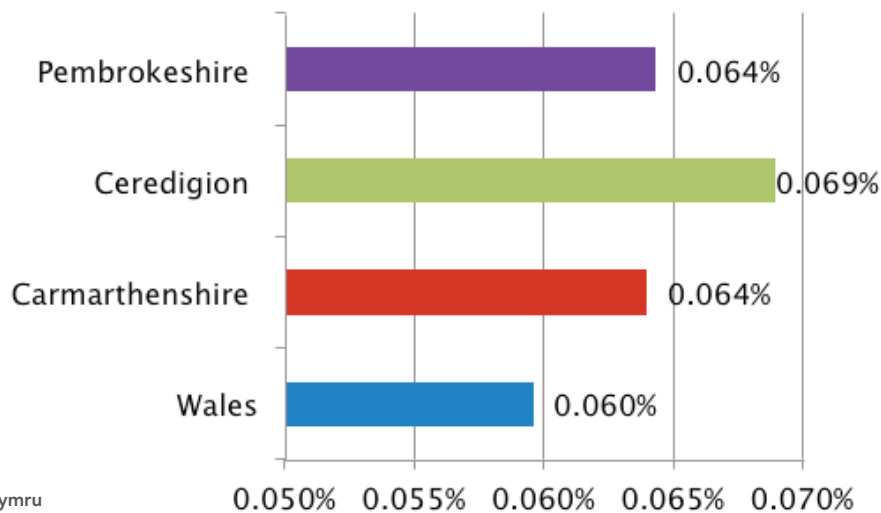
Around 75% of people with a mental health issue have a common mental disorder (which include depression, anxiety disorder, panic disorder, obsessive-compulsive disorder and post-traumatic stress disorder). The following chart shows the predicted percentage change between 2015 and 2030 of people with a mental health disorder in each of the counties. Carmarthenshire is expected to see the biggest percentage changes across all disorders shown when compared to Ceredigion, Pembrokeshire and Wales.

Figure 11:2 Predicted percentage change between 2015 and 2030 of people with a mental health disorder



Source: Welsh Government

Figure 11:3 Percentage of people aged 30-64 with early onset dementia



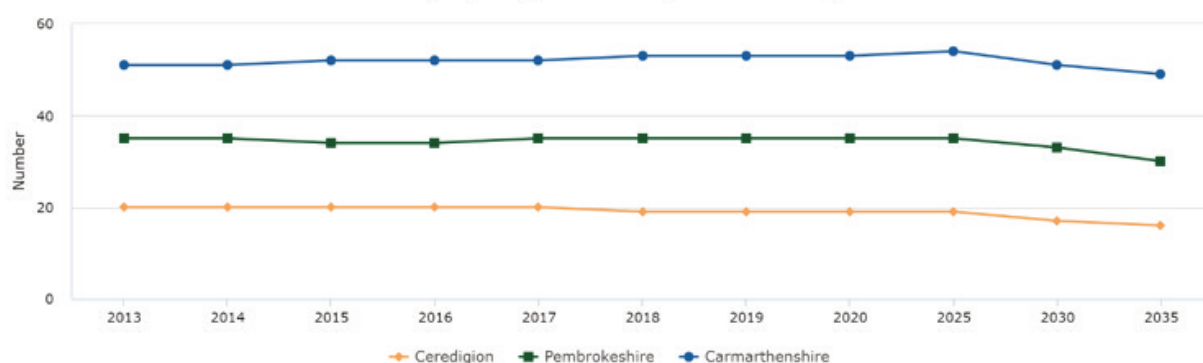
Source: Daffodil Cymru

Dementia in people aged less than 65 is described as early onset dementia, young onset dementia or working age dementia. It is estimated that 1 in 1000 people in Wales have early onset dementia. This figure is slightly higher in Carmarthenshire and Pembrokeshire, and slightly higher still Ceredigion.

The symptoms of dementia may be similar regardless of a person's age, but younger people often have different needs, and therefore require some different support. There is a wider range of diseases that cause early onset dementia and a younger person is much more likely to have a rarer form of dementia. However, people under 65 do not generally have the co-existing long-term medical conditions of older people – for example diseases of the heart and circulation. They are usually physically fitter and dementia may be the only serious condition that a younger person is living with (Alzheimers Society, 2015). The following chart shows the numbers of people with early onset dementia in Pembrokeshire, Ceredigion, Carmarthenshire and Wales.

The Alzheimers Society predict a small decrease in the numbers of people aged 30-64 with early onset dementia by 2035 (Alzheimers Society). The following graph shows how this trend will affect the population in West Wales.

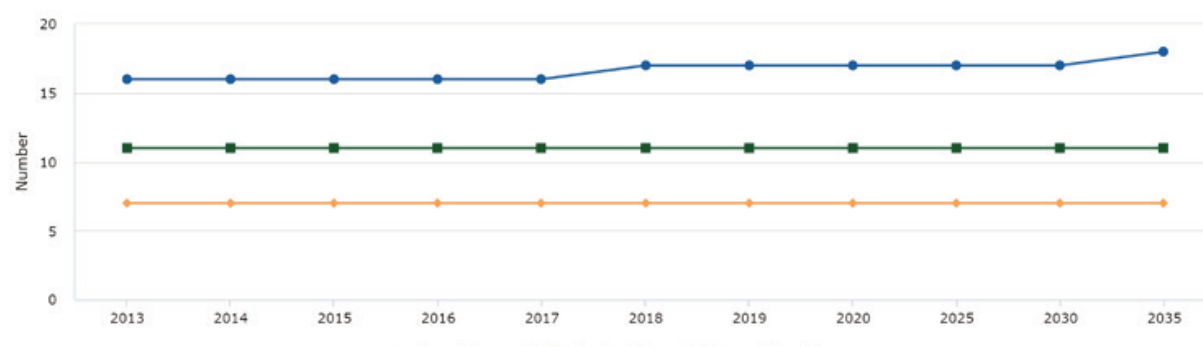
**Figure 11:4 Predicted number of people aged 30-64 with early onset dementia**



Source: Welsh Government

Suicide in people aged 15 + is also relatively rare however the following graph suggests there is predicted to be a small increase in the numbers by 2035. Suicide reaches its peak among males between the ages of 20-39 and for females between the ages of 40-54 (Welsh Assembly Government, 2008).

**Figure 11:5 Predicted number of mortalities of people aged 15+ from suicide**



Source: Welsh Government

### 11.3. Current and Future Care and Support Needs

A 2013 survey of attitudes towards mental health showed there is a need for a better understanding of mental health issues (Opinion Research Services, 2014). The survey suggests:

- 1 in 7 believe that people with a mental illness can never recover
- 1 in 7 believe that as soon as a person shows signs of mental illness they should be hospitalized
- 1 in 4 people believe said that being around someone with a mental illness can make them feel uncomfortable
- Nearly 1 in 10 believe that people with mental health issues should not be given any responsibility

Organisations in West Wales are working in partnership to improve the health and wellbeing gains for people who are, or have potential to experience, mental health problems. This work is being driven through the Transforming Mental Health Services Programme (TMHSP).

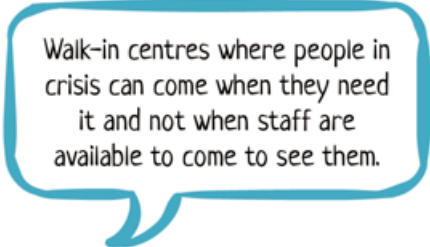
Consultation activities to inform the TMHSP have identified the following key care and support needs for individuals with mental health problems:

- Improve access to care and support services with clear pathways into and through services, including evenings and weekends
- Improve services and support for young people in transition; Improve collaboration between statutory organisations, including primary care, to respond to unscheduled care needs
- Improve bed availability and management, and develop community alternatives to hospital in a crisis
- Improve transport and conveyancing in relation to the Mental Health Act;
- Improve services and support for people with Autism and Autistic Spectrum Disorders (ASD)
- Develop a collaborative approach with the third sector to facilitate information, advice and assistance that supports the development of population resilience
- Build upon awareness raising initiatives that help tackle the stigma and discrimination faced by those who have mental health issues
- Improve response for individuals with low-levels of anxiety / depression;
- Improve access to counselling services
- Improve support for carers
- Access to a range of accommodation options and accommodation support

Need better links between statutory and voluntary sector in providing social aspects of social care and support.



- Improve availability of meaningful day time employment opportunities
- Access to age-appropriate environments should be provided for children and young people; and
- Service users must continue to be at the heart of service design and provision



Walk-in centres where people in crisis can come when they need it and not when staff are available to come to see them.

Alongside the engagement events the Mental Health Programme Group (MHPG) have been working closely with West Wales Action for Mental Health (WWAMH) to produce a report on independent service user and carer perspectives on alternative models of care (Wright et al, 2016).

#### 11.4. Current Care and Support Provision

The mental health needs of society have changed significantly over the past decade. Treatment advances have also changed with delivery of services moving away from a reliance on hospital care and instead providing services in community settings where people can remain supported primarily by families and friends or, when required, by services delivered by health, social care and the third sector.

Since 2012 and the introduction of the Mental Health (Wales) Measure 2010 (the Measure), the vast majority of people with mental health problems are treated at a primary care level, either through their GP or Primary Care Mental Health Services. This promotes early intervention for people experiencing mental health difficulties, the aim being to reduce the likelihood of their condition deteriorating and the need for secondary mental health services.

The introduction of the Local Primary Mental Health Support service (LPMHSS) has enabled closer integration of mental health services with primary care and GP services to provide short term psychological interventions, both individual and group, to individuals with a mild to moderate mental health problem. In addition, the LPMHSS also provide support and training to professionals working within primary care teams in relation to their management of individuals on their caseloads with mental health issues.

The significant numbers of people accessing Primary Mental Health Support Services in West Wales during 2015/16 are summarised below, and reflect the priority given to early intervention support.

Figure 11:6 Number of individuals referred to Primary Mental Health Support Services in 2015-16

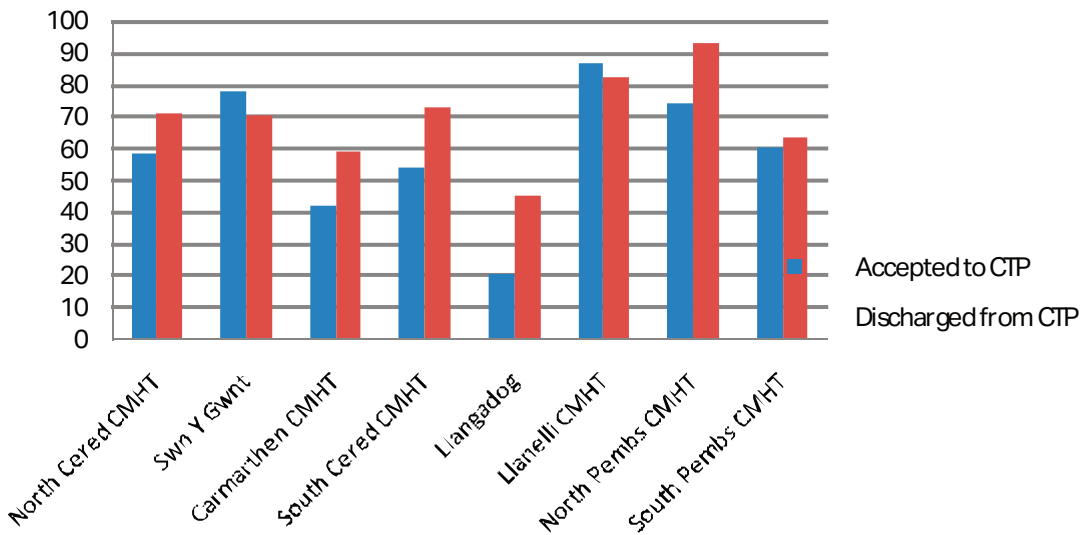
Carmarthenshire	1727
Ceredigion	1130
Pembrokeshire	1822
Hywel Dda Total	4679

Source: Local data

In West Wales, Community Mental Health Teams (CMHTs) are a partnership between Social Services and Hywel Dda University Health Board and are the central point of referral for those requiring access to secondary mental health services. Part 2 of the Measure specifies that any individual receiving secondary mental health services must also have an up-to-date care and treatment plan. CMHTs have a duty to assess anyone who appears to be experiencing mental health difficulties which are affecting their ability to lead their usual life.

The figure below shows how many individuals were accepted into secondary services during 2015/16, and also how many have been discharged. Mental health services focus on a recovery model; this means that many individuals do not need to remain under the care of secondary mental health services throughout their lives.

Figure 11:7 CMHT Care Treatment Plans 15/16



Source: Hywel Dda University Health Board

Most individuals experiencing mental health crisis or more severe problems prefer not to be treated in hospital. HDUHB established Crisis Resolution Home Treatment (CRHT) Teams in December 2012 that are able to work flexibly and intensively, outside normal working hours, to treat people at home and to help them avoid admission to hospital.

The CRHT Teams also work closely with in-patient units to ensure that people are able to be discharged as early as possible. The numbers of people referred to CRHT services in 2015/16 are summarised in the table below.

**Figure 11:8 Referrals to Crisis Resolution Home Treatment Teams 2015/16**

Carmarthen CRHT	840
Ceredigion CRHT	520
Llanelli CRHT	1010
Pembrokeshire CRHT	775
<b>Total</b>	<b>3145</b>

Source: Hywel Dda University Health Board

Specialist Services such as psychological and occupational therapies and psychiatric interventions deliver services in a range of community and in-patient settings, including forensic mental health provision. Inpatient mental health services are provided by the Health Board, or commissioned from the independent sector. The numbers of admissions to hospital have fallen since 2009 as shown below.

**Figure 11:9 Admissions to Psychiatric Inpatient services**

Year	2009	2010	2011	2012	2013	2014	2015	2016
Hywel Dda UHB Psychiatric Inpatient Admissions	165	156	164	133	132	119	114	123

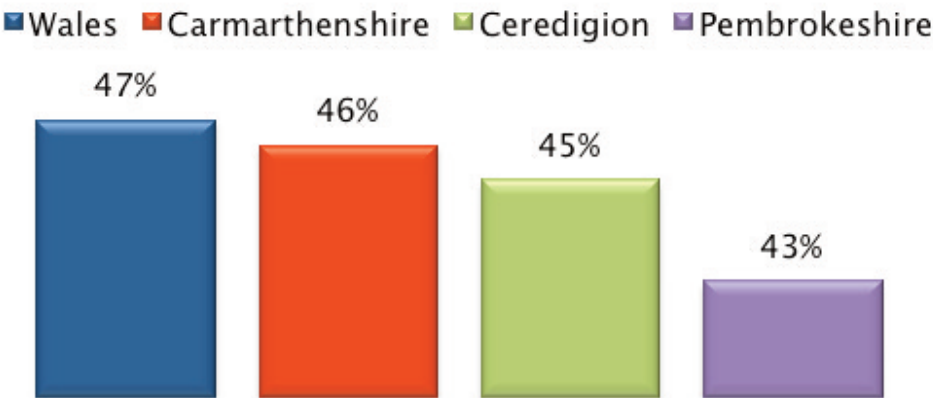
Source: NHS Informatics Service, 2016

The number of individuals detained under Section 2 of the Mental Health Act has risen from 217 in 2013/14 to 303 in 2015/16 and based on in-year activity. A further increase is expected to be reported at the end of 2016/17.

There are still significant numbers of people receiving residential care services and as illustrated below this is set to continue to rise by 2030.

A priority for the local authorities is to reverse this trend and develop housing options to prevent admission to hospital and residential settings, and facilitate discharge from hospital. There is need to jointly commission a range of community accommodation options and services that offers more choice and control for individuals using mental health services. 97% of those in residential placements are in independent sector care homes under contract, with 17% of these receiving nursing care in those settings.

Figure 11:10 Percentage change for 18+ receiving residential services 2015-2030



Source:Daffodil Cymru

Deprivation of Liberty Safeguards

Any one of us at some point in our lives may lose our mental capacity. This is more likely as we get older and for many mean receiving care and support in an environment where there are restrictions or deprivations of liberty.

Capacity Act (MCA) Deprivation of Liberty Safeguards (DOLS) provides a legal framework to protect vulnerable adults, who may become, or are being deprived of their liberty in a care home or hospital setting.

These safeguards are for people who lack capacity to decide where they need to reside to receive treatment and / or care and need to be deprived of their liberty, in their best interests, otherwise than under the Mental Health Act 1983 (MCA Code of Practice). The safeguards came into force in Wales and England on the 1st April 2009. Following the Supreme Court judgement on the Cheshire West case of March 2014, the number of people who should be considered under the Safeguards has increased dramatically. This has placed increasing burdens on local authorities and health and social care practitioners administering the Dols. For example prior to the Cheshire West judgement Ceredigion received approximately 10 Dols requests a year. In 2015/16 requests increased to 421.

The following table shows the number of DOLS requests and the waiting list for DOLS in each county.

Figure 11:11 DOLS requests and waiting lists

	Carmarthenshire	Ceredigion	Pembrokeshire
DOLS referrals – 2015/16	629	421	623
Dols waiting list - current	685	305	277

Source: Local data

The Health Board and Local Authorities commission a range of third sector organisations to support people with mental health needs including advocacy services, information and advice, activities, healthy lifestyles and a range of supported accommodation and tenancy related support services. There are many voluntary and community organisations and social enterprises working with people with mental illness including Pembrokeshire Mind, Carmarthenshire Mind, Mind Aberystwyth, Hafal, and FRAME.

West Wales Action for Mental Health (WWAMH) supports voluntary organisations with an interest in mental health and seeks to improve the services and opportunities available to people with mental health problems, their families and carers. WWAMH has an active presence across the West Wales area, and a number of service users have been involved or contributed towards future service developments.

Direct payments provide another way for individuals to access a range of opportunities and services, by being able to choose who provides the services they need. The numbers of adult social services clients with mental health needs who are receiving direct payments are shown in the following graph. Although numbers are low there has been a small upward trend in Ceredigion and Pembrokeshire since 2011.

### 11.5. Gaps and Areas for Development

The TMHSP programme have developed a shared vision for a modern mental health service (Hywel Dda University Health Board, 2015) which should:

- **be accessible 24 hours a day** so that the person who needs help or their supporters can walk into a mental health centre at any time and establish a safe relationship to discuss their needs and agree immediate support
- **have no waiting lists** so that the first appointment can take place within 24 hours, with planned meetings to follow that agree the support and treatment needed
- **move away from hospital admission and treatment to hospitality and 'time out'** so that the mental health centres can provide night hospitality from one night to several weeks in order to address crisis periods when there is a higher need for protection and/or to support the needs of the family, when hospital admission is not the best option; and
- **day time out and opportunities** to provide therapeutic day service options for the individual to access the care and support that is needed, for a few hours or a whole day

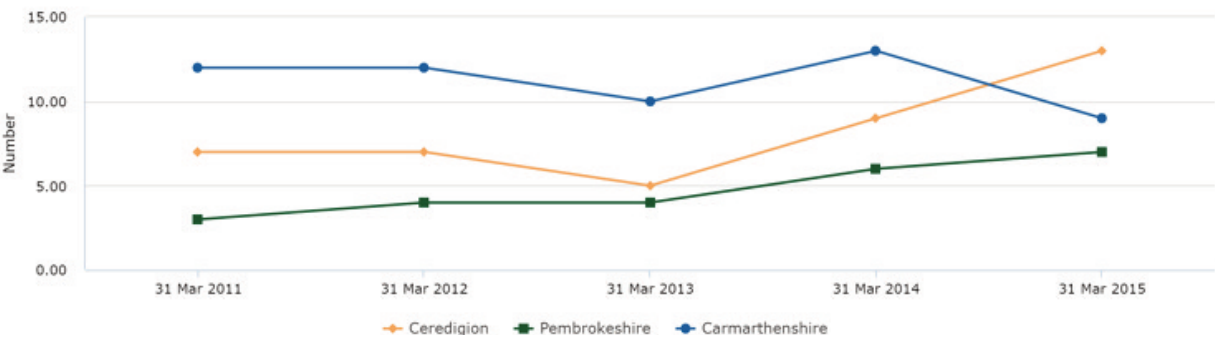
As part of TMHSP work is underway to consider the implementation of the Trieste Model in Italy which places a major focus on community based resources that look at the whole person, break down barriers to accessing services by operating an open door policy, and are more service user led. The model works on a network of Community.

Mental Health Centres that are active 24 hours a day, 7 days a week (24/7 CMHCs), with a few hospitality / crisis beds, supported housing facilities and several social enterprises.

In the Trieste model, 80% of the budget is spent on community based support with 20% on in-patient services; this is the direct opposite of the current West Wales area expenditure profile. The TMHSP are exploring the possibility of developing a joint funding bid with Trieste in order to access funding to support the transformation of mental health services in the West Wales area, and to share this learning more widely across Wales and Europe.

The development of fit for purpose services right across the range is an on-going journey and there are a number of areas in which further improvements can be made. These are set out below against the core principles of the SSWB Act.

**Figure 11:12 Number of social services clients aged 18-64 with Mental Health problems receiving direct payments 31 March**



Source: Welsh Government

### Voice and Control

- Develop an outcome focused and “risk-enablement” approach to service provision to support a flexible approach
- Although fewer individuals with mental health needs are being detained in police custody, further work is required to improve service user experience and conveyancing in relation to S136 of the Mental Health Act

### Prevention and early intervention

- Improve prevention and early intervention services, alternatives to hospital services such as a safe haven, respite and transfer of care liaison services, and access to services, especially for those in crisis
- Improve direct access services as many people are not reaching the high threshold for secondary mental health services, and so problems are escalating
- Wellbeing centres and befriending schemes could be used to support people while waiting for a diagnosis or access to more specific care

### Wellbeing

- Address the lack of Tier 4 specialist services and forensic services within the region
- Improve the availability of alternatives to hospital assessment and crisis intervention to manage placement breakdown

- Improve access to specific mental health welfare rights support and increased support for carers and carers need to be involved in Care and Treatment planning
- Work as therapy could be better supported, and this could include “time credits” to engage more difficult clients with peer support and/or mentoring

### Co-production

- Ensure unmet need data is recorded as part of individual assessment processes and is effectively aggregated to inform future planning
- Increase outreach community based activity which builds social networks, confidence and supports integration

### Co-operation, partnership and integration

- Development of a flexible and responsive workforce across health and social care to successfully deliver new models of mental health service
- Lack of good transport links within very rural regions adds to the difficulty of accessible service delivery and recruitment challenges
- Increase the range of community based activity such as the golfing projects recently run by the CMHT in partnership with West Wales Action for Mental Health;
- There are opportunities to base mental health workers at police stations
- Benefit services should be better linked with mental health services because livelihood fears exacerbate mental health issues

## 11.6. References

**Alzheimer's Society (2015). What is young-onset dementia? [online].**

[https://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=164](https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=164)

**Cyhlarová E. (2010). Economic burden of mental illness cannot be tackled without research investment. London: Mental Health Foundation.**

<http://www.bmj.com/rapid-response/2011/11/03/economic-burden-mental-illness-cannot-be-tackled-without-research-investme>

**Daffodil Cymru (2014a). People aged 16 and over predicted to have a mental health problem, by gender, projected to 2035. [Online].**

<http://www.daffodilcymru.org.uk/index.php?pageNo=1071&PHPSESSID=cs35hl8ciis91rom8k1la1gnv6&at=a&sc=1&loc=1&np=1>

**Daffodil Cymru (2014b). People aged 30-64 predicted to have early onset dementia, and people aged 65 and over predicted to have dementia, by age and gender, projected to 2035. [Online].**

<http://www.daffodilcymru.org.uk/index.php?pageNo=1076&PHPSESSID=ki572ehkefsdj86be6qu72n055&at=a&sc=1&loc=1&np=1>

**Daffodil Cymru (2014c). People aged 18 and over receiving residential services, by age, projected to 2035. [Online].**

<http://www.daffodilcymru.org.uk/index.php?pageNo=1079&PHPSESSID=uogbmcgq06au4l6kta41qoouf6&at=a&sc=1&loc=1&np=1>

**Hywel Dda University Health Board (2015) Transforming Mental Health Services.**

<http://www.wales.nhs.uk/sitesplus/862/page/82535>

**Mental Health Foundation (2015). Fundamental Facts about Mental Health. London: Mental Health Foundation.**

<https://www.mentalhealth.org.uk/sites/default/files/fundamental-facts-15.pdf>

**Mental Health Foundation (2016). Mental Health in Wales: Fundamental Facts 2016.**

<https://www.mentalhealth.org.uk/sites/default/files/FF16%20Wales.pdf>

**NHS Informatics Service (2016).**

**Opinion Research Services (2014). Attitudes to mental illness research report.**

[http://www.mind.org.uk/media/1514683/121168\\_attitudes\\_to\\_mental\\_illness\\_2013\\_report.docx](http://www.mind.org.uk/media/1514683/121168_attitudes_to_mental_illness_2013_report.docx)

**Rethink Mental Illness (2016). 20 years too soon.**

**Physical health: the experiences of people affected by mental illness.**

[https://www.rethink.org/media/511826/20\\_Years\\_Too\\_Soon\\_FINAL.pdf](https://www.rethink.org/media/511826/20_Years_Too_Soon_FINAL.pdf)



*Welsh Assembly Government (2008). Talk to Me, Suicide and Self Harm reduction strategy for Wales. Cardiff: Welsh Assembly Government.*

<http://www.wales.nhs.uk/documents/talktomee%5B1%5D.pdf>

*Welsh Government (2012). Together for Mental Health: A Strategy for Mental Health and Wellbeing in Wales.*

<http://gov.wales/docs/dhss/publications/121031tmhfinalen.pdf>

*Wright, S., Forde, E. and Attala, L. (2016). Co-producing Mental Health Services in Hywel Dda University Health Board: A report of engagement with public, staff and stakeholders.*

<http://www.cavo.org.uk/wp-content/uploads/2016/05/Engagement-Evaluation-Report-June2016FINALno-appendices.pdf>



## Section 12

# Older People

**West Wales Population Assessment** March 2017

## 12.1. Overview and Key Messages

The population of West Wales has a higher proportion of older people than the Welsh average, and that already high proportion is predicted to increase significantly in the coming years, as average life expectancy in the region follows the national upwards trend (Office for National Statistics, 2011).

The change in the profile of the population will undoubtedly have an impact on health, as older people are statistically more likely to have a life limiting health condition (Office for National Statistics, 2011) These changes will significantly impact on the health and social care services provided, as demand for hospital and community services by those aged 75 and over is in general more than three times that from those aged between 30 and 40 (Parliamentary Select Committee on Public Service and Demographic Change, 2013) .

A number of 'accelerating factors' add to the challenge of providing effective services to older people in West Wales, from pockets of significant deprivation to large areas of rurality and high levels of migration of older people to certain areas (Henry, 2012)

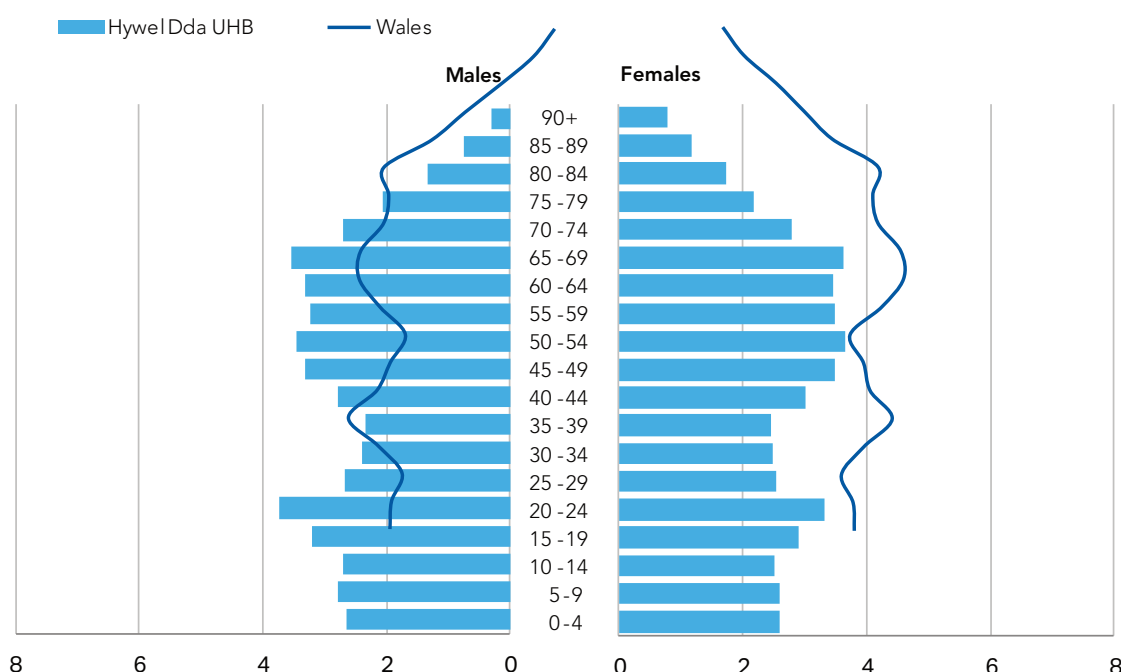
In 2013-14 an estimated £91 million was spent in West Wales on services specifically for older people including Tier 1 – Community, Universal and Prevention Services, Tier 2 - Early Intervention and Reablement and Tier 3 - Specialist and Long Term Services. Across the UK public expenditure related to older people is expected to rise from 20.1% of GDP in 2007-08 to 26.7% in 2057 (Mid and West Wales Health and Social Care Collaborative, 2015). The Office for Budget Responsibility (2011) has noted that;

*"public finances are likely to come under pressure, primarily as a result of an ageing population".*

## 12.2. Demographics and Trends

Demographic data suggests three key factors in relation to older people in West Wales:

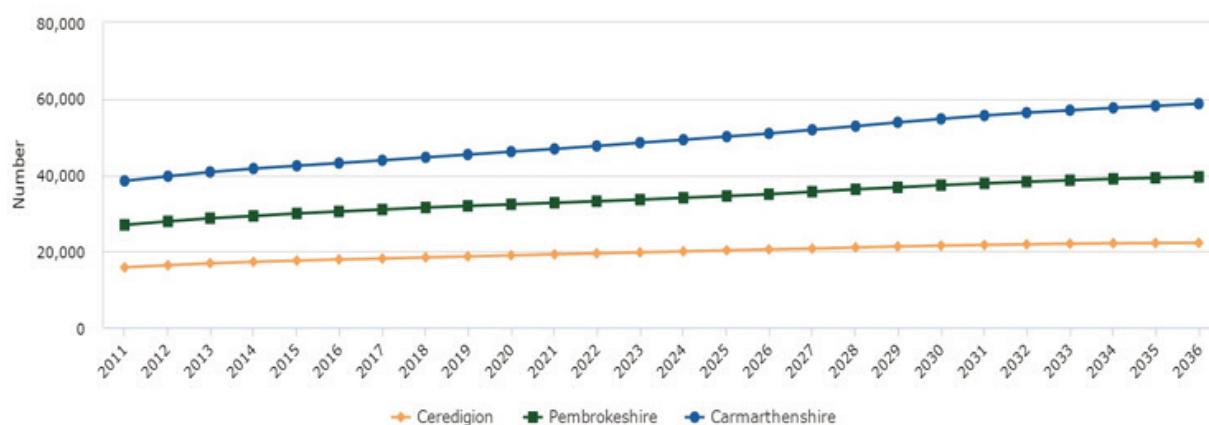
**1) There are increasing numbers of older people across Carmarthenshire, Ceredigion and Pembrokeshire**

**Figure 12:1 Population by age and sex and aged over 65 by LA**

Source: Hywel Dda University Health Board

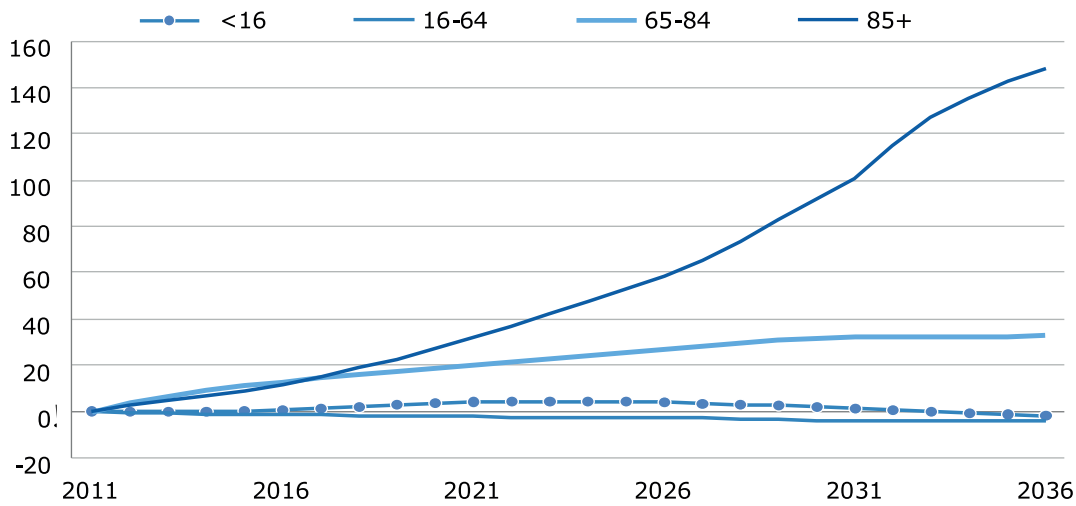
Current projections on Daffodil Cymru (2014a) suggest that the total population of people aged over 65 living in West Wales will rise from 89,780 in 2015 to 119,510 by 2035. This represents an approximate 60% increase.

In addition there has been, and will continue to be, a significant increase in the people aged over 85 in this area with the greatest predicted increase in population growth represented in the over 85 age group. An increase of 122% in West Wales overall by 2035, with a 116% increase predicted in Carmarthenshire, 125% in Ceredigion and 129% in Pembrokeshire.

**Figure 12:2 Projected number of people aged 65+**

Source: Welsh Government

Figure 12:3 Population projections by age



Source: Hywel Dda University Health Board

Over the same period there is expected to be a marked decline in the working age population. By 2033 the proportion of the population between 0-14 years in West Wales will reduce to 15% and 15 –24 year olds will also reduce to 11%. Older people in this region currently represent a higher percentage of the population with 21.3% of the area being 65 or over compared with 18.6% in Wales a whole. This raises into question capacity and resources to care and support the older age group. (Nuffield Trust, 2014).

With large parts of Carmarthenshire, Ceredigion and Pembrokeshire being both rural and coastal, the region attracts high levels of inward migration of people over 65. People from elsewhere in the UK already account for almost 22% of the population of Wales, with the vast majority of the new arrivals retiring from England (Bingham, 2014). The highest levels are found in Pembrokeshire with a 31% migration rate with 87% of these being over 65. Ceredigion has the largest percentage of residents with a second home in the whole of the UK. Whilst this may be explained in part by the large student population, census data shows that 325 people over 65 in Ceredigion have second addresses outside the county. Of equal importance; data indicates that 1,182 pensioners have second homes in Ceredigion; these individuals have not moved permanently into the area but still spend a significant amount of time there, during which periods they might access health and social care services.

2) Older adults in the West Wales area have increasingly complex needs

Healthy and disability-free life expectancy is rising more slowly than life expectancy. People are living longer but with increased levels of illness and disability. Males in West Wales have a life expectancy of 77.4, with disability free life estimated at 59.4 and healthy life at 64. The equivalent figures for females are 82, 61.2 and 65.7 respectively (Public Health Wales, 2016).

Limiting long-term conditions and disability are generally more prevalent amongst the older age group, with 55% of the over 65 population in the three LA areas reporting having a long-term illness or disability (Hywel Dda University Health Board, 2016a). The number of people over 65 with limiting long term illness has been steadily increasing and predictions suggest that this will continue to varying degrees across all LA areas, with the highest increase predicted in Carmarthenshire.

Frailty is a complex concept as it not an illness but a distinctive state of health, related to the ageing process, in which multiple body systems gradually lose their in-built reserves. We have no specific data on the prevalence of frailty in the West Wales region but national research shows that around 10% of people aged over 65 years have frailty (Clegg, 2013). It is estimated that one in four people aged 85 and over is living with frailty. This typically means that a person is at a higher risk of a sudden deterioration in their physical and mental health, can be expected to have longer stays in hospital, experience increased rates of re-admission and is more likely to be discharged to residential care (British Geriatrics Society, 2014).

The risk of being admitted to hospital also increases with age; whilst 21% of the current West Wales population is over 65, 55% of all emergency admissions are of those who are over 65, with 78% of emergency admission beds taken up by people who are over 65, which equates to 57% of all bed days (Hywel Dda University Health Board, 2016a). There is an also a significantly increased likelihood of a person over 65 with a chronic condition receiving inpatient care.

As people age they are more likely to need help with self-care, domestic tasks and have reduced mobility. Evidence in the three LA areas supports this, with data trends predicting an increasing need to support older people with the activities of daily living.

The prevalence of dementia is also associated with aging and the condition is one of the major causes of disability in later life. Above the age of 65 the risk of developing dementia doubles roughly every 5 years, with estimates that dementia affects 1 in 14 people over 65 and 1 in 6 over 80. Recent projections show a rapid increase in dementia across all LA areas with some of the more rural areas, including North Carmarthenshire and Pembrokeshire, seeing the highest rises of up to 44% by 2035 (Roberts and Charlesworth, 2014; Public Health Wales Observatory, 2013). People with dementia stay far longer in hospital than other people who come in for the same procedure; at least 40–50% of bed days relating to emergency admission in West Wales will relate to people who have dementia as part of their multi-morbidity (Hywel Dda University Health Board, 2016). It has been estimated that Hywel Dda has the lowest rates of dementia diagnosis in Wales at 37.2% (Alzheimer's Society, 2015).

It appears that residents in West Wales have increasingly complex needs associated with dementia and associated lack of capacity; Hywel Dda University Health Board made the greatest number of applications for Deprivation of Liberty Safeguards in 2013-14, with Carmarthenshire LA having the highest number of applications in Wales (Care and Social Services Inspectorate Wales, 2015). Whilst this may reflect improved processes and systems, it may also suggest a heightened level of need particular to this area, with dementia not being diagnosed but still recognised in a residential setting.

Falls are a common and serious problem for older adults and it has been reported that more than 50% of people over the age of 85 fall at least once a year (Age UK, 2013). Daffodil Cymru data suggests that the number of hospital admissions because of a fall predicted to increase in the area by almost 70% by 2035.

A significant percentage of older people in West Wales provide unpaid care to support family or friends with the greatest predicted increase in those over 85 providing more than 50 hours of unpaid care of 122% by 2035. (Daffodil Cymru, 2014b).

### **3) A range of 'accelerating factors' are likely to exacerbate the needs of some older adults**

The West Wales region is the second most sparsely populated in Wales. Research into ageing in rural communities has described a set of compounding factors which result in 'multiple disadvantage' (Hartwell et al, 2007) as rurality impacts on many factors including housing, deprivation, access to services and, vitally, levels of physical and social isolation. Evidence indicates that rural areas are also ageing faster, the projected increase of the 65+ age group by 2021 in rural areas is 29% compared to 20% in urban ones (International Longevity Centre, 2013).

In nearly all instances, people living in the more deprived areas experience worse health than those in more affluent ones. Deprivation has an impact on older adults especially in relation to healthy and disability free life expectancy. There are a number of areas of high deprivation in the region, with the largest concentration around Llanelli in the east of Carmarthenshire. Data shows that people living in the least deprived areas of Carmarthenshire can expect to live healthily for nearly 14 years longer than those in the most deprived ones (Public Health Wales, 2011).

The West Wales region reports the second largest instance of excess winter deaths in the over 65s in Wales (Hywel Dda University Health Board, 2016a). There is a strong relationship between poor insulation and heating of houses, low indoor temperature and excess winter deaths of older people (Marmot Review Team, 2013). With respiratory disease being the major cause of seasonal mortality (Office of National Statistics, 2015) and the proved causality between damp housing and asthma (Basham, 2002), levels of



fuel poverty and heating may be adversely impacting on this group. Census data suggest that the older the occupant, the less likely they are to have central heating. Data on Daffodil Cymru suggests that 3.3% of households in the area do not have central heating with Ceredigion being the highest at 5.4%; this is in stark comparison to the Welsh average of 1.9%. Large parts of the region are also in Fuel Poverty, with some areas having a rate of 17% or higher of fuel poverty compared to the 14% Welsh average.

Evidence suggests that older people are particularly vulnerable to loneliness and social isolation (NHS, 2015). Whilst living alone in itself does not equate to loneliness, research shows that those who do live alone are more likely to be lonely (De Jong et al, 2011). In West Wales there are currently 40,496 people 65+ living alone, which represents 45% of this group, with the likelihood of living alone increasing with age (Daffodil, 2014c). It is predicted that between 2008 and 2033 there will be a 44% increase in the number of 65–74-year-olds living alone, a 38% increase in those aged 75–85 and a 145% increase in those aged 84+ (Department for Communities and Local Government, 2010). Levels of loneliness and isolation could be further compounded by other factors, such as high levels of rurality and lack of access to transport. The most recent evidence in this area indicates that 14% of people aged 65 and over felt they were unable to manage walking down the road without assistance (The Young Foundation, 2006).

The Quality of Life Indicators for Older People (Public Health Wales Observatory, 2012) published by Public Health Wales show that accelerating factors for this group vary across the different LA areas; with those in Carmarthenshire presenting higher instances of poor health and disability, with Pembrokeshire having higher levels of obesity compared with the Welsh average.

### 12.3. Current and Future Care and Support Needs

Whilst it is not possible to equate population changes precisely with need for increased care and support (Bolton, 2016), the predicted care and support needs of older people are summarised below. A holistic approach which supports resilience and independence needs to underpin all levels of care and support. This will provide integrated, coordinated and person-centred care, appropriate rapid and effective support at times of crisis, high quality acute care and choice, and control and support towards the end of life. In identifying care and support needs, reference has been made to relevant data and research as well as expressed views of older people. A range of quantitative data has been obtained from the wellbeing survey undertaken on behalf of the three Public Service Boards in the summer of 2016, early responses to the initial wellbeing questionnaires distributed to service users by local authorities and from 'what matters to you?' conversations which form an integral part of individual integrated assessments. Local 'Ageing Well' consultation data and material emerging from engagement with fora such as 50 + groups in each LA area and the Carmarthenshire Dementia Action Board, have also been taken into account.

Care and support needs of older people generally will include:

### **Support to maintain health and wellbeing**

The World Health Organization (WHO) estimates that more than half of the burden of disease among people over 60 is potentially avoidable through changes to lifestyle (Oliver et al, 2014). These can be broadly defined as preventative community services which promote engagement, healthy behaviours/eating and physical activity. Evidence shows that many age-related conditions, including frailty, can be prevented or delayed by helping maintain individuals' resilience (Pacala, 2013). Work commissioned by the Social Services Improvement Agency (SSIA) suggests that targeted support in the areas of information, relationships, psychological resources, finance, physical health, home, community and work and learning is most effective in achieving this (Blood et al, 2015).

### **Effective information, advice and assistance services**

This is a key theme within the SSWB Act 2014 and services, including advocacy, are of particular value for older people in helping them access services, make informed decisions, exercise choice and participate in their community. Research by Age UK suggested that generic information, advice and assistance services need to be tailored to fit older people's needs which are likely to include social contact and care, finance and housing, health and practical support. (Age UK, n.d). Targeted IAA services might be appropriate for those people aged 65 and over that retire to the region.

In a recent poll the single most important thing to people over 60 planning to move was access to the countryside. More than 80% of those polled put the countryside ahead of social life or access to healthcare. It also suggested that people do not consider their potential care needs as most people indicated "don't know" when asked about the provision of care and support in the area they were planning to retire to (McVeigh, 2009).

### **Suitability of living accommodation**

It has been estimated that older people spend 70-90 % of their time at home, which means that an environment that is conducive to supporting wellbeing is crucial (ODMP, 2006 cited in Careter and Hillcoat-Nallétamby, 2015: 3). The housing environments in which we age plays a determining role in ensuring that people maintain autonomy and independence and remain engaged in their local communities (Institute of Public Care, 2012).

### **Age-friendly communities**

An age-friendly community can be simply defined as one where local people have decided their priorities to better support people as they age. This can include physical design, promoting better access and mobility, promoting people's social engagement and developing support and relationships between the generations. The most

important aspect is that it is an integrated approach to thinking about the places where people live and how best to promote older people's wellbeing and engagement with their physical and social environments.

### **Maintaining connection and community contribution**

Ageing Well in Wales defines loneliness and isolation as cross-cutting issues that seriously impact on the health and wellbeing of older people in Wales (Ageing Well in Wales, 2015: no pagination). Research shows that loneliness and social isolation are harmful to health: lacking social connections is a comparable risk factor for early death as smoking 15 cigarettes a day, and is more detrimental to health outcomes than well-known risk factors such as obesity and physical inactivity.

### **Effective access to treatment for 'minor' needs that may compromise independence**

Many older people experience needs that tend to be characterised as 'minor', but which can significantly affect their independence and wellbeing if not supported effectively. These can include mobility problems, foot health, chronic pain, sensory impairment, incontinence, malnutrition and oral health. Proactive, early identification of such problems, using structured assessment tools coupled with tailored interventions, can have significant benefits for older people's wellbeing and independence. (Melis et al, 2008).

Older people with more complex needs are likely to require a range of care and support, which will include:

### **Effective management of frailty**

based on a population-led approach that prevents or delays the onset of the condition through early identification and anticipatory care management across the primary and community sectors, integrated assessment and care planning, measures to avoid inappropriate hospital admission and targeted falls prevention programmes. Evidence shows these can reduce the incidence of falls by between 15 and 30%.

### **Holistic support for dementia and cognitive impairment**

including improved rates of diagnosis, quality support in a range of settings and the development of dementia-friendly communities.

### **Appropriate and efficient intermediate care services**

including rapid response care and support, therapeutic rehabilitation, reablement, step-up/ step-down placements and supported discharge schemes, in which the third sector can play a major role.

### **Person-centred, dignified long-term care which optimises independence**

which requires outcomes-focused assessment and care management and domiciliary care, appropriate residential provision based on an enablement approach, effective

assistive technology, telecare and telehealth, effective adaptations and effective advanced planning which includes choice and control for end of life care.

### **Effective support structures for older Carers**

to ensure that they maintain wellbeing and are able to continue their support for the relative for whom they are caring for as long as possible.

### **Integrated mental health services**

Evidence suggests that in the UK depression affects 22% of men and 28% of women aged 65 and over, with another study estimating that depression affects 40% of older people in care homes (Age UK, 2016).

For those older people experiencing any or all of the 'accelerating' factors identified in the previous section, support needs will include:

### **Measures to reduce isolation**

through effective public transport and generally improved access to health and social care provided on a locality basis. Evidently the appropriate model of support for older adults in a deprived urban ward of Llanelli will be different from those of a coastal area such as Aberporth or rural hamlet such as St Dogmaels. The Kings Fund recommends the establishment of place-based 'systems of care' in which health and social care collaborate to address the challenges and improve the health of the populations they serve (Ham and Aldewick, 2015). Availability of broadband can also play a role in reducing the effects of social exclusion in later life (Age UK, 2013).

### **Support that addresses specific needs of older people living in areas of deprivation**

through benefit and income maximisation, employment opportunities for those wanting to work and increased public health activity to reduce limiting factors such as smoking and obesity.

### **Prevention activity targeting excess winter deaths**

through anticipatory care, public awareness and tackling fuel poverty.

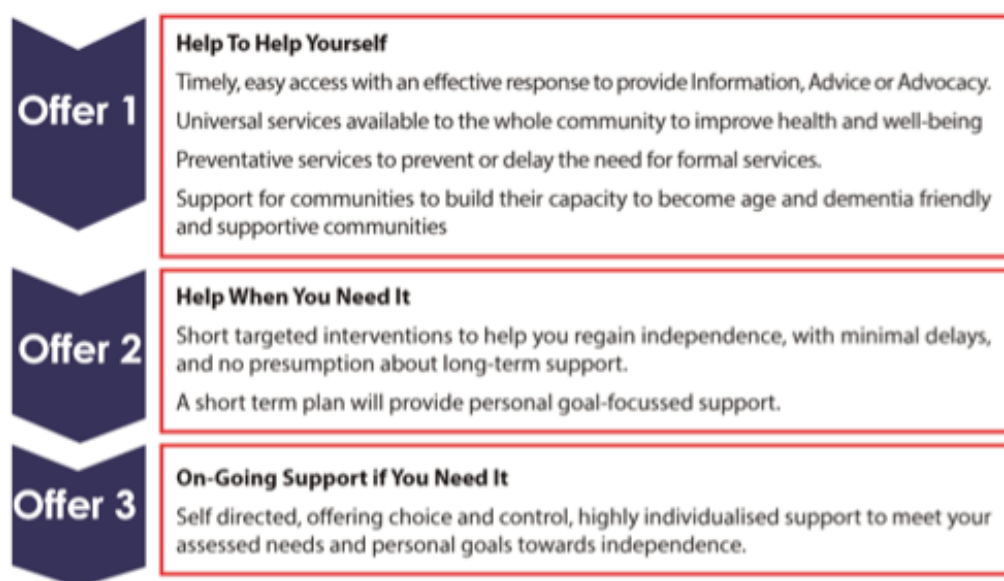
## **12.4. Current Care and Support Provision**

All partners in the region are moving towards a consistent model of care for older people based on the principles of wellbeing and prevention encapsulated in the SSWB Act and informed locally by a range of plans and strategies including Ageing Well plans, the Health Board's Integrated Medium Term Plan, Carmarthenshire County Council's 'Vision for Sustainable Social Services for Older People 2015-25 and the regional Statement of Intent for the Integration of Services for Older People with Complex Needs in West Wales (2014).

Delivery across the region varies in detail but in each county area it is based around three levels of service each of which aim to meet person-centred outcomes, as shown in the following figure.

These three levels can be described as 'offers' to individuals according to their need and circumstance and are as follows:

**Figure 12:4 Three Levels Of Service**



Source: Carmarthenshire County Council

More detail of each offer is provided below:

### **Offer 1: Help to help yourself**

These are services which build resilience of individuals and communities, aimed at helping people help themselves and prevent the need for ongoing care. Roles such as community connectors and community resilience development officers have been introduced to build third sector capacity and improve sign-posting of individuals. Locally funded community-based projects such as Solva in Pembrokeshire and Llandysul in Ceredigion aim to provide holistic, community-based support that promote and sustain independence.

Provision includes:

- Information, Advice and Assistance which help people achieve their outcomes by directing them to support available within the community. This should be targeted when appropriate to support people experiencing one or more 'accelerating factors' as described earlier in the report
- Advocacy to help people articulate needs and access appropriate care and support
- Community-based home to hospital provision which facilitates effective hospital discharge, prevents readmission and inappropriate admission
- Third sector services promoting independence, social engagement and inclusion
- Time banking, social prescription and volunteering
- Primary and community care initiatives funded through the cluster development programme

Data from the regional Market Position Statement for older people’s services in West Wales (Mid and West Wales Health and Social Care Collaborative, 2015) suggests that spend on these services represents between 3% and 11% of total older people’s budgets.

Case Study

**Remodelling and Co-designing Services in Llandysul, Ceredigion**

Ceredigion has taken an innovative approach to developing services for older adults and working with communities to remodel services. A small cross organisational group made up of representation from HDUHB, Ceredigion County Council and Ceredigion Association of Voluntary Organisations has been established to deliver a place based system of care within a town in Ceredigion and scope opportunities for Alternative Delivery Models for public services. The project aims to understand the opportunities and challenges associated with alternative delivery models and explores various forms of service delivery such as social enterprises, cooperatives and user led services. The dialogue includes:

- Sessions for officers from LA, UHB, CAVO with the aim of raising awareness of the principles of Alternative Delivery Models, including Community Asset Transfer, social enterprise, cooperatives
- Sessions for elected members to understand Alternative Delivery Models and the opportunities for the key partners
- Sessions with community groups and individuals to discuss the support and options available

Case Study

**Pembrokeshire Intermediate Voluntary Organisations Team (PIVOT)**

The PIVOT Project was established as a third sector collaborative in Pembrokeshire to facilitate hospital discharge, support those who are at risk of admission to hospital for non-medical reasons and reduce support required from statutory agencies. The project is coordinated by Pembrokeshire Association of Voluntary Services and includes, British Red Cross, Pembrokeshire Care & Repair and Pembrokeshire Association of Community Transport Organisations. The PIVOT partners have many years of experience providing support that builds confidence and self-esteem to enable people to live independently within their own homes. PIVOT provides home-based low level support for up to six weeks for people who would benefit from low level prevention and reablement support in the community.

## Offer 2: Help when you need it

Here care and support is designed to support people to regain their previous level of independence after an illness or injury, which include reablement and rehabilitation at home. Examples include:

- Rapid access domiciliary care provision
- Acute response teams to facilitate rapid nursing needs in the community
- Equipment provision, telecare and telehealth and home adaptations
- Housing related support to maintain independence at home
- Support for carers
- Residential reablement placement in care homes and rehabilitation facilities in community hospitals
- Anticipatory care processes such as multi-disciplinary meetings and proactive care-planning
- Targeted projects funded by the Intermediate Care Fund to build effectiveness in intermediate care, such as TOCALs – a frailty discharge service aimed at facilitating effective and appropriate discharge from hospital

The WG's Intermediate Care Fund has provided resources to develop new, integrated approaches to care and ensure a level of consistency across the region in relation to key aspects of care and support.

Analysis shows that this tier accounts for the second largest proportion of the overall budget in the region at between 4 to 13% (Fig 32). This however does not consider the significant investment of ICF funds which amounted to £8.4 million in 2014-15, some of which supported projects aimed at improving intermediate care and reducing reliance on acute services.

### Case Study

#### Multi-disciplinary Teams (MDTs) and Stay Well Plans in Carmarthenshire

Effective anticipatory care of frail older adults was identified as a priority in the 2Ts GP cluster of Carmarthenshire. In partnership with integrated health and social care teams an MDT approach was embedded to manage frail patients more effectively and pro-actively in their own home will enhance their experience of care, improve their outcomes and reduce acute care costs and bed days. As part of the project, practices nominated a clinical frailty lead and to identify frail patients utilising a practice based IT Risk Stratification System. The MSDi (software) tool is then used to risk stratify patients. Patients identified receive a written Stay Well Plan which includes details of a carer, health and social care summary, optimisation and maintenance plan, and escalation and urgent care plan.



The project also identifies optimising Multi-disciplinary Teams (MDT) working through the adoption of the MDT best practice guidance and the appointment of a generic Occupational Therapy/Physiotherapy (OT/PT) technician who attends all MDT meetings and accepts referrals to undertake low levels assessments.

### Offer 3: Ongoing support

The third level of support includes services for people whose conditions or circumstances mean that they need longer-term specialist or substitute care or support. The route into this level of care and support is usually through an integrated assessment and multi-disciplinary professional support; a care and support plan is based on the question 'what matters to you' and an outcome plan delivered accordingly.

Services include:

- Domiciliary care support, direct payments and residential placements in care homes for assessment, respite or on long-term basis
- Social support and day opportunities are provided through accessing community based services, direct payments or day centre provision
- Health led services include community nursing and hospital services, continuing healthcare and end-of life care. Over 60% of the £37,602,320 spent in 2014-2015 on continuing healthcare in HDUHB was spent on older adults, which included both domiciliary and residential nursing care (Hywel Dda University Health Board, 2016b)
- Residential and nursing care. Across the region, several residential options are available which range from extra care to EMI nursing. Approximately 668 residential care beds are registered for older people with dementia and 645 EMI nursing home beds, with 1,257 residential placements and 673 nursing ones; as well as currently having 254 units of extra care accommodation across the region
- A significant proportion of older people who live in a residential setting in West Wales currently fund their own placement but may need financial support at a later date. The Local Government Information Unit (LGIU) estimated that an average of 41% of people entering residential care each year self-fund, and of those, 25% will run out of money during their stay. Estimating the precise numbers of self-funders in the area is difficult, however a market survey of care home providers in each county suggests that Carmarthenshire and Pembrokeshire have a similar rate of self-funders (34% and 33%) while Ceredigion has a lower number (23%). Another calculation which estimates numbers of self-funders, and considers the number of beds funded by NHS continuing health care provided similar results for Ceredigion at 21.5%, but higher for Carmarthenshire (43%) and Pembrokeshire (41%). (Mid and West Wales Health and Social Care Collaborative, 2015)
- Safeguarding services to protect against abuse and neglect.
- Comprehensive telecare support



- Management of specific conditions through community nursing which includes; clinics and district nursing services

Providing services to those with ongoing need overwhelmingly represents the largest part of the budget in region.

## 12.5. Gaps and Areas for Improvement

Current provision as set out in the previous section provides a valuable foundation for further development to ensure that rising levels of need across the region are effectively met. A number of areas need further development if the requirements of the Act, including wellbeing outcomes for older people and the aspirations of existing strategies are to be fully addressed. These are set out below against the core principles of the SSWB Act.

### Voice and control

- Ensuring effective community based advocacy services for older adults is available and accessible across the region
- Improving the level of services available through the medium of Welsh

### Prevention and early intervention

- Reducing the reliance on residential and nursing care in favour of lower level, preventative and wellbeing services
- Mainstreaming integrated approaches across primary, community and social care, adopting local successful practice across the region where positive impact is evidenced and further aligning ICF and cluster development programmes
- Increasing the level and range of low level support services such as befriending, shopping and lunch clubs are not able to recruit volunteers in some areas – where there are specific befriending services demand greatly outweighs capacity
- Building good-neighbour schemes to promote community connection and resilience
- Improving availability of rapid response services for older people who have short term need
- Improving the level and quality of rehabilitation across the region
- Attaining improved and standardised levels of telehealth and telecare across the region
- Achieving a consistent approach to frailty; the recent adoption by Hywel Dda University Health Board of a frailty strategy (Hywel Dda University Health Board, 2016c) is an important first step; the objectives within the strategy need to be taken forward in an integrated way with all partners working in collaboration

### Wellbeing

- Improving community transport to enable older people to access care and support at the appropriate level; feedback from communities consistently cite effective transport as a barrier accessing services and provision

- Joined up service provision to support mental wellbeing and address depression
- Ensuring services (including primary care, domiciliary care, residential care and reablement) and communities are 'dementia friendly'
- Improving dementia diagnosis rates
- Ensuring appropriate levels of residential and nursing care are available in all parts of the region

### **Co-production**

- Involving older people more in the design and delivery of services that affect them
- Maintaining a dialogue with older people in relation to personal responsibility for maintaining wellbeing and care and support available

### **Cooperation, partnership and integration**

- Working in partnership across commissioners and providers to articulate and promote a consistent service model
- Improving anticipatory care across the health, social care and other sectors to avoid escalation of need
- Building on local pilots for integration of health and social care roles, in keeping with national guidance on third party delegation, to ensure responsiveness of services and sustain independence for older people
- Developing integrated commissioning to achieve market sustainability across the region in residential and domiciliary care
- Growing an integrated approach to quality assurance and contract monitoring of care homes to identify and address emerging concerns and prevent placement breakdown

The role of the RPB will be vital in sustaining this drive for improvement, using the Area Plan and funding such as the Integrated Care Fund to achieve the paradigm shift still needed. A partnership approach will be needed in tackling key challenges such as development of new services in an environment of financial austerity, setting clear and shared outcome targets to measure progress and impact of transformation, achieving market sustainability across levels of care and support, and ensuring an appropriately qualified and skilled workforce is in place to deliver the changes still needed.

## 12.6. References

*Age UK (n.d.). Information and Advice for Older People: Evidence Review. London: Age UK.*

[http://www.ageuk.org.uk/Documents/EN-GB/For\\_professionals/Research/IA\\_for\\_Older\\_People\\_Evidence\\_Review\\_update.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/For_professionals/Research/IA_for_Older_People_Evidence_Review_update.pdf?dtrk=true)

*Age UK. (2013a). Later Life in the United Kingdom: A metadata Analysis. [online].*

[http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later\\_Life\\_UK\\_factsheet.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true)

*Age UK (2013b). The Challenges of Rural Living For Older People.*

<http://www.ageuk.org.uk/latest-press/archive/the-challenges-of-rural-living-for-older-people/>

*Age UK (2016). Later Life in the United Kingdom.*

[http://www.ageuk.org.uk/Documents/ENGB/Factsheets/Later\\_Life\\_UK\\_factsheet.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/ENGB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true)

*Ageing Well in Wales (2015). Loneliness & Isolation [online].*

<http://www.ageingwellinwales.com/en/themes/loneliness-and-isolation>

*Alzheimer's Society. (n.d.). Risk Factors and Prevention [online].*

[https://www.alzheimers.org.uk/info/20010/risk\\_factors\\_and\\_prevention](https://www.alzheimers.org.uk/info/20010/risk_factors_and_prevention)

*Alzheimer's Society (2015). Wales Dementia Diagnosis:*

*Progress on improving diagnosis of dementia 2014-2015.*

<https://www.alzheimers.org.uk/site/scripts/download.php?type=downloads&fileID=2797>

*Basham, M. (2002). Qualitative Study of Central Heating – its influence on the use of the house, the behaviour and relationships of the household particularly in wintertime.*

[http://www2.warwick.ac.uk/fac/cross\\_fac/healthatwarwick/research/devgroups/healthyhousing/healthhousing\\_papers/bashampaper2](http://www2.warwick.ac.uk/fac/cross_fac/healthatwarwick/research/devgroups/healthyhousing/healthhousing_papers/bashampaper2)

*Bingham, J. (2014). "Welsh could become a minority in Wales as English set sights west". The Telegraph [online].*

<http://www.telegraph.co.uk/news/uknews/wales/10878554/Welsh-could-become-a-minority-in-Wales-as-English-set-sights-west.html>

*Blood, I., Copeman, I. and Pannel, J. (2015). The anatomy of resilience: helps and hindrances as we age. A review of the literature.*

*Social Services Improvement Agency.*

<http://www.ssiacymru.org.uk/resource/150721-ssia-older-people-barriers-evidence-review--final.pdf>

*Bolton, J. (2016). Predicting and managing demand in social care, discussion paper. Institute of Public Care.*

[https://ipc.brookes.ac.uk/docs/John\\_Bolton\\_Predicting\\_and\\_managing\\_demand\\_in\\_social\\_care-IPC\\_discussion\\_paper\\_April\\_2016.pdf](https://ipc.brookes.ac.uk/docs/John_Bolton_Predicting_and_managing_demand_in_social_care-IPC_discussion_paper_April_2016.pdf)

*British Geriatrics Society (2014). Fit for Frailty: Consensus best practice guidance for the care of older people living with frailty in community and outpatient settings.*

[http://www.bgs.org.uk/campaigns/fff/fff\\_full.pdf](http://www.bgs.org.uk/campaigns/fff/fff_full.pdf)

*Care and Social Services Inspectorate Wales (2015).*

*Deprivation of Liberty Safeguards Annual Monitoring Report for Health and Social Care 2013-14.*

*Carmarthenshire County Council. (2015). Carmarthenshire's Vision for Sustainable Social Services for Older People for the Next Decade: Promoting Independence, Keeping Safe, Improving Health and Well-Being.*

<http://www.carmarthenshire.gov.wales/media/1223819/older-people-vision.pdf>

*Carter, L. and Hillcoat-Nallétamby, S. (2015). Housing for Older People in Wales: An Evidence Review. Public Policy Institute for Wales.*

[http://www.housinglin.org.uk/\\_library/Resources/Housing/OtherOrganisation/Report\\_Housing\\_for\\_Older\\_People\\_in\\_Wales\\_Evidence\\_Review\\_FINAL.pdf](http://www.housinglin.org.uk/_library/Resources/Housing/OtherOrganisation/Report_Housing_for_Older_People_in_Wales_Evidence_Review_FINAL.pdf)

*Clegg, A. (2013). Frailty in elderly people. The Lancet, 381 (9868), pp. 752 – 762.*

[http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(12\)62167-9.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(12)62167-9.pdf)

*Daffodil Cymru (2014a). Population by age: Population aged 18 and over, by age, projected to 2035 [online].*

<http://www.daffodilcymru.org.uk/index.php?pageNo=1033&PHPSESSID=3apr2dq1eakid51thdthtkbej5&at=a&sc=1&loc=5&np=1>

*Daffodil Cymru (2014b) Provision of unpaid care: People aged 16 and over predicted to provide unpaid care, by age and hours of care provided, projected to 2035 [online].*

<http://www.daffodilcymru.org.uk/index.php?pageNo=1043&arealD=17&loc=17>

*Daffodil Cymru (2014c). Living alone: people aged 16 and over predicted to be living alone, by age and gender, projected to 2035 [online].*

<http://www.daffodilcymru.org.uk/index.php?pageNo=1039&arealD=18&loc=18>

*De Jong Gierveld, J., Fokkema, C.M. & Van Tilburg, T.G. (2011).*

*Alleviating Loneliness Among Older Adults: Possibilities and Constraints of Interventions. In Safeguarding the Convoy; A Call to Action from the Campaign to End Loneliness, pp 40-45. Oxon: Age UK Oxfordshire*

*Department for Communities and Local Government (2010).*

*Household Projections, 2008 to 2033, England.*

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/6395/1780763.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/6395/1780763.pdf)

Ham, C. and Aldewick, H. (2015). *Place-based systems of care: A way forward for the NHS in England*. The King's Fund [online].  
[https://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/Place-based-systems-of-care-Kings-Fund-Nov-2015\\_0.pdf](https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Place-based-systems-of-care-Kings-Fund-Nov-2015_0.pdf)

Hartwell, S., Kitchen, L., Milbourne, P. and Morgan, S. (2007). *Population change in Rural Wales: Social and Cultural Impacts, Research Report, vol. 14*. Wales Rural Observatory.  
<http://www.walesruralobservatory.org.uk/sites/default/files/14.%20Population%20Change%20in%20Rural%20Wales%20-%20Social%20and%20Cultural%20Impacts.pdf>

Henry, G. (2012). "Retirees moving from England push up the average age of Wales - putting pressure on services". Wales Online.  
<http://www.walesonline.co.uk/news/wales-news/retirees-moving-england-push-up-2036624>

Hywel Dda University Health Board (2016). *Health Needs Assessment Report 2016*.  
<http://www.wales.nhs.uk/sitesplus/862/page/85702>

Hywel Dda University Health Board (2016b). *Integrated Medium Term Plan 2015-18 Our Health: Our Future (1st draft submission)*.  
<http://www.wales.nhs.uk/sitesplus/862/page/79042>

Hywel Dda University Health Board (2016c). *Frailty: The importance, Progress and Framework for Delivery*

Institute of Public Care (2012). *Health, Wellbeing, and the Older People Housing Agenda*. Oxford: Oxford Brookes University.  
[http://ipc.brookes.ac.uk/publications/pdf/HWB\\_and\\_the\\_Older\\_People\\_Housing\\_Agenda.pdf](http://ipc.brookes.ac.uk/publications/pdf/HWB_and_the_Older_People_Housing_Agenda.pdf)

International Longevity Centre (2013). *Ageing, Longevity and Demographic Change*.  
[http://www.ilcuk.org.uk/images/uploads/publication-pdfs/ILC-UK\\_Factpack.pdf](http://www.ilcuk.org.uk/images/uploads/publication-pdfs/ILC-UK_Factpack.pdf)

Marmot Review Team (2013). *The Health Impacts of Cold Homes and Fuel Poverty*. London: Friends of the Earth.  
<http://www.instituteofhealthequity.org/projects/the-health-impacts-of-cold-homes-and-fuel-poverty>

Melis, R., Adang, E., Teerenstra, S., van Eijken, M., Wimo, A., van Achterberg, T., van de Lisdonk, E. and Olde Rikkert, M. (2008). "Cost-effectiveness of a multidisciplinary intervention model for community-dwelling frail older people". *Journals of Gerontology: Medical Sciences*, 63 (3), pp. 275 – 282

**McVeigh, T. (2009). "How Britain is coming to terms with growing old". *The Guardian* [online].**

<https://www.theguardian.com/uk/2009/may/17/ageing-population-retirement-saga-housing>

**Mid and West Wales Health and Social Care Regional Collaborative (2015). *Market Position Statement - Services for Older People*.**

<http://www.wwcp.org.uk/documents/>

**NHS (2015). *Loneliness in older people, Live Well Series*.**

<http://www.nhs.uk/Livewell/women60-plus/Pages/Loneliness-in-older-people.aspx>

**Nuffield Trust. (2014). *A Decade of Austerity in Wales? The Funding Pressures Facing the NHS in Wales to 2025/26*.**

<https://www.nuffieldtrust.org.uk/files/2017-01/decade-austerity-wales-web-final.pdf>

**Office for Budget Responsibility (2011). *Fiscal Sustainability Report*. London: TSO.**

<http://budgetresponsibility.independent.gov.uk/wordpress/docs/FSR2011.pdf>

**Office for National Statistics (2011.) *2011 Census data*. [Online].**

<http://web.ons.gov.uk/ons/data/web/explorer>

**Office for National Statistics (2011).**

***National Population Projections 2010 Based Statistical Bulletin*.**

<http://webarchive.nationalarchives.gov.uk/20160105160709/http://ons.gov.uk/ons/rel/npp/national-population-projections/2010-based-projections/index.html>

**Office for National Statistics (2015).**

***Excess Winter Mortality in England and Wales: 2014/15 (Provisional) and 2013/14 (Final)*.**

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/excesswintermortalityinenglandandwales/201415provisionaland201314final>

**Oliver, D., Foot, C., Humphries, R. (2014).**

***Making our Health and Care Systems Fit For an Ageing Population*.**

[https://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/making-healthcare-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf](https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/making-healthcare-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf)

**Pacala, J. T (2013). *Prevention of Frailty* [online].**

<https://www.msmanuals.com/en-gb/professional/geriatrics/prevention-of-disease-and-disability-in-the-elderly/prevention-of-frailty>

**Parliamentary Select Committee on Public Service and Demographic Change (2013). *Ready for ageing? Annex 9 – Increasing demand for health and social care*.**

<http://www.publications.parliament.uk/pa/ld201213/ldselect/ldpublic/140/14012.htm>

***Public Health Wales (2016): Measuring Inequalities:  
Trends in Mortality and Life Expectancy in Hywel Dda UHB.***

[http://www2.nphs.wales.nhs.uk:8080/PubHObservatoryProjDocs.nsf/3653c00e7bb6259d80256f27004900db/eace59365015b70380257ff8002b1966/\\$FILE/MeasuringInequalities2016\\_HywelDdaUHB\\_v1.docx](http://www2.nphs.wales.nhs.uk:8080/PubHObservatoryProjDocs.nsf/3653c00e7bb6259d80256f27004900db/eace59365015b70380257ff8002b1966/$FILE/MeasuringInequalities2016_HywelDdaUHB_v1.docx)

***Public Health Wales (2011). Large differences in healthy life expectancy within Carmarthenshire, Pembrokeshire and Ceredigion found [online].***

<http://www.wales.nhs.uk/sitesplus/888/page/58464>

***Public Health Wales Observatory (2012). Quality of life indicators (WHS).***

<http://www.wales.nhs.uk/sitesplus/922/page/61604>

***Public Health Wales Observatory (2013). GP Cluster Profiles: Hywel Dda HB.***

<http://www.wales.nhs.uk/sitesplus/922/page/67714>

***Roberts, A and Charlesworth, A. (2014). A decade of austerity in Wales?  
The funding pressures facing the NHS in Wales to 2025/26.  
London: Nuffield Trust.***

[http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/140617\\_decade\\_of\\_austerity\\_wales.pdf](http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/140617_decade_of_austerity_wales.pdf)

***Young Foundation (2006). Mapping Britain's Unmet Needs.  
A report prepared for the Commission on Unclaimed Assets.***

[http://youngfoundation.org/wp-content/uploads/2013/06/06\\_06\\_Mapping\\_Britains\\_unmet\\_needs.pdf](http://youngfoundation.org/wp-content/uploads/2013/06/06_06_Mapping_Britains_unmet_needs.pdf)





## Section 13

# Sensory Impairment

**West Wales Population Assessment** March 2017

### 13.1. Overview and Key Messages

- Sensory impairment can be a significant life limiting condition and its incidence increases with age. This means the challenges associated with the condition are likely to grow over coming decades
- The condition includes sight loss, hearing loss, and dual sensory loss (deafblind).
- Accelerating factors in relation to sight loss include diabetes and obesity
- People with sensory impairment have a range of care and support needs. Early identification is vital, as is prevention, support to reduce loneliness, isolation and promote mental health and wellbeing and measures to support access to employment
- Effective care and support is likely to reduce other risks associated with age and frailty, such as falls
- A range of services are available across West Wales. These provide a foundation for improvement in the future
- Improvements need to focus on further development of generic and specialist services and improving access to other services for people with a sensory impairment. This will require collaborative approaches to ensure consistency and that common challenges are addressed

### 13.2. Demographics and Trends

Sensory impairment includes sight loss, hearing loss and dual sensory loss (a condition also referred to as 'deaf blind'). Incidence of sensory impairment across these categories primarily affects older age groups, although there are other significant groups within the population that are susceptible particularly to sight loss and genetic conditions and injury can also give rise to a range of sensory impairment.

The prevalence in West Wales of each of these three conditions is examined below.

#### Sight Loss

The charts below provide numbers of adults predicted to have visual impairment in each part of the region, in 2015 and 2030. These are based on generic forecasting and demonstrate that, whilst the proportion of younger people affected is very small, people are more likely to suffer sight-related conditions as they grow older. Forecasting predicts that:

- Approximately 0.06% of adults between the ages of 18 and 64 will have a severe visual impairment
- Moderate or severe visual impairment will be experienced by around 5.6% of older adults aged between 65 and 74
- Around 12% of people aged 75 and over will have a moderate or severe visual impairment
- Approximately 6.4% of people aged 75 and over will have registerable eye conditions

The most common sight-threatening conditions are age-related macular degeneration, cataract, glaucoma and diabetic retinopathy. This will become significant as the population of the region ages over the next 2 decades.

Other conditions such as diabetes and obesity are underlying causes of sight loss and as the incidence of these increases this will also impact on the preponderance of vision-related problems within the population (Action for Blind People, n.d).

**Figure 13:1 Predicted levels of visual impairment, Carmarthenshire**

	2015	2030
People aged 18-64 predicted to have a severe visual impairment	70	70
People aged 65-74 predicted to have a moderate or severe visual impairment	1,308	1,437
People aged 75 and over predicted to have a moderate or severe visual impairment	2,382	3,631
People aged 75 and over predicted to have registerable eye conditions	1,220	1,859

Source: Daffodil Cymru

**Figure 13:2 Predicted levels of visual impairment, Ceredigion**

	2015	2030
People aged 18-64 predicted to have a severe visual impairment	30	28
People aged 65-74 predicted to have a moderate or severe visual impairment	540	532
People aged 75 and over predicted to have a moderate or severe visual impairment	988	1,498
People aged 75 and over predicted to have registerable eye conditions	506	767

Source: Daffodil Cymru

Figure 13:3 Predicted levels of visual impairment, Pembrokeshire

	2015	2030
People aged 18-64 predicted to have a severe visual impairment	45	43
People aged 65-74 predicted to have a moderate or severe visual impairment	917	948
People aged 75 and over predicted to have a moderate or severe visual impairment	1,692	2,551
People aged 75 and over predicted to have registerable eye conditions	866	1,306

Source: Daffodil Cymru

The following table provides the latest figures on the numbers of people registered as partially sighted or blind in each county.

Figure 13:4 Numbers of people registered as partially sighted or blind

	Carmarthenshire	Ceredigion	Pembrokeshire
Numbers of people registered as partially sighted or blind (2013/14)	1,029	365	663

Source: Stats Wales

Other statistics (RNIB, 2016) relating to sight loss include:

- Nearly two-thirds of people living with sight loss are women
- Adults with learning disabilities are 10 times more likely to be blind or partially sighted than the general population
- People from non-white ethnic groups are at a higher risk of certain sight conditions

NHS Wales spends around £113 million (Welsh Assembly Government, 2011) on eye health including costs associated with inpatient treatments and outpatient attendances, and also the cost of NHS funded eye tests and yet over 50 per cent of sight loss can be avoided (Public Health Wales, 2013). In published NHS programme budgets Hywel Dda Health Board combined spend on problems of vision is £15.6 million (2.2% of the overall budget). Indirect costs of sight loss are significant and include the provision of unpaid care by family and friends, lower employment, absenteeism and the cost of specialist equipment and modifications.

## Hearing loss

Hearing loss has been identified as a major public health issue. The vast majority of people with hearing loss and profound hearing loss are older people aged 65+, so once again as the population profile of the region ages the number of people with hearing loss is set to grow (Action on Hearing Loss, 2015).

The following table shows how the estimated numbers of people aged 18+ with a hearing impairment is set to grow in the West Wales region by 2030.

**Figure 13:5 Estimated numbers of people aged 18+ with a hearing impairment**

Those aged 18+ with hearing impairment	2015	2030	2015-2030 % Change
Moderate or severe hearing impairment	46,973	61,907	32%
Profound hearing impairment	1,075	1,529	42%

Source: Daffodil Cymru

Hearing loss affects us and is more likely to be experienced alongside other conditions, as we age:

- From the age of 40 onwards, a higher proportion of men than women develop hearing loss. This may be because more men have been exposed to high levels of industrial noise (Action on Hearing Loss, 2015)
- 71.1% of over-70-year-olds have some kind of hearing loss (Action on Hearing Loss, 2016)
- Among people over the age of 80, more women than men have hearing loss, which is due to women living longer than men on average, not because women are more likely to become deaf (Action on Hearing Loss, 2016)

## Dual Sensory Loss (Deafblind)

Deafblindness is when a combination of both sight and hearing loss cause difficulties in communication, mobility and access to information. People can be born deafblind, or become deafblind through illness, accident or in older age. Deafblindness is a growing issue in the UK (SENSE, 2010). Dual sensory loss can be found in all age groups, including children, but the incidence is greatest in older adults. Once again, this number is set to grow substantially over the next two decades as the population ages.

The following table sets out the estimated numbers of people of all ages with some degree of and more severe dual sensory loss (RNIB, n.d).

Figure 13:6 Estimated numbers of people with some degree of and more severe dual sensory loss

	Carmarthenshire	Ceredigion	Pembrokeshire
Estimated number of people living with some degree of dual sensory loss	1,345	931	546
Estimated number of people living with more severe dual sensory loss	455	320	191

Source: RNIB

13.3. Current and Future Care and Support Needs

The positive impact of prevention, early identification, practical and emotional support and accessibility of services is common across all categories of sensory loss. Whilst many people with sensory impairment will not need direct care and support for their condition, they are more likely to suffer with depression, anxiety, loneliness, loss of independence and isolation, along with poorer employment prospects and the financial impact that can bring, than the general population. Appropriate low level support can play a key role in mitigating the effect of these and in improving the general wellbeing of people with these conditions.

Since, as outlined above, sight loss can often be accompanied by other chronic conditions, people may often be receiving other care and support relating, for example, to stroke, diabetes and dementia.

Care and support needs are explored in further detail overleaf.

Prevention and early identification

Research by the RNIB suggests that 50% of blindness and serious sight loss could be prevented if detected and treated in time (RNIB, 2016).

It is much easier for people to maintain their independence as their sight deteriorates if they can learn coping techniques early in the process rather than trying to re-incorporate activities into their routine that they have previously decided are off-limits. Adaptations in the home such as better lighting can be of significant benefit (Rotheroe et al, 2013). Early diagnosis of hearing loss and dual sensory loss can also facilitate better adjustment to these conditions and better levels of independence and wellbeing. Diagnosis of hearing loss can currently can take on average 10 years to obtain. Evidence suggests that GPs fail to refer up to 45% of people reporting hearing loss for an intervention such as a referral for a hearing test or hearing aids (Action on Hearing Loss, 2009).

Appropriate services, accessed with the help of communication aids, is the single biggest need for dual sensory impairment. An example of need is the availability of guides/communicators to facilitate social interaction and ensure equality of opportunity in accessing services (Orr et al, 2006). Early intervention is, again, crucial. People with dual sensory impairment rely on tactile communication and this is easier to teach whilst individuals are still able to receive audio and visual information. Once people have lost almost all their sight and hearing, highly-skilled practitioners are needed to support people in learning tactile communication skills (RNIB, 2013).

Coping strategies for single sensory loss often rely on the other senses working harder to compensate; audio readers can support those who are unable to read printed materials and those with hearing loss may rely on lip reading. Where both senses are impaired, implications for the individual are profound; the impact of losing both senses is 'more than the sum of its parts' (Rotheroe et al, 2013).

### **Mental health and wellbeing**

People with vision impairment have an increased risk of depression (Thomas Pocklington Trust, 2016) and over one-third of older people with sight loss are estimated to be living with this condition (Hodge et al, 2010 cited in Action for Blind People, n.d). The provision of emotional and practical support at the right time can help people who are experiencing sight loss to come to terms with the situation, retain their independence and access the support they need, thus reducing possible triggers for depression (RNIB, 2013).

Research findings suggest that deaf people are more likely than their hearing counterparts to suffer from mental health problems (McClelland et al, 2001). 40% of the deaf and hard of hearing people in the UK are likely to experience a mental health problem at some time in their lives. The culturally deaf (that is, those using British Sign Language (BSL)) have a 50% chance of a mental health crisis (Orr et al, 2006).

### **Social isolation and loneliness**

Research by the Thomas Pocklington Trust identified a significant need among people with a visual impairment for greater social contact (Percival, 2003).

RNID research undertaken in 2000 found that 66% of deaf and hard of hearing people feel isolated due to the fact that their condition excludes them from everyday activities. Research conducted by FMR (a social research consultancy) in 2002, suggests that deaf people experience social exclusion, discrimination, and barriers in access services and facilities because of difficulties in communication (Orr et al, 2006).

People of different ages face distinct and particular issues when sensory loss is not diagnosed. Older people are likely to become more vulnerable, isolated and less independent if visual loss is not diagnosed and addressed. This concern is highlighted in an in-depth interview with a service user who said:

*"I feel I want to scream just for human conversation... I feel that I'm deteriorating so much because I have no stimulant, I suppose. I hardly sleep at all."*

Bristol City Council, 2014

For young people, life chances are affected as they may struggle to build the necessary resilience to cope with transition periods, for example when moving from education to employment. Social isolation within mainstream schools and the workplace can also be a problem for people with sight loss (Rotheroe et al, 2013).

### Falls reduction

A 2012 study found that between 40% to 50% of older adults with visually impairing eye disease limited their activities due to a fear of falling. This puts people at further potential risk for social isolation and disability (Wang et al, 2012)

Every year in Wales half of those over 80 will have a fall in their home. Resulting injuries such as hip fractures have a hugely detrimental effect on individual wellbeing and require costly health interventions. Across Wales, falls have been estimated to directly cost the NHS £67 million per year (Davidson et al, 2011) and evidence suggests around 10% of all falls can be attributed to sight loss (Boyce, 2011). Appropriate adaptations and aids in the home can play a vital role in reducing risk in this area.

### Access to education and employment

Across the UK it is estimated that two-thirds of registered blind and partially sighted people of working age are not in paid employment (Douglas et al, 2006 cited in Action for Blind People, n.d). Over two-fifths of people living with sight loss say that they have some or great difficulty in making ends meet (RNIB, 2013).

Figures from the Office of National Statistics show that people with hearing loss are less likely to be employed (65% are in employment) compared with 79% of people with no long term health issue or disability (Action for hearing loss, 2016).

## 13.4. Current Care and Support Provision

A range of care and support is available for people with sensory loss in West Wales. Whilst the precise nature of provision varies in each county area, generally these include:

- **Rehabilitation Officers for the Visually Impaired (ROVIs)** located within social care who provide rehabilitation service for people of all ages who are certified blind, partially sighted or are registerable under these categories of reduced vision. A ROVI's role is to help build confidence, provide emotional support, regain lost life-skills and teach new skills, maintain and promote independence and choice



and assess people's need for specialist equipment and adaptations. The ROVIs work closely with partner agencies such as the Low Vision Service Wales (LVSU) and the third sector to ensure clients' needs can be fully recognised, supported and progressed. They also build links with other services to ensure the needs of visually impaired people are taken into account. A recent example is engagement with Aberystwyth University in Ceredigion which resulted in the opening of an art gallery with audible provision. Finally, ROVIs work within communities to provide visual awareness training and look to set up local support groups for people with vision impairment

- **Low Vision service Wales (LVSU)-accredited practitioners** located within primary care, who provide advice and guidance to those who have had diagnosis of a specific eye condition. People can access LVSU practitioners from the community or when in secondary care. Practitioners currently operate in 32 community optometric (optician) practices and a further 11 offering a domiciliary service
- **Eye Care Liaison Officers (ECLOs)** operating from ophthalmology departments across the region and provide support and advice to patients with vision impairment; this service is limited and is provided by RNIB in Carmarthenshire and Pembrokeshire and by Sight Cymru in Ceredigion
- **Specialist equipment** available to facilitate daily activities, such as mobility and communication equipment (including Braille and hearing loop systems) and lip-reading services (in Carmarthenshire), where appropriate
- **General awareness raising and engagement activities** for example with 50 + forums which takes place across the region and interaction with other services such as education, highways and the third sector (in Pembrokeshire) to improve provision for people with sensory loss. Local engagement activities include work conducted through the West Wales Audiology Group, facilitated by Hywel Dda University Health Board and bringing together professionals and service users to consider and address relevant service issues and the publication in Pembrokeshire of a monthly audio magazine for the visually impaired which encourages feedback from citizens on the type and level of services they would like to receive. Wales Council for the Blind convenes a quarterly 'Your Voice Shared Vision' meeting across Mid and West Wales (including Powys) to discuss service-related issues and obtain the views of users and carers
- **Support for Carers of people with sensory loss** including information, signposting to appropriate support and advice on carers' assessments
- **Partnership working between the statutory and third sectors** at national level with organisations such as British Wireless for the Blind, Blind Veterans UK, RNIB, SENSE Cymru, Deaf Children's Society, Welsh Interpreting and Translation Services, Wales Council for Deaf People and locally with groups such as Pembrokeshire Association of Voluntary Services and the Llanelli Blind Society, to deliver a range of support services. These include social interaction and activities and specific facilities such as wireless for the blind, talking newspapers

Regional initiatives to improve provision for people with sensory loss include the Sensory Friendly Awareness Awards programme, the first to be piloted and rolled out in Wales and led by Hywel Dda University Health Board. The programme aims to raise awareness and understanding among health care providers of the needs of people with sensory loss and their carers and to respond to these appropriately. Its initial focus is on secondary wards.

Along with other LHBs across Wales, Hywel Dda University Health Board has recently introduced a sensory e-learning course, in conjunction with SENSE Cymru, to raise awareness of sensory impairment issues among staff. Service user feedback has been positive. One user commented:

*"I was dreading going into hospital due to being virtually blind and I feared I would not be helped, however I could not have asked for any more help. They guided me, gave excellent verbal instruction and even told me when my meal had been placed in front of me, which has never happened to me before"*

### 13.5. Gaps and Areas for Improvement

The biggest single challenge in relation to people with sensory loss is lack of diagnosis. This is also an issue where individuals are receiving other services such as residential and nursing care. Research undertaken in 2012 (Watson and Bamford, 2012) revealed that eye care and sight testing are both neglected in care homes for older people. A similar situation prevails for hearing loss (Echalier, 2012). Ensuring people are diagnosed with sensory loss as soon as possible can help them to remain independent for as long as possible and avoid other risks such as falls.

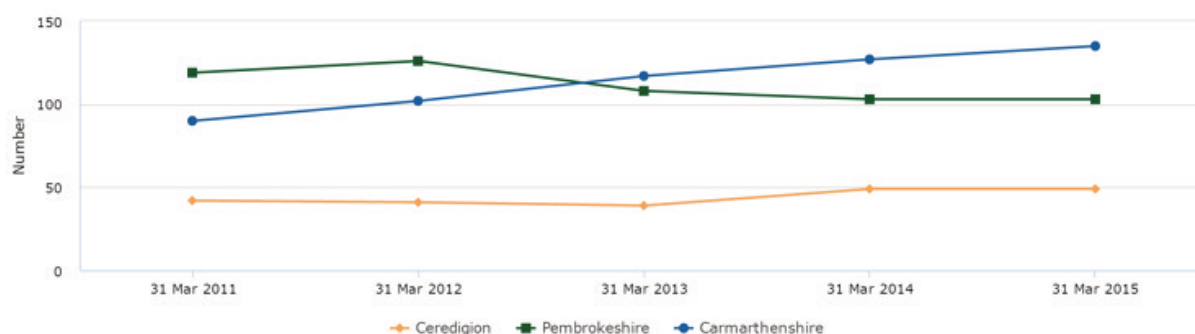
The following gaps and areas for further improvement are set out below against the core principles of the SSWB Act. These show that ensuring people with sensory loss have a voice and are in control of their disability is paramount.

#### Voice and Control

- There is a need for greater awareness of sensory loss and its impact so that service providers take specific needs into account and make their services more accessible. This is particularly important given that sensory loss often exists alongside other age-related conditions such as dementia and frailty. Information and advice needs to be provided in accessible formats. Wider services need to be made accessible so that people are not turned away inappropriately, or give up because, for example, they are unable to navigate the health and social care system. Thought also needs to be given to how people receive information, for example about hospital appointments. Difficulties in reading these can mean people with visual impairment missing out on other vital health care

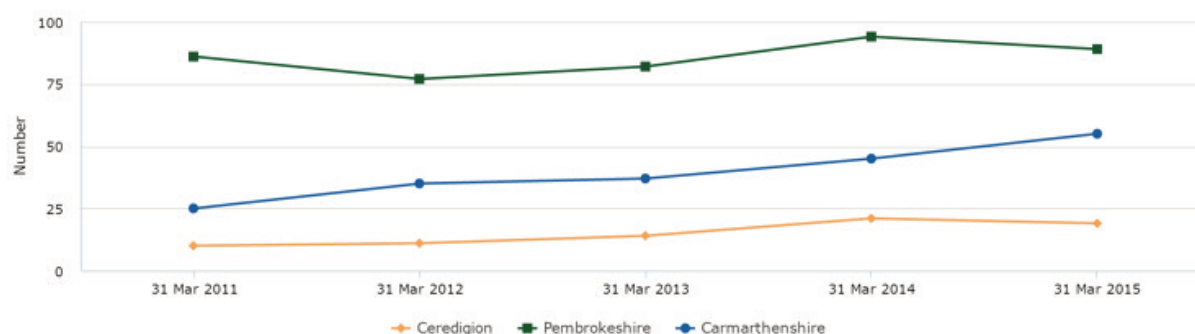
- Awareness of the NHS Low Vision Service in West Wales needs to be raised, thus increasing the number of referrals to the service and enabling appropriate support to be provided
- Specific support services such as interpretation, translation, lip reading and talking therapies need to be enhanced to ensure they are available and accessible across the region
- Take-up of Direct Payments should be encouraged to ensure that people can exercise genuine choice and control over the care and support they receive

**Figure 13:7 Numbers of social services clients aged 18-64 with physical or sensory disability or frailty receiving direct payments.**



Source: Welsh Government

**Figure 13:8 Numbers of social services clients aged 65+ with physical or sensory disability or frailty receiving direct payments.**



Source: Welsh Government

- Social care assessment processes should be reviewed to ensure that sensory loss is identified and steps taken to put appropriate care and support in place

### Prevention and Early Intervention

Wales leads the UK in many areas of eye care, including clinical and research arenas. But where sight cannot be saved, there must be provision for preventing further functional deterioration and providing mitigating strategies that enable independent living. Rehabilitation for the Vision Impaired meets the Article 26 UN Convention on the Rights of Disabled People. Specialist services such as ophthalmology and glaucoma clinics need to be sufficiently resourced to ensure timely intervention and to guard against further deterioration in conditions.

Although as stated earlier there is evidence that GPs fail to refer 45% of those reporting hearing loss (Action on Hearing Loss, 2009) in 2013 Wales became the first country in the UK to develop guidance on dealing with people with sensory loss for distribution in GP surgeries and hospitals.

### Wellbeing

- There is a need to 'grow' low level care and support within communities, such as facilities to reduce isolation and loneliness and assist people in retaining independence and wellbeing
- There is a need for improved levels of rehabilitation for people experiencing vision impairment; this can be highly effective in helping people regain independence, avoid associated decline in physical and mental health, reduce the risk of accidents and support carers in understanding and adapting to the needs of the person they are caring for

### Co-operation, partnership and integration

There is a need for a collaborative approach across the region in building on current success and ensuring fit for purpose services that enable people with a sensory impairment to live fulfilled lives and optimise their wellbeing. Existing commitments such as those contained in a Strategic Statement of Intent recently developed by the West Wales Sensory Loss Standards Group (2015) provide useful mechanisms for taking this work forward. The RPB provides a further opportunity for addressing identified challenges in a focused and joined-up way:

- There is a need for closer working between sensory impairment services and other services, such as residential, nursing and domiciliary care to raise awareness and increase referral rates
- Further links between sensory impairment and learning disability and mental health teams is needed to ensure appropriate support is available to people with sensory loss
- Similarly, further work is needed with other partners such as employers, to ensure that the needs of people with sensory impairment are recognised and addressed
- Greater recognition is needed of accessibility issues when designing the built environment
- Insufficient resources in a time of financial constraint
- Rurality of the region and poor public transport which can hinder access to services
- Workforce issues relating to difficulties in recruiting appropriately qualified staff and ensuring their skills develop in line with changing needs and advances in technology
- The need to develop capacity within the third sector to improve community-based support
- Ensuring consistency of provision across the region and appropriate levels of specialist services in all areas
- Developing self-reliant individuals and resilient communities to support people to remain independent in their own communities

## 13.6. References

*Action for Blind People (n.d.). Key statistics.*

<https://actionforblindpeople.org.uk/about-us/media-centre/key-statistics/>

*Action on Hearing Loss (2009). Hearing Matters.*

*Action on Hearing Loss (2015). Hearing Matters:*

*Why urgent action is needed on deafness, tinnitus and hearing loss across the UK.*

[https://www.actiononhearingloss.org.uk/~media/Documents/Policy%20research%20and%20influencing/Research/Hearing\\_Matters\\_2015/Hearing%20Matters%20Report.ashx](https://www.actiononhearingloss.org.uk/~media/Documents/Policy%20research%20and%20influencing/Research/Hearing_Matters_2015/Hearing%20Matters%20Report.ashx)

*Action on Hearing Loss (2016).*

*Facts and figures on hearing loss, deafness and tinnitus.*

<http://www.actiononhearingloss.org.uk/your-hearing/about-deafness-and-hearingloss/statistics/~media/56697A2C7BE349618D336B41A12B85E3.ashx>

*Boyce, T. (2011). Falls - costs, numbers and links with visual impairment.*

London: RNIB

*Bristol City Council (2014). Social Isolation and Physical and Sensory Impairment: Research Findings Report.*

[https://www.bristol.gov.uk/documents/20182/34732/Social%20isolation%20and%20physical%20and%20sensory%20deprivation\\_0\\_0\\_0.pdf/393c572d-5eeb-4b01-b013-b7139843af8e](https://www.bristol.gov.uk/documents/20182/34732/Social%20isolation%20and%20physical%20and%20sensory%20deprivation_0_0_0.pdf/393c572d-5eeb-4b01-b013-b7139843af8e)

*Daffodil Cymru (2014a). People aged 18 and over predicted to have a moderate or severe visual impairment by age, and people aged 75 and over predicted to have registerable eye conditions, projected to 2035. [Online].*

<http://www.daffodilcymru.org.uk/index.php?pageNo=1056&PHPSESSID=r5gr5unq74u6t4i8jsp0qjjnq6&at=a&sc=1&loc=1&np=1>

*Daffodil Cymru (2014b) People aged 18 and over predicted to have a moderate or severe, or profound, hearing impairment, by age and gender, projected to 2035. [Online].*

<http://www.daffodilcymru.org.uk/index.php?pageNo=1052&PHPSESSID=k4nchq6qmm6f6qknd4p1tnaqk7&at=a&sc=1&loc=1&np=1>

*Davidson, M., Nicol, S., Roys, M. and Beaumont, A. (2011).*

*The Cost of Poor Housing in Wales. Bracknell: HIS BRE Press.*

*Echalier, M. (2012). A World of Silence:*

*The case for tackling hearing loss in care homes. Action on Hearing Loss.*

<https://www.actiononhearingloss.org.uk/aworldofsilence.aspx>

McClelland, R., Chisholm, D. and Powell, S. (2001). "Mental Health and Deafness: an investigation of current residential services and service users throughout the UK". *Journal of Mental Health*, 10 (6), pp. 627-636

Orr, K., Leven, T., Bryan, R. and Wilson, E. (2006). *Community Care And Mental Health Services For Adults With Sensory Impairment In Scotland*. Scottish Executive Social Research.

<http://www.gov.scot/resource/doc/129826/0030944.pdf>

Percival, J. (2003). *Meeting the needs of older people with visual impairment: social care or social exclusion*. London: Thomas Pocklington Trust.

<http://discovery.ucl.ac.uk/3322/1/3322.pdf>

Public Health Wales (2013). 'Look after your eyes' at your local pharmacy this July [press release].

<http://www.wales.nhs.uk/sitesplus/888/news/27804>

Rotheroe, A., Joy, I. and Bagwell, S. (2013). *In Sight: A Review Of The Visual Impairment Sector*. London: New Philanthropy Capital.

<http://www.thinknpc.org/publications/in-sight-a-review-of-the-visual-impairment-sector>

RNIB (n.d.). *RNIB Sight Loss Data Tool v 3.2 [online]*.

<http://www.nib.org.uk/knowledge-and-research-hub-key-information-and-statistics/sight-loss-data-tool>

RNIB (2013). *Sight loss UK 2013: The latest evidence*.

[https://www.nib.org.uk/sites/default/files/Sight\\_loss\\_UK\\_2013.pdf](https://www.nib.org.uk/sites/default/files/Sight_loss_UK_2013.pdf)

RNIB (2016). *Key information and statistics*.

<http://www.nib.org.uk/knowledge-and-research-hub/key-information-and-statistics>

SENSE (2010). *A sense of urgency*.

[https://www.sense.org.uk/sites/default/files/A\\_Sense\\_of\\_Urgency\\_Summary\\_report\\_CEDR\\_Research.pdf](https://www.sense.org.uk/sites/default/files/A_Sense_of_Urgency_Summary_report_CEDR_Research.pdf)

Stats Wales (2016). *Physically/sensory disabled persons by local authority, disability and age range. [Online]*.

<https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Social-Services/Disability-Registers/physicallysensorydisabledpersons-by-localauthority-disability-agerange>

Tomas Pocklington Trust (2016). *Access to psychological therapies for people with sight loss and depression: what is the evidence?*

<http://pocklington-trust.org.uk/wp-content/uploads/2016/06/Access-to-psychologicaltherapies-for-people-with-sight-loss-and-depression.pdf>

Wang, M. Y., Rousseau, J., Boisjoly, H., Schmaltz, H., Kergoat, M. J., Moghadaszadeh, S., Djafari, F. and Freeman, E. E. (2012). "Activity limitation due to a fear of falling in older adults with eye disease". *Investigative Ophthalmology & Visual Science*, 53 (13), pp. 7967 – 7972.

Watson, J. and Bamford, S. M. (2012). *Undetected sight loss in care homes: an evidence review*. London: International Longevity Centre.  
[http://www.ilcuk.org.uk/files/Undetected\\_sight\\_loss\\_in\\_care\\_homes.pdf](http://www.ilcuk.org.uk/files/Undetected_sight_loss_in_care_homes.pdf)

West Wales Sensory Loss Standards Group (2015).  
*Statement of Intent For Services For Physically Disabled And/Or Sensory Impaired Adults In South West Wales*.





## Section 14

# Substance Misuse

**West Wales Population Assessment** March 2017

## 14.1. Overview and Key Messages

This report considers the care and support needs of those affected by alcohol and drug misuse, the effects of which are far reaching; impacting on children, young people, adults, whole families and communities. Partnership work to address this agenda is taken forward through the Dyfed Area Planning Board for Substance Misuse who are developing their own comprehensive needs assessment to inform their new strategy and action plan. This thematic report therefore provides a brief summary only.

The Welsh Government's 10 year strategy (Welsh Government, 2008) provides the framework for partner organisations in West Wales to tackle the harms associated with drug and alcohol misuse across four key themes;

- Preventing harm
- Support for those that misuse drugs and alcohol in order to improve their health and aid and maintain recovery
- Supporting and protecting families
- Tackling availability and protecting individuals and communities via enforcement activity

Those at risk of harm from alcohol misuse come from across the spectrum of society. They include chronic heavy drinkers, adults at home drinking hazardous or harmful levels and children and young adults who suffer from the consequences of parental alcohol misuse. The health impact of misuse of alcohol is considerable; more people die from alcohol related causes than from breast cancer, cervical cancer and MRSA infection combined. Foetal alcohol syndrome is also a risk to the babies of mothers who use alcohol. Most recent data on hospital admissions for Hywel Dda University Health Board show that over 5,000 bed days were taken up by patients with alcohol related conditions at a cost to the Health Board of over £5.2million per year in in-patient treatment alone.

Misuse of drugs, both legal and illegal, and other mind-altering substances such as solvents, can damage health in a variety of ways. These include fatal overdoses, addiction, mental health problems, infections caused by injecting and the toxic effects of the many substances that dealers mix with the active substance. Although the greatest harms are associated with the use of illicit drugs, the misuse of prescription only medicines and over the counter medicines continues to be a problem.

## 14.2. Demographics and Trends

Within the West Wales region the percentage of adults drinking above the recommended guidelines has reduced by 5% since 2010/11 and from 40% to 37% in 2014/15 (Welsh Government, 2016). Similarly, the percentage of adults binge drinking has reduced by 4% over the same time period from 24% to 20%. Hywel Dda UHB is below the Welsh average for both indicators.

Whilst there has been some decreases for Ceredigion and Pembrokeshire in alcohol related hospital admissions, in Carmarthenshire there has been an overall increase of 6.7% between 2014/15 and 2015/16. Similarly, for alcohol attributable hospital admissions both Pembrokeshire and Carmarthenshire have seen rises of 1.3% and 1.7% respectively since 2014/15. (Public Health Wales, 2016)

In 2015/16 there were 1137 referrals for alcohol treatment with 82% successfully completing treatment. In the same year there were 713 referrals for drug treatment with 79% completing treatment. The figures for those successfully completing treatment are above the Welsh baseline.

Of those accessing drug treatment 65% were male and the largest number of referrals were in the 30-39 years age group (27%), followed by 24% in the 40-49 year age group and 13% in the 50-59 year age group.

There are considerable variations between local authorities in the proportion of Children in Need cases where parental substance misuse is a factor. The figures for the West Wales region are below the Welsh average and Ceredigion and Pembrokeshire have the lowest proportions in Wales. These areas have dedicated Hidden Harm services and Integrated Family Support Services (IFSS) which may account for the lower figures.

West Wales area data for school exclusions due to substance misuse are not available, but Welsh data (Public Health Wales, 2016) indicates that permanent exclusions as a result of drug or alcohol related incidents across Wales was 20.2% in 2015/16. Exclusion from school is a key vulnerability for young people and can result in lack of meaningful daily learning and activities.

There has been an increase in drug related deaths during 2016 compared to 2015/16 and a similar increase is being experienced elsewhere in Wales and in England.

### 14.3. Current and Future Care and Support Needs

The Dyfed Area Planning Board for Substance Misuse are developing their commissioning strategy in order to address the following population outcomes:

- To stop people from starting to take drugs, and to reduce harm from alcohol through ensuring the whole population is informed of the risk and side effects of drug and alcohol misuse
- To minimize the impact of drug and alcohol use on the health and wellbeing and safety of children, young people and families
- To support people with substance misuse issues to achieve a good quality, meaningful life and to make a positive contribution to the community
- To reduce health related harm as a result of drug and alcohol misuse and make communities safer through tackling issues created by drug and alcohol misuse within communities

## 14.4. Current Care and Support Provision

In April 2015 a new Dyfed wide drug and alcohol service (DDAS) was commissioned by the Dyfed Area Planning Board for Substance Misuse in partnership with the Police and Crime Commissioner, National Probation Service, Hywel Dda University Health Board and two of the three local authorities. The service provides a single point of contact for access to all adult drug and alcohol treatment services, including for criminal justice clients, and is delivered by a consortium of third sector partners.

The region adopts a partnership approach and in each LA area weekly meetings are held between DDAS, HDUHB and LA Substance Misuse teams to manage risk, where appropriate share information and oversee the transfer of care between teams. Teams are co-located in dedicated bases throughout the region and have established systems and protocols to reduce the barriers to effective partnership working.

Referrals into Tier 4 treatment – Inpatient Detoxification or Residential Rehabilitation – are also managed by the Tier 3 community teams. Social Care teams also access other types of specialist accommodation such as that commissioned through the Supporting People Programme for example 'dry house' or supported accommodation provision, as well as Floating Support for individuals with substance misuse needs within their own homes in the community.

The UHB and LAs commission a range of third sector organisations to support people with substance misuse needs including information and advice, counselling services as well as treatment and support services. There are many voluntary and community organisations and social enterprises working with people with substance misuse needs including Drugaid, Chooselife and Cais.

A specialist children and young people's service is provided by Drugaid Choices West, a third sector organisation who link closely with a range of other partners including the Police School Liaison Officers, Specialist Child and Adolescent Mental Health Services (Sp CAMHS), Children's Services, Youth Services, HDUHB Youth Health Team and Youth Offending Services. The Dyfed Area Planning Board also commission a dual-diagnosis service for young people who have co-occurring mental health and substance misuse needs and this is provided by Hywel Dda UHB Specialist CAMHS.

## 14.5. Gaps and Areas for Development

The Dyfed Area Planning Board for Substance Misuse is in the process of developing its third Commissioning Strategy for Drug and Alcohol Misuse. This will involve the development of a full needs assessment, market and service mapping, gap analysis and the development of future commissioning intentions. The development of fit for purpose services right across the range is an on-going journey but a number of areas in which further improvements can be made have been set out below against the core principles of the SSWB Act. The further development of services will be in the context

of strategic priorities within the national 'Working Together to Reduce Harm – Substance Misuse Delivery Plan 2016-18' (Welsh Government, 2016).

### **Voice, Choice and Control**

- Ensuring that children, young people and families are able to access services through their language of choice and that the 'active offer' of services through the medium of Welsh is always available
- Use of direct payments so that individuals can choose who provides the services they need

### **Prevention and Early Intervention**

- Establishing a more co-ordinated and coherent approach to drug and alcohol misuse education and awareness raising for young people across schools and for those who are not in education, employment and training (NEET)
- Provide support for the further development and roll out of the Alcohol Liaise Nurse scheme in secondary care settings across the West Wales area
- Establish clear and coherent treatment options for young people and their families with drug and alcohol problems to provide a more holistic approach to prevention and early intervention ensuring that there is a clear link to the Adverse Childhood Experiences (ACE) agenda

### **Wellbeing**

- Re-evaluation of treatment options for young people aged between 18-25 years old
- Re-evaluation of treatment options for older people with alcohol issues.
- Lack of clear funding and treatment options for patients with Alcohol Related Brain Damage

### **Co-production**

- Increasing service user involvement, including carers, young carers, parents or significant others, in service delivery and service planning

### **Co-operation, Partnership and Integration**

- Development of housing options and reintegration opportunities within the community for recovering service users
- Establish, develop, implement and manage a robust process for the review of both fatal and non-fatal overdoses including the rollout of the distribution of Naloxone across hospital sites
- Support the development and implementation of the alcohol and assault data project between the University Health Board, Welsh Ambulance Services NHS Trust, Dyfed Powys Police and Public Health Wales in order to improve information sharing arrangements between partners involved in reducing harm in the night time economy
- Ensure clear pathways between services for service users with co-occurring substance misuse and mental health

### 14.6. References

*Public Health Wales (2016).*

*Piecing the Puzzle - Profile of Substance Misuse in Wales 2015-16.*

<http://www.wales.nhs.uk/sitesplus/documents/888/Piecing%20the%20Puzzle%20FINAL%202016%2C%20v2%2C%2025%20Oct%202016.pdf>

*Welsh Government (2008). Working Together to Reduce Harm*

*– The Substance misuse Strategy for Wales 2008-2018.*

<http://gov.wales/dsjlg/publications/communitysafety/strategy/strategyen.pdf?lang=en>

*Welsh Government (2016a). Working Together to Reduce Harm*

*– Substance Misuse Delivery Plan 2016-18.*

<http://gov.wales/docs/dhss/consultation/160106consultationcy.pdf>

*Welsh Government (2016b). Welsh Health Survey 2015-16.*

<http://gov.wales/statistics-and-research/welsh-health-survey/?lang=en>

## Section 15

# Violence Against Women, Domestic Abuse and Sexual Violence

**West Wales Population Assessment** March 2017

# 15.1. Overview and Key Messages

- Violence against women, domestic abuse and sexual violence (VAWDASV) is a fundamental violation of human rights, a cause and consequence of inequality and has far reaching consequences for families, children and society as a whole (Welsh Government, 2016)
- Domestic Abuse costs Wales £303.5m annually. This includes £202.6m in service costs and £100.9m to lost economic output. If the emotional and human cost is factored in there are added costs of £522.9m (Walby, 2009 cited in Welsh Women's Aid, n.d)
- The cost, in both human and economic terms, is so significant that marginally effective interventions are cost effective (Welsh Government, 2016)
- New requirements under the Wellbeing of Future Generations (Wales) Act 2015, the SSWB Act, and Violence Against Women, Domestic Abuse and Sexual Violence Act, 2015 impact this area and are likely to increase the number of cases of domestic abuse identified
- Improving partnership responses to survivors could reduce the levels of need for specialist services

# 15.2. Demographics and Trends

VAWDASV includes domestic abuse, sexual violence, forced marriage, female genital mutilation (FGM), 'honour-based violence', sexual exploitation, trafficking and child sexual abuse. This can happen in any relationship regardless of age, ethnicity, gender, sexuality, disability, income, geography or lifestyle (Welsh Government, 2016).

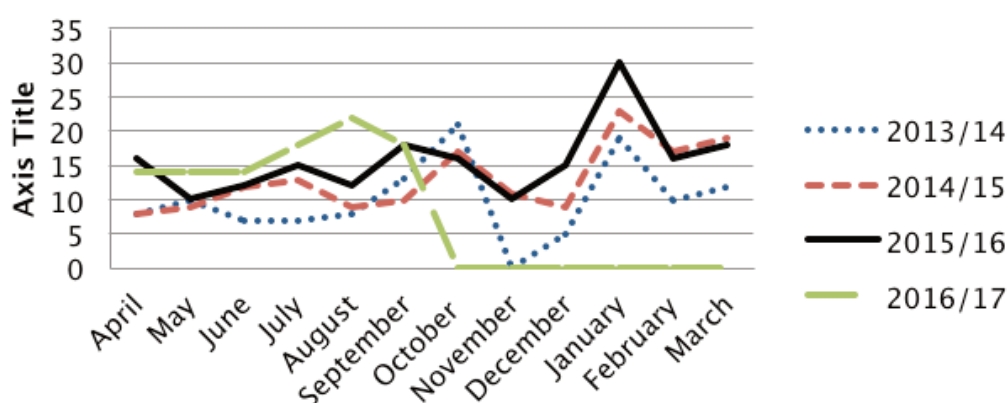
- 1.4 million women and 700,000 men aged 16-59 report experiencing incidents of domestic abuse in England and Wales. Younger women aged 16-24 are most at risk and a woman is killed every 2.4 days in the UK, with 148 UK women killed by men in 2014
- Extrapolating this data to Wales shows that 11% women and 5% men a year experience 'any domestic abuse', while rates of 'any sexual assault' in the last year were also higher for women (3.2%) than men (0.7%)
- Approximately 124,000 women, men, boys and girls over the age of 16 in Wales, have been the victim of a sexual offence
- There has been a 26% increase in the number of recorded sexual offences involving children under 16 in Wales in the past year. Figures have more than doubled in the last decade (Bentley et al, 2016). Last year the rate of recorded sexual offences against children under 16 in Wales was 3.3 per 1000 children
- In 2011 an estimated 137,000 girls and women were living with consequences of FGM in the UK and in 2011 an estimated 60,000 girls under the age of 15 were living in the UK who were born to mothers from FGM practising countries and therefore could be at risk of FGM. It is estimated there are 140 victims of FGM a year in Wales



- 80% of cases dealt with by the Forced Marriage Unit involved female victims; 20% involved male victims. It is estimated there are up to 100 victims of forced marriage a year in Wales
- 750,000 children and young people, across the UK witness or experience domestic abuse every year and a significant proportion experience abuse in their own relationships
- In a study of young people in intimate relationships by the NSPCC (Barter et al, 2009), 25 % of the girls and 18% of the boys experienced physical abuse; 75% of girls and 14% of boys experienced emotional abuse, and 33% of the girls and 16% of the boys experienced sexual abuse. It found that not only do girls experience more abuse, but they also experience more severe abuse more frequently, and suffer more negative impacts on their welfare, compared with boys
- People with additional vulnerabilities including mental health needs, substance misuse issues, disabilities and older people with support needs are more likely to be affected by Domestic Abuse (Local Government Association, 2015)

The number of high risk and **very high risk cases of domestic abuse** discussed via the Multi Agency Risk Assessment Conference process (MARAC) has increased year on year since the process began over ten years ago.

**Figure 15:1 MARAC referrals**



Source: Carmarthenshire, Ceredigion and Pembrokeshire IDVA Services, 2016

**Note** MARAC data from October 2016 was not available at the time of writing.

The graph shows increases in MARAC referrals from the Dyfed counties (Carmarthenshire, Ceredigion, Pembrokeshire and Powys) and indicates a year on year upward trend in referrals over the last three full financial years. Data for 2016/17 are included up to and including August 2016 and suggest the upward trend continues. The new requirements of the SSWB Act and changes in the way that Police record crime and incidents are thought to be contributing factors to the upward trend. National figures from Her Majesty's Inspectorate of Constabulary show the number of domestic abuse cases reported to the police in England and Wales rose by 31% between 2013 and 2015 (BBC, 2015).

There are peaks and troughs in referrals. There is a peak around the Christmas period when additional pressures can impact on families already experiencing abuse and there is a trough around August where fewer people are in work and children are not in school so identification leading to a referral can be lower.

Cases are only heard at MARAC when they become high or very high risk cases and therefore only represent a small proportion of the total number of actual cases. Research suggests only around 2% of domestic assaults are reported to the police and that on average, a woman will be assaulted 35 times before she contacts the police (Yearnshire, 1997).

Figure 15:2 MARAC cases

MARAC data 2015/16	Carmarthenshire	Ceredigion	Pembrokeshire	TOTAL
Number of cases heard at MARAC	454	189	341	984
Safe Lives recommended number of cases	310	130	210	650
Number of children in MARAC households	448	257	402	1462
Number of repeats	79 (17%)	31 (16%)	44 (12%)	154 (15%)
BME referrals	21	6	7	34
Alleged victim has a disability (physical, mental etc.)	5 or under	5 or under	5 or under	10 or greater
Referrals where there is an alleged male victim	28	15	32	75
LGBT cases discussed	Under 5	Under 5	Under 5	Fewer than 5
Cases where the person causing harm is aged 17 and below	Under 5	Under 5	Under 5	Fewer than 5

Source: Carmarthenshire, Ceredigion and Pembrokeshire IDVA Services, 2016

- The number of male victims discussed varies across counties and the numbers are confounded by a number of factors. Perpetrators of abuse often make counter allegations of abuse against the actual victim. However, research (ONS, 2015) also suggests
  - 1/3 of victims of abuse in Wales are male
  - male victims are more than twice as likely as women not to tell anyone about the partner abuse they are suffering (29% and 12%, respectively)

- Levels of reporting for those with a disability appear to be low when it is taken into account that their additional vulnerability is a known area for increased susceptibility to being abused; research (Bennett et al, 2013) suggests
  - people with a learning disability are not always listened to or believed when reporting abuse
  - disabled children and adults are at greater risk of experiencing abuse and violence than their non-disabled peers
  - people with a learning disability are more likely to be subjected to abuse than non-disabled people and possibly at greater risk than other disabled people
- Very few younger victims are discussed at MARAC. Safeguarding processes are in place in each county's children's services department where high risk cases are also managed

Cases of abuse in older people appear to be an area where there is underreporting. The National Strategy (Welsh Government, 2016) suggests:

*"There is sometimes confusion between the experience of domestic abuse in later life and "elder abuse" (a term which encompasses all forms of violence, abuse and neglect experienced by older people). Such confusion can result in victims of abuse falling between the systems which are designed to offer them protection and as a consequence do not receive appropriate support to help them to stop the abuse or make them safe."*

Work is ongoing through a pilot in Carmarthenshire and Cardiff led by Aberystwyth University to improve responses and so improve outcomes for older people.

### 15.3. Current and Future Care and Support Needs

The Violence Against Women, Domestic Violence and Sexual Abuse Act, 2015 makes it clear that partners including Local Authorities, Local Health Boards, NHS Trusts, Fire and Rescue Authorities, Police, Police and Crime Commissioners, education services, housing organisations, the third sector, specialist services, survivors, crime and justice agencies, and probation services need to work together to:

- Prevent violence against women, domestic abuse and sexual violence
- Protect victims of violence against women, domestic abuse and sexual violence
- Support people affected by violence against women, domestic abuse and sexual violence

The National Strategy (Welsh Government, 2016) makes it clear that this requires;

*"targeted action and support to overcome barriers to accessing safety and support. Women who are known to be especially vulnerable to violence and/or who are marginalised, such as women in prostitution, women from BME communities, disabled women, women with mental health or substance abuse problems, young women in care, will require specialised approaches"*

Feedback suggests survivors of domestic abuse have a range of support needs including better awareness and understanding, help with feelings of isolation, non- time limited support, and support for children within the abusive relationship;

*"I think we need more awareness of what is available [...] a lot of people are afraid of going into a refuge."*

*"I think we need more awareness earlier – in early teens."*

*"Being understood by support workers is really important."*

*"The group was the most helpful thing as it made me feel less isolated. I had contact with other women and realised for the first time in years that I wasn't the only one living with this."*

*"We need more support for us so we're not seen as a case to be closed or passed on to someone else, we have needs in our own right, and support should be available for as long as we need it, not time limited."*

*"The worse thing was the children didn't have the option of speaking to someone. They wouldn't say anything to a teacher or a police officer... but if there was a support worker there for children they'd have spoken to them."*

*"For a long time I felt confused...Was I just as bad as (dad)? How could I love someone who hits my mum?"*

Source: Welsh Women's Aid, 2016.

There is also a need to deal with the effects of coercive control that prevents many victims from getting in touch with any services and some people may not recognise that they are in an abusive relationship. To help address this issue controlling or coercive behaviour has been made a crime under section 76 of the Serious Crime Act 2015 (CPS, 2015).

## 15.4. Current Care and Support Provision

Welsh Government contracted with Hafan Cymru in 2015 to provide awareness-raising in primary and secondary schools across all schools in Wales through the SPECTRUM Project. This aims to assist with children having access to dedicated sessions around healthy relationships. Discussions are ongoing regarding how this contract can be enhanced to further support the guidance. In addition to this each county's specialist support providers provide awareness raising sessions in schools and youth settings.

Community campaigns are coordinated during the year to improve the community's understanding of abuse and the support that is available. Domestic Abuse Coordinators, specialist services and partners also utilise opportunities to raise awareness in community settings.

A mandatory National Training Framework is in place with training modules currently under development to ensure that staff are training appropriately for their level of involvement and are able to target enquiry and act appropriately where abuse or violence is disclosed. Training has also been arranged for Health Board staff in Domestic Abuse, Risk Assessment and MARAC training and Domestic Abuse and the Older Person. Carmarthenshire has a dedicated Domestic Abuse social worker in its children's team and Ceredigion has a part-time mediator funded through Flying Start and Families First.

The following table shows the range of services from universal services through to those for acute needs and approximate stages for services to become involved or hand over to other services. Some services may become involved earlier and remain involved. Others may only be involved once, or for specific support at different times when needed. New legislation may impact these areas of support so this represents current service configuration.

Figure 15:3 Range of services

Universal services	Additional support	More complex needs	Protection / Safeguarding needs
GPs	Flying start services		
Midwifery	Specialist Safeguarding Team within Health		
Community nursing team	Specialist Safeguarding Midwife	Looked After Children Service	
Hospitals	Child and Adolescent Mental Health Services	Specialist Safeguarding Health Visitor Flying Start	
	Community Psychiatric Team attached to Mental Health Services		
	Substance misuse services	Social Care tier 3 services for substance misuse	
Childcare	Children and family services	Social Care Child and adult safeguarding and protection teams	Multi agency Child protection Multi agency Adult protection
Family centres	Families first services		
	Team around the family		
	Generic community support services		
	Disability services		
	Older people's services		
	Victim support	Counselling services	
	Independent Domestic Abuse Adviser (IDVA)	Refuge/safe accommodation	
	New Pathways		Courts & legal services (civil, family & criminal)
Police		Police Protecting Vulnerable People Units	Probation
			Community Rehabilitation Company
Citizens advice			
	Victim support	Counselling services	
Benefits, Financial services	Families first services		
Housing	Homelessness options		
Education		Safeguarding Leads in school	

Source: Local data

Peer support can assist survivors with early recovery and specialist services offer group support work such as the Freedom Programmes, which benefit survivors in understanding healthy relationships and so reduce the likelihood of abuse in future relationships.

The MARAC process is led by Dyfed Powys Police and the process allows all relevant partner agencies to come together to increase safety options for victims of domestic abuse. Each county has an Independent Domestic Abuse Adviser (IDVA) service that provides short to medium term support to those at high or very high risk.

Target hardening (strengthening of the security of a building or installation in order to protect it in the event of attack) which allows survivors to stay in their own homes when it is safe to do so rather than flee to refuge is a preferred option and can reduce dependency on specialist services.

Each county has specialist services that provide refuge accommodation, move on accommodation and community support. In addition to this, Carmarthenshire have a dedicated Domestic Abuse Social worker in their children's team and Ceredigion have a part time mediator through Flying Start and Families First funding.

Each LA has dedicated safeguarding teams that provide support and protection to vulnerable people. Hywel Dda University Health Board have a safeguarding team that works with other agencies to address risk and support needs.

## 15.5. Gaps and Areas for Improvement

There are a range of gaps and areas for improvement that need to be addressed in the context of the new requirements under recent legislation. These are set out below against the core principles of the SSWB Act.

### Voice and Control

Despite a significant amount of work in Wales including many awareness raising campaigns there remains a public perception that domestic abuse is 'something that doesn't happen around here' and so signs of abuse in friends and family can be missed in the community. There are also enduring social problems of violence against women, domestic abuse and sexual violence and many men, women and children are still at risk of, or experiencing violence or abuse. More work across agencies is required to challenge perceptions and provide earlier interventions for survivors of abuse.

There is no benchmark for the number of children and young people reached through awareness raising sessions in schools and youth settings although each county reports increased concerns in teenagers and young adults' understanding of what constitutes a healthy relationship.

It would be helpful to have a better understanding of the numbers of children and young people reached through these sessions and to have the involvement of specialist services during campaigns to support disclosure. Awareness raising sessions for adults also need to be expanded with improved effectiveness and resources.

A more robust awareness raising strategy also needs to be developed to raise awareness of elder abuse building on the pilot in Carmarthenshire and Cardiff.

There is a gap in services for those that are not able to engage with services which could be because of fear of repercussions or the effects of coercive control. Historically Domestic Abuse services provided an outreach service which allowed victims to maintain a level of contact with services and the time to be able to accept support. There is no dedicated outreach service in the region and although specialist charities make efforts to offer outreach via volunteers, they are often hampered by a lack of resourcing to recruit volunteers and manage the service effectively. Where gaps exist survivors could benefit from improved support from universal services which are able to keep in touch with the survivor and offer additional support via specialists at the right time. There is also a need to deal with the effects of coercive control that prevents many victims from getting in touch with any services.

### **Prevention and Early Intervention**

The introduction of targeted enquiry through the Ask and Act process that targets enquiry through services that are likely to come into contact with those experiencing abuse is likely to lead to an increase in demand for support and therefore waiting lists. In Ceredigion some targeted work in training staff in education has resulted in a large increase in direct support for children, which resulted in increases in waiting lists for support. Clearly this is problematic as it delays intervention, support and ultimately recovery. Early intervention can prevent inappropriate development becoming embedded longer term and can break the cycle of abuse so that it does not carry on into the next generation.

When teenagers exhibit violent and abusive behavior there is a gap in services to address violence. This requires a partnership response to combat abusive behaviour in teenagers and reduce escalation.

Perpetrator programmes which aim to reducing abusive and violent behaviour vary across the region:

- Ceredigion lacks any perpetrator programme except where there is a court conviction and relies on being able to refer onto programmes in neighbouring counties
- Carmarthenshire have a pilot charity-funded project to provide support to whole families including perpetrators of abuse
- Pembrokeshire run a non-RESPECT accredited programme that is suitable for some perpetrators and not others



There is a need to consider what model of support is effective and how such work can be resourced.

The IDVA is a key part of the pathway for survivors of high and very high risk cases. These services are currently part funded from Welsh Government Grants and part funded from Home Office Grants. Current IDVA provision and pathways vary greatly across the region and each county lacks the levels required for the number of MARAC cases heard. The following table shows the number of FTE IDVAs in each county, the number recommended by Safe Lives, and the number required to service current case numbers. In Carmarthenshire and Ceredigion the number of FTE IDVAs is less than the Safe Lives recommended levels and the numbers required to service current case loads. In Ceredigion the number of FTEs is between these benchmarks. The aggregated figures for the region also fall short of both benchmarks.

**Figure 15:4 MARAC cases and IDVA support**

MARAC data	Carmarthenshire	Ceredigion	Pembrokeshire	TOTAL
Number of cases heard at MARAC	454	189	341	984
Safe Lives recommended number of cases	310	130	210	650
Number of Full Time Equivalent (FTE) IDVAs recommended by Safe Lives	4	1.5	3	8.5
Number of FTE IDVAs to serve current volume of cases	5.8	2.2	4.5	12.5
<b>Current IDVA FTE</b>	<b>2.56</b>	<b>1.8</b>	<b>2.45</b>	<b>6.9</b>

Source: Carmarthenshire, Ceredigion and Pembrokeshire IDVA Services, 2016

If this happens there will be an opportunity to ensure that services in each county are appropriate to the identified level of need and that there is a consistent IDVA pathway across the region. In order to support the targeted enquiry process it would also be helpful for staff working across public services to be able to signpost appropriately through having a directory of services.

Specialist support and protection services include refuge and move on accommodation which are funded by Supporting People Programme Grant which provides housing related support to vulnerable people. However, capacity levels are low and services across the region advise that they are operating at maximum capacity. The following table shows the numbers supported by specialist services across the three counties.

Figure 15:5 Refuge and Move on services

	Carmarthenshire	Ceredigion	Pembrokeshire
Refuge number supported	99		29
Number supported in move on units	24	79	9
Total	123	79	38
Floating (community) support	227	78	68

Source: Carmarthenshire, Ceredigion and Pembrokeshire IDVA Services, 2016

Refuges are managed by specialist services, with the refuges being owned by LA or Social Housing Landlords. Funding for support in refuges comes from Supporting People. Rents are covered through housing benefits, providing that the survivor is able to access the benefits system. Housing are a vital partner in addressing accommodation issues for survivors of domestic abuse.

One Stop Shops have been funded through capital grants from Welsh Government, where specialist services either purchased buildings or leased them utilising the grant. Specialist services welcome partners utilising these buildings to assist with partnership working.

Currently target hardening options are limited in the three counties. Police utilise locksmith services for emergencies for the most acute needs but options are lacking further down the scale. Target hardening can improve feelings of safety and can contribute to a reduction in demand for refuge services. There is a need to identify cost effective target hardening solutions with a partnership approach.

There is also a need to consider how to assist migrant, refugee and asylum seeking women who have no recourse to public funds but who may be subject to FGM, 'honour' based violence, forced marriage, domestic abuse and sexual violence. Although the numbers are difficult to estimate accurately (for example the total number of asylum seekers and refugees living in Wales is estimated to be between 7,500 and 11,500) (Crawley, 2013), there is a need to consider appropriate pathways for these women who may be suffering abuse and to identify and access funding that may exist for example from the Home Office for non EU women on spousal visas.

Data collection from specialist services other than IDVA services is lacking. Specialist providers across all three counties accept referrals from marginalised groups. Each LA considers equality impact in any decision-making around the commissioning of services.

Black and Minority Ethnic (BME) communities are able to access domestic abuse services although specialist support for BME communities and Gypsy and Traveller

communities is required as there are particular risks associated with some communities. Also the BAWSO service across Wales which provided generic and specialist services for BME communities ended in 2015/16.

There is evidence that individuals who attend the Sexual Abuse Referrals Centres (SARC) may also have been victims of domestic abuse, although further work is required to identify the actual numbers. Support is given by third sector organisations such as New Pathways. Victims attending the SARC will often require sexual health services and as such there are robust pathways in place to support this service and allow easy access for victims. Pathways are also in place for easy access to the Emergency Departments, should victims require urgent treatment. The follow up of such victims will be an important element of their physical and mental Health care. It is these follow up services that may require further in-depth analysis as to what currently exists.

### Wellbeing

There is a high correlation between escalation in abuse with mental health issues and drug and alcohol use. HDUHB have undertaken some work within Mental Health Services and some of the specialist teams do work closely with partner organisations. Public Health and Health Visiting Flying Start/Specialist mental health services will support some areas, however, it is recognised that more investment and a more consistent approach across all counties would be helpful.

There is also a lack of supply of suitable, affordable, good quality single person and 2 bedroomed accommodation in Carmarthenshire that cannot be met through social housing leading to a reliance on the private sector. However, private sector landlords are reluctant to let to people who are benefit dependent. This lack of supply is having a detrimental impact on the capacity and capability of both supported and unsupported temporary accommodation to meet the needs of service users. There is a need to improve working relationships with landlords and providers of housing related support.

### Co-production

There is published research following engagement with survivors of VAMDASV (both nationally) for example; 'Are you Listening' and 'Am I Being Heard' (Welsh Women's Aid, 2016 ) that sets out the care and support needs of this group in their own words but more work is needed locally to engage people with lived experience in this area to co-design and deliver support.

### Co-operation, Partnership and Integration

Under requirements of the VAWDASV Act a regional strategic board comprising all partners (Dyfed Powys Police, Mid Wales Fire and Rescue Service, Welsh Ambulance Trust, Health Boards, Local Authorities, Education, Probation, Specialist Third Sector) needs to be established which will report to Welsh Government. The Board will be based around the Dyfed Powys Police footprint so will include Powys organisations.

Consideration should be given to adapting the existing Regional Domestic Abuse Forum for this purpose. The Board could consider and co-ordinate a regional response to the new requirements placed upon public services and the gaps and areas for development highlighted in this report and to support delivery of the 6 objectives set out in the National Strategy:

- Increase awareness of violence against women, domestic abuse and sexual violence
- Enhance education about healthy relationships and gender equality
- Challenge perpetrators, hold them accountable for their actions and provide interventions and support to change their behaviour
- Ensure professionals are trained to provide effective, timely and appropriate responses to victims and survivors
- Provide victims with equal access to appropriately resourced high quality, needs led, strength based, gender responsive services
- Work together to understand and meet the needs of communities

## 15.6. References

**BBC (2015). Domestic abuse: Police 'nearly overwhelmed' by increase.**

<http://www.bbc.co.uk/news/uk-35093837>

**Barter, C., McCarry, M., Berridge, D. and Evans, K. (2009).**

**Partner exploitation and violence in teenage intimate relationships. NSPCC.**

<https://www.nspcc.org.uk/globalassets/documents/research-reports/partner-exploitation-violence-teenage-intimate-relationships-report.pdf>

**Bennett, D., Flood, S., Howarth, J., Melsome, M. and Northway, R. (2013).**

**Looking into Abuse: Research by People with Learning Disabilities.**

**University of Glamorgan.**

[http://udid.research.southwales.ac.uk/media/files/documents/2013-03-05/Final\\_report.pdf](http://udid.research.southwales.ac.uk/media/files/documents/2013-03-05/Final_report.pdf)

**Bentley, H., O'Hagan, O., Raff, A. and Bhatti, I. (2016).**

**How safe are our children? 2016. London: NSPCC.**

<https://www.nspcc.org.uk/services-and-resources/research-and-resources/2016/how-safe-are-our-children-2016/>

**Crawley, H. (2013). Asylum seekers and refugees in Wales.**

**Wales Migration Partnership.**

<http://www.wmp.org.uk/documents/wsmpp/News%20and%20Events/Migration%20Briefings/Asylum%20Seekers%20and%20Refugees%20in%20Wales.pdf>

**CPS (2015). Controlling and coercive behaviour can "limit victims' basic human rights" as new domestic abuse law introduced [online].**

[http://www.cps.gov.uk/news/latest\\_news/new\\_domestic\\_abuse\\_law\\_introduced/](http://www.cps.gov.uk/news/latest_news/new_domestic_abuse_law_introduced/)

**Local Government Association (2015). Adult safeguarding and domestic abuse,**

**A guide to support practitioners and managers, 2nd edition.**

[http://www.local.gov.uk/c/document\\_library/get\\_file?uuid=5928377b-8eb3-4518-84ac-61ea6e19a026&](http://www.local.gov.uk/c/document_library/get_file?uuid=5928377b-8eb3-4518-84ac-61ea6e19a026&)

**ONS (2016). Focus on Violent Crime and Sexual Offences:**

**Year ending March 2015.**

<https://www.ons.gov.uk/peoplepopulationandcommunity/crimeandjustice/compendium/focusonviolentcrimeandsexualoffences/yearendingmarch2015>

**Welsh Government (2016). National Strategy on Violence Against Women,**

**Domestic Abuse and Sexual Violence, 2016 – 2021.**

<http://gov.wales/docs/dsjlg/publications/commsafety/161104-national-strategy-en.pdf>

*Welsh Women’s Aid (n.d.). Statistics & Research [online].*

[http://www.welshwomensaid.org.uk/index.php?option=com\\_content&view=article&id=49&Itemid=55](http://www.welshwomensaid.org.uk/index.php?option=com_content&view=article&id=49&Itemid=55)

*Welsh Women’s Aid (2016). Are you listening and am I being heard?*

<http://www.rhianbowendavies.com/wp-content/uploads/2016/09/Are-you-listening-and-am-I-being-heard-FINAL-July-2016.pdf>

*Yearnshire, S. (1997). “Analysis of cohort”.*

*In: Bewley S, Friend J and Mezey G. (e d s.) Violence against women.*

## Section 16

# Appendices

**West Wales Population Assessment** March 2017

## Appendix 1 List of figures and tables

Figure 4:1	Proportion of Welsh speakers in each County	40
Figure 6:1	Projected population counts by age group, Hywel Dda UHB, 2013-2036	52
Figure 6:2	Percentage of Population by age and sex, Hywel Dda UHB and Wales 2014	53
Figure 6:3	Key Population Statistics	53
Figure 6:4	Population Pyramids	54-55
Figure 6:5	All cause mortality, EASR per 100,000, count and crude rate, under 75, Wales local authorities, health boards, 2012-14	55
Figure 6:6	Welsh Index of Multiple Deprivation, Hywel Dda UHB 2014	56
Figure 6:7	Observed percentage of adults who reported key health-related lifestyles, by LA, Health Board and Wales, 2013/14	57
Figure 8.1:	Level 2 threshold including English/Welsh and Mathematics	75-76
Figure 8:2	Percentage of children and young people not in education, employment or training (NEET) 2015	76
Figure 8:3	Service continuum	78
Figure 8:4	Numbers of children supported through a range of statutory and non-statutory services	81-83
Figure 9:1	Adults who reported health related lifestyles	90-91
Figure 9:2	The Determinants of Health	91
Figure 9:3	Numbers of people aged 18-64 in receipt of care and support services	93
Figure 10:1	Numbers (current and predicted) of people aged 75 and over with a moderate or severe learning disability	103
Figure 10:2	Open cases for people with autism in Ceredigion and Pembrokeshire 2016	104
Figure 10:3	Circle of support for learning disability	106
Figure 11:1	Percentage of people aged 16+ years free from a common mental disorder – 2013-14	115
Figure 11:2	Predicted percentage change between 2015 and 2030 of people with a mental health disorder	116
Figure 11:3	Percentage of people aged 30-64 with early onset dementia	116
Figure 11:4	Predicted number of people aged 30-64 with early onset dementia	117
Figure 11:5	Predicted number of mortalities of people aged 15+ from suicide	117
Figure 11:6	Number of individuals referred to Primary Mental Health Support Services in 2015-16	120
Figure 11:7	CMHT Care Treatment Plans 15/16	120



Figure 11:8	Referrals to Crisis Resolution Home Treatment Teams 2015/16	121
Figure 11:9	Admissions to Psychiatric Inpatient services	121
Figure 11:10	Percentage change for 18+ receiving residential services 2015-2030	122
Figure 11:11	DOLS results and waiting lists	122
Figure 11:12	Number of social services clients aged 18-64 with Mental Health problems receiving direct payments 31 March	124
Figure 12:1	Population by age and sex and aged over 65 by LA	131
Figure 12:2	Projected number of people aged 65+	131
Figure 12:3	Population projections by age	132
Figure 12:4	Three Levels of Service	139
Figure 13:1	Predicted levels of visual impairment, Carmarthenshire	153
Figure 13:2	Predicted levels of visual impairment, Ceredigion	153
Figure 13:3	Predicted levels of visual impairment, Pembrokeshire	154
Figure 13:4	Numbers of people registered as partially sighted or blind	154
Figure 13:5	Estimated numbers of people aged 18+ with a hearing impairment	155
Figure 13:6	Estimated numbers of people with some degree of and more severe dual sensory loss	156
Figure 13:7	Numbers of social services clients aged 18-64 with physical or sensory disability or frailty receiving direct payments	161
Figure 13:8	Numbers of social services clients aged 65+ with physical or sensory disability or frailty receiving direct payments	161
Figure 15:1	MARAC referrals	175
Figure 15:2	MARAC cases	176
Figure 15:3	Range of services	180
Figure 15:4	MARAC cases and IDVA support	183
Figure 15:5	Refuge and Move on services	184

## Appendix 2 Group membership and acknowledgements

A wide range of colleagues from across partner organisations contributed to the Assessment, through thematic working groups and an editorial group. Thanks are recorded to the following colleagues who contributed in this way:

### Carers

Liz Blazey, Pembrokeshire County Council  
 Dr Gareth Morgan, Hywel Dda University Health Board  
 Pennie Muir, Hywel Dda University Health Board  
 Catherine Moyle, Ceredigion County Council  
 Jonathan Rees, Carmarthenshire County Council  
 Heather West, Ceredigion County Council

### Children and Young People

Liz Blazey, Pembrokeshire County Council  
 Heulwen Davies, Ceredigion County Council  
 Margaret Devonald Morris, Hywel Dda University Health Board  
 Joy Fereday, Ceredigion county Council  
 Billy Goodfellow, Ceredigion County Council  
 Isobel Hall, Hywel Dda University Health Board  
 Joff Lee, Ceredigion County Council  
 Stefan Smith, Carmarthenshire County Council  
 Dr Michael Thomas, Hywel Dda University Health Board  
 Noeline Thomas, Carmarthenshire County Council

### Health and Physical Disability

Jean Davies, Pembrokeshire County Council  
 Corinne Wreford, Ceredigion County Council  
 Joff Lee, Ceredigion County Council  
 Gareth A Miller, Carmarthenshire County Council  
 Sandra Morgan, Hywel Dda University Health Board  
 Martyn Palfreman, West Wales Care Partnership  
 Judi O'Rourke, Ceredigion County Council  
 Dr Michael Thomas, Hywel Dda University Health Board  
 Julia Wilkinson, Carmarthenshire County Council

### Learning Disability and Autism

Anna Bird, Hywel Dda University Health Board  
 Kelvin Barlow, Carmarthenshire County Council  
 Anna Bird, Hywel Dda University Health Board  
 Liz Blazey, Pembrokeshire County Council  
 Avril Bracey, Carmarthenshire County Council  
 Kim Conroy, Ceredigion County Council  
 Julie Denley, Hywel Dda University Health Board  
 Neil Edwards, Carmarthenshire County Council  
 Melanie Evans, Hywel Dda University Health Board  
 Joff Lee, Ceredigion County Council  
 Joel Sven Martin, Carmarthenshire County Council  
 Silvana Sauro, Carmarthenshire County Council  
 Nigel Miller, Hywel Dda University Health Board  
 Donna Pritchard, Ceredigion County Council  
 Mary Rendell, Ceredigion County Council

### Mental Health and Substance Misuse

Anna Bird, Hywel Dda University Health Board  
 Avril Bracey, Carmarthenshire County Council  
 Jean Davies, Pembrokeshire County Council  
 Julie Denley, Hywel Dda University Health Board  
 Mark Evans, Carmarthenshire County Council  
 Melanie Evans, Hywel Dda University Health Board  
 John Forbes-Jones, Ceredigion County Council  
 Carys James, Ceredigion County Council  
 Richard Jones, Hywel Dda University health Board  
 Donna Pritchard, Ceredigion County Council  
 Dr Boika Rechel, Hywel Dda University Health Board  
 Joel Sven Martin, Carmarthenshire County Council  
 Joff Lee, Ceredigion County Council  
 Silvana Sauro, Carmarthenshire County Council  
 Dr Michael Thomas, Hywel Dda University Health Board

### Older People

Jean Davies, Pembrokeshire County Council  
 Melanie Evans, Hywel Dda University Health Board  
 Dr Gareth Morgan, Hywel Dda University Health Board  
 Sandra Morgan, Hywel Dda University Health Board  
 Judi O'Rourke, Ceredigion County Council  
 Martyn Palfreman, West Wales Care Partnership  
 Dr Michael Thomas, Hywel Dda University Health Board  
 Julia Wilkinson, Carmarthenshire County Council

**Sensory Impairment**

Jean Davies, Pembrokeshire County Council  
Joff Lee, Ceredigion County Council  
Dr Gareth Morgan, Hywel Dda University Health Board  
Judi O’Rourke, Ceredigion County Council  
Mellony Richards, Ceredigion County Council  
Julia Wilkinson, Carmarthenshire County Council

**Violence Against Women, Domestic Abuse and Sexual Violence**

Liz Blazey, Pembrokeshire County Council  
Alun Davies, Ceredigion County Council  
Nicola Edwards, Hywel Dda University Health Board  
Sinead Henahan, Pembrokeshire County Council  
Joff Lee, Ceredigion County Council  
Alun Jones, Carmarthenshire County Council  
Mandy Nichols-Davies, Hywel Dda University Health Board  
Sian Passey, Hywel Dda University Health Board  
Lowrie Proctor, Dyfed Powys Police  
Matthew Richards, Ceredigion County Council  
Helen Twidle, Ceredigion County Council

**Editorial Group**

Anna Bird, Hywel Dda University Health Board  
Martyn Palfreman, West Wales Care Partnership  
Mary Palmer, Project Manager  
Dr Michael Thomas, Hywel Dda University Health Board



