



Partneriaeth Gofal Gorllewin Cymru
West Wales Care Partnership



Population Needs Assessment
DRAFT REPORT
June 2022

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Foreword

The Regional Partnership Board brings together partners from local government, the NHS, third and independent sectors with service users and carers. Our aim is to transform care and support services in West Wales. Our region covers the area of Hywel Dda University Health Board and includes the local authority areas of Carmarthenshire, Ceredigion and Pembrokeshire.

We are required to produce a Population Needs Assessment (PNA) under section 14 of the Social Services and Wellbeing (Wales) Act and in 2017 published our first. This was an important document, as it was the first time we had produced an assessment of the health and care needs of our population in this way.

The findings from this assessment have since guided our planning, investment and service delivery in West Wales. We are now required to publish our second. This is an opportunity to update and refresh the findings of our first PNA and to consider the progress we have made.

Central to our approach has been engagement and collaboration with the people who live in West Wales. We have worked closely with our stakeholders, including our Public Service Boards (PSBs), our professional and stakeholder working groups and, most importantly, wherever we can, our citizens.

Welsh Government provides detailed guidance for population assessments and there are a few important changes for this version. Firstly, we must give specific attention to the needs of Autistic people and those living with Dementia.

Secondly, we must take account of the impact of COVID-19. We know this has affected everyone in our community, but particularly those who use health and social care services.

Also, the Welsh Government has asked that this year we undertake a 'Market Stability Report.' This is a separate report which will consider whether we have sufficient services in the care sector and how able they are to meet future demand.

Whilst these assessments are important pieces of work, more important are our actions that will follow them. These will be developed and included in our West Wales Area Plan, which we will produce by April 2023, setting out our ambitions for the years ahead.

We want our assessments to be accessible to people in West Wales and, alongside our detailed reports, we will be publishing them on our [online data portal](#). This will ensure that the information is continually refreshed and updated. We are also committed to ensuring that 'engagement' is not a one-off activity; rather, a continuous and collaborative conversation with our citizens.

We are in unprecedented times and the impact of the COVID-19 pandemic and other global events will continue to present us with significant challenges in West Wales. However, we believe that our Population Needs Assessment, and the approach we



have taken to complete this, will enable us to overcome these challenges together, to evolve and continue to deliver excellent outcomes for the people of West Wales.

Judith Hardisty

Chair, West Wales Regional
Partnership Board



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1. Executive Summary

According to the Office for National Statistics (ONS) by 2025, the population of the West Wales region is estimated at 389,719, an increase of 1.34% since the 2017 population assessment was undertaken.

- 48.8% of the population in the region live in Carmarthenshire, 18.7% in Ceredigion and 32.5% live in Pembrokeshire.
- 40% of adults in Carmarthenshire, 49% of adults in Ceredigion and 22% of adults in Pembrokeshire speak Welsh.
- 2021 estimates from the ONS indicate that people over 65 make up 24.1% of the population in Carmarthenshire, 26.2% in Ceredigion and 26.7% in Pembrokeshire and, as large parts of West Wales are both rural and coastal, the area attracts high levels of inward migration of people over 65

By 2043, current Welsh Government population projections predict an increase in the total population of West Wales to 396,000, with a predicted rise in those aged over 65 to 124,587 or 31.5% of the total population.

Overview and Summary by Population Group

1. Older People

Overview and key messages

West Wales has a higher proportion of older people than average across Wales, with inward migration a major accelerating factor for the growth of the older population. Pembrokeshire has an older population than Carmarthenshire and Ceredigion. The projected increase in those 85 and over is 28% by 2030, with local variation as follows: Carmarthenshire=25%; Ceredigion=26% and Pembrokeshire=33%.

People are living longer with increasingly complex issues, whilst wanting to remain in their own homes and live as independently as possible for as long as possible. COVID-19 has had a significant impact on the physical and mental wellbeing of older people. This is as a result of long periods of social isolation, lack of access to health and care services as well as the direct impact of contracting COVID-19.

Care and support arrangements should be designed with older people; should be flexible and include a range of community, digital and technology-based solutions.

Gaps and areas for improvement

Include:

- Involving older people and their carers in assessment and care planning, including discharge planning
- Helping people to remain independent in their homes for longer through continuing development of digital and telehealth support, particularly for those in very rural areas and where transport is an issue

- Providing additional support for carers managing multiple and complex conditions
- Continuing development of community connectivity, well-being and resilience services that address a range of needs including loneliness and isolation
- Increasing supply of alternative accommodation options such as extra-care schemes.
- Ensuring older people and their families can access services through their language of choice and the active offer through the medium of Welsh is available.

The impact of COVID -19:

COVID-19 has led to widespread social isolation, with lasting implications on the mental health of older people. People have delayed seeking help during the pandemic and now are presenting with much more complex health issues.

Due to the reported mortality rates in residential care older people are now far more reluctant to go into residential care creating a greater demand for alternative accommodation.

2. Dementia

Overview and key messages

As life expectancy and inward migration of older people impacts on the percentage of older people in the region, the number of People Living with Dementia (PLWD) in West Wales is expected to increase in the coming decades.

The Dementia Action Plan for Wales (DAP) 2018 – 2022 sets out a clear vision for “Wales to be a dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities.”

Our [West Wales Regional Dementia Strategy](#) informs the development of person-centred dementia pathways, co-produced with users and carers.

Key messages are as follows:

- The incidence of dementia on the Quality Assurance and Improvement Framework (QAIF) disease register in Hywel Dda in 2019-20 was 0.7%, in line with the Welsh national average of 0.7%
- In 2016-17 dementia diagnosis rates were one of the lowest in Wales at 45.6% indicating that prevalence rates are likely to be closer to 1.4% although, the number of those diagnosed has increased an average of 3% per annum to 2947 in 2020.
- Over thirty genetic, medical, lifestyle, cultural and societal factors have been identified, which impact the risk of cognitive decline differently depending on gender. Some of these factors increase risk more dramatically in women than in men.

Gaps and areas for improvement

These include:

- Continuing to improve awareness, identification, and diagnosis of dementia, including onset of dementia in younger people
- To ensure timely diagnosis and access to appropriate care and support
- Improving co-production of services by including PLwD
- Increasing diagnosis rates in non-specialist community settings by:
 - Improving training and awareness of new evidence-based best practice dementia models within primary care, based on the Good Work Framework
 - Supporting GPs, allied health professionals (AHPs) and nurses to make assessments
 - Improving quality of referrals into specialist care for those requiring it
- Developing more consistent rights-based person-centred care and support
- Continuing improvements in community support, training and help for PLwD to discuss their diagnosis, navigate/co-ordinate services, to build resilience and maintain balance across all aspects of their life
- Ensuring equal access to physical health services and treatment for PLwD
- Ensuring advance care planning and end of life care is fully embedded within our approach.
- Improving research into dementia by involving care homes in the region in research opportunities
- Continuing the development of a “hub” or single point of contact approach for PLwD to access information and support.

The impact of COVID -19:

COVID-19 has had a disproportionately negative impact on PLwD, with dementia being shown as an age-independent risk factor for severity and death in COVID-19 patients.

Although the exact impact on the diagnosis and incidence rate of dementia is unclear, stakeholders have identified that COVID-19 has impacted timely diagnosis due to late presentations.

Full information on the impact of COVID-19 upon those with dementia and their carers is not yet available. However, there is some concern that it may cause damage to the brain in the longer term.

3. Unpaid Carers

Overview and key messages

2011 ONS Census data indicates there are more than 47,000 known unpaid carers across West Wales, of which, 3,436 were Young Carers (defined as 5-17 years old),

representing 12.5% of residents. It is also recognised that there is a considerable number of 'hidden' carers who do not define themselves as such.

Early identification and self-identification of unpaid carers is vital to ensure they access the right help and support at the right time, as well as maintain their own health, well-being and independence.

Support for unpaid carers in West Wales is driven through the West Wales Carers Development Group (WWCDG), a formal sub-group of the West Wales Regional Partnership Board (RPB) and a partnership between Hywel Dda University Health Board, the three Local Authorities of Carmarthenshire, Ceredigion and Pembrokeshire, Third and Voluntary sector organisations and representatives of service users and Carers in West Wales.

The Regional Partnership Board published their Carers Strategy in November 2020 [WWCDG West Wales Carers Strategy 2020-2025](#). The West Wales Carers Development Group (WWCDG) are responsible for ensuring that an annual action plan is in place to respond to the key priority areas.

Gaps and areas for improvement

- Continuing improvements in the consistency of approach, information, advice and assistance provided across the region, within a more integrated system
- Reviewing information provided to carers to ensure it is current, relevant, more accessible and easier to find
- Extending use of social media and technology to identify and provide information to carers and maintain regular contact, particularly for young carers
- Developing a single point of contact to help people navigate the system
- Ensuring respite care fits the needs of both the carer and the cared for
- Addressing the challenges of accessing support in rural areas
- Improving the statutory carers assessment process, which can be challenging, often takes too long and may not always consider carers needs appropriately
- Improving delivery of the "active offer" through the medium of Welsh. Carers want to feel comfortable using their preferred language of choice, including languages other than English and Welsh

Young carers report:

- They struggle to have a break, are not seeing their friends and don't have their own space.
- They find it difficult to balance schoolwork, homework and their caring role and can feel stressed, worried and anxious at school, as they are away from the person that relies on them for care
- They may require extra support for their mental health and wellbeing.

The impact of COVID -19:

Caring is such an important part of life and the role of unpaid Carers has become increasingly prominent. A significant number of unpaid carers have sought support with their caring role and many carers reported:

- Feeling isolated during the pandemic
- Being cautious of people coming into their homes due to the risk in virus transmission, with many choosing to suspend domiciliary care, putting further strain on their wellbeing and mental health
- Experiencing financial pressure, as they have had to take more time off work to support the person they care for
- Concern over the adverse effect of limited social contact on the well-being of loved ones in hospitals and care homes, due to strict visiting restrictions
- Young carers missed the break from caring and social interaction with peers that schooling usually provides
- Improved access to support due to the increased availability of on-line services in response to the pandemic

4. Learning Disabilities

Overview and key messages

The population of People with a Learning Disability (PwLD) in West Wales is projected to remain relatively stable. However, projections suggest the number of people diagnosed with severe or profound and multiple learning disabilities (PMLD) is expected to grow by 1.8% each year. The number of older people with a learning disability is set to increase.

PwLD often have additional diagnoses and/or co-existing conditions such as: autism; physical disabilities; sensory and communication impairment. They are more likely to experience poorer physical and mental health and multiple morbidities, often linked to poor diet, low levels of physical activity, smoking, alcohol use and difficulties in accessing preventative health services.

Through the Regional Improving Lives Partnership, PwLD have worked together with partners to develop the [West Wales Charter](#) – a simple list of things they expect, and need, to live fulfilling lives. The charter is supported by the Welsh Government; County Councils of Carmarthenshire, Ceredigion and Pembrokeshire, Hywel Dda University Health Board and a range of community and 3rd sector organisations.

Gaps and areas for improvement

Include:

- Improving awareness of the needs of PwLD and through training and education of service providers, healthcare workers, families and carers

- Improving the quality of communication with and information for PwLD (easy read)
- Widening access to supported accommodation in a location of choice
- Strengthening access to education, volunteering and paid work opportunities in local communities
- Improving processes for managing transition between children's and adult services and specialist health services
- Supporting self-advocacy for PwLD
- Increasing planning and resources for people with PMLD and their carers

The impact of COVID -19:

COVID-19 has had a particular effect on the physical and mental health of PwLD and their care and support network. This has been exacerbated by the availability of the services and care, such as day opportunities and short breaks.

Many PwLD have been required to shield during the pandemic, limiting their opportunities to contribute to many of the consultations and planning events as part of this assessment.

5. Autism

Overview and key messages

Autism is a term used to describe people with a group of complex neuro developmental symptoms, of variable severity which affects how people communicate and interact with the world. Autism is generally described as a spectrum and can cover a wide range of behaviours and needs. Autism was covered under the Learning Disability chapter in the 2017 Population Assessment. However, in response to the introduction of the [Autism Code of Practice](#) in 2021, a separate Autism chapter is being developed.

The term 'autistic people' rather than 'people with autism', reflects the language preferences expressed by autistic people. The term 'people' refers to children, young people and adults.

Estimates of the prevalence of autism spectrum disorders suggest rates of around 1% in the general population. This would suggest there are about 4000 autistic people living in West Wales. However, there is much debate and the suggestion that not all individuals are identified [1].

New services for adult diagnosis have been set up across Wales at a time of rising awareness of the spectrum of autism experiences; however, until recently no studies have examined adult autism prevalence in Wales

Increased rates of diagnosis and more prevalence of autism will require more specialist support in the community.

Feedback from engagement meetings across the region identified the following:

Gaps and areas for improvement:

- Improve waiting times for diagnosis and diagnosis rates for both children and adults
- Improve access to information and advice for Autistic people and their families, including the autism strategy and the associated support services available in West Wales.
- Improve awareness of Autism and the Autistic Spectrum Conditions across health, social care services, education and all public services.
- Greater emphasis on user engagement and coproduction in service development
- Improving the transition for Autistic Young people when they leave school
- Increasing opportunities for volunteering, work experience, employment opportunities and networking for autistic people.

The impact of COVID -19:

The pandemic has impacted on the care and support available for autistic people as many support services were paused. In addition, the uncertainty and frequent changes to routines and rules will, in some cases have had a significant impact upon people's mental-health and wellbeing. This has placed increased pressure on family members and carers.

For Autistic People the resumption of and reintegration to activities such as education following prolonged periods of lock down has also presented significant challenges.

6. Children and Young People

Overview and key messages

There are over 82,000 children and young people in the region, approximately 22% of the total population. Although the population of children and young people up to the age of 25 will remain relatively stable, the number of children aged 10-15 in the region is expected to decline by 8% by 2031. It is estimated that 6,105 children and young people live with a long-term condition or disability.

Children and young people are considered under the following three groups:

- Up to the age of 18
- Up to the age of 21 if they've been in care
- Up to the age of 25 if they've been in care and are still in education

The region has a lower number of looked After Children (LAC) than the national average. The Capped 9-point score (Year 11 pupils' best 9 results from qualifications available in Wales) is 361.7, above the Wales average of 353.8.

At 14%, the number of young people not in education, employment or training in West Wales is marginally lower than the Welsh average.

Gaps and areas for improvement:

These include:

- Further integration with early years services
- Involvement of children and young people, including care experienced young people and those with complex needs such as disability in the planning of services.
- Further development of preventative and early intervention services, building on established programmes such as Family Information Services, Families First and Team Around the Family and trauma informed models of support
- Considering the importance of physical, mental and emotional wellbeing of children and the key role of community services play in achieving this
- Enhancing partnership working to deliver a '*No Wrong Door*' approach to services so that children and young people receive the support they need regardless of where they enter the system.
- Developing resilience and wellbeing in families to enable children and young people to remain within their families and/ or communities so long as it is safe for them to do so
- Continuing development of multi-agency and individualised approach to supporting children with complex needs
- Developing a regional transition process for children and young people into adult services where appropriate

The impact of COVID -19:

Children and Young People's Mental Health and Wellbeing has been significantly affected during the pandemic. School closures, quarantine periods, fear of becoming unwell and impact upon older relatives are factors that have contributed to a decline in their Mental Health and Wellbeing.

In addition, Children and Young People from areas of poverty were subject to increased risk of poor Mental Health and Wellbeing. Contributing factors included the increased worry of parent financial insecurity, lack of social support, housing quality and poor nutrition.

Children's Social Services have maintained face-to-face contact for children identified as at risk throughout the pandemic. However, enforced absences from school and time at home has presented significant challenges in identifying and responding to risk.

The region has experienced a rise Children and Young People seeking support with complex emotional and mental health difficulties, including behaviours that challenge.

7. Mental Health

Overview and key messages

Our mental health affects how we think, feel and act. A healthy outlook can reduce both the intensity and duration of illnesses, whereas poor mental health can have the opposite effect. It has been shown that depression and its symptoms are major risk factors in the development of coronary heart disease and death after myocardial infarction. Stigma surrounding mental illness is common and can play a role in people potentially hiding issues surrounding their mental health rather than seeking help, which can be mitigated through increasing the information, education and public awareness.

According to the Welsh Government's [Together for Mental Health Strategy](#):

- 1 in 4 adults experience mental health problems or illness at some point in their lifetime
- 1 in 6 adults are experiencing symptoms at any one time
- 1 in 10 children between the ages of 5 and 16 has a mental health problem, and many more have behavioural issues
- Approximately 50% of people who go on to have serious mental health problems will have symptoms by the time they are 14 and many at a much younger age

The Hywel Dda Mental Health Quality and Outcomes Framework (QOF) register records approximately 4,100 patients in 2019.

Through a range of facilitated engagement sessions we were able to identify:

Gaps and areas for improvement

- Improving integration and communication between services, so that patients with multiple issues have access to the range of support and care needed
- Improving processes for those experiencing crisis, to reduce instances where patients in crisis have difficulty accessing services
- Promoting and supporting self-management by educating people on how to manage their conditions, live more independently and make their own choices.
- Shifting the emphasis to community-based services
- Recognising the effect of COVID-19 and the resulting increased demand for mental health services.

The impact of COVID -19:

COVID-19 has led to increased isolation and a disruption of normal life, which could have short term effects on mental health. It is not clear what the long-term effects of COVID on mental health and wellbeing might be however, in the period immediately

before the pandemic, it was reported that 11.7% of Welsh people suffered from severe mental health issues, which reportedly climbed to 28.1% in April 2020 [2].

COVID-19 has also had a worse effect on particular on those groups who already experience poor mental health outcomes, including those from black and minority ethnic backgrounds, those with existing physical or learning disabilities and those in areas of high poverty.

8. Health and Physical Disabilities

Overview and key messages

Most people in the West Wales region between the age 18 to 64 will not access care and support for a specific need or protected characteristic. Instead, they are served by public health information and national and local programmes designed to encourage healthy lifestyles and practices. These programmes are aimed at reducing specific health risk factors such as cardiovascular disease, often achieved by strategies to reduce obesity and smoking and improve diets.

There are a proportion of people who have a range of specific needs because of physical disability or chronic health conditions that may require extra support to enable them to live as independently as possible.

Gaps and areas for improvement

identified through engagement include:

- Involving people with a range of disabilities at the planning and design phase of new developments and accommodation, to ensure they are easy to use and accessible.
- Improving early identification, treatment and management of preventable and chronic conditions including diabetes, heart disease and respiratory illness, to improve long term well-being and reduce complications.
- Improving appropriate access to a range of information, advice and assistance.
- Increasing use of assistive technology, such as telecare to transform domiciliary care and supported living services
- Improving access support for assisted living. Many of the current rules and regulations about supporting and helping people with disabilities are too rigid.
- Improving access to and communication of financial support such as personal independence payments, disabled facilities grant, direct payments
- Improving the process for home improvements and modifications.
- Increasing the flexibility of step up and down provision to respond to changing needs
- Improving access to transport.

The impact of COVID -19:

COVID-19 has led to widespread social isolation, with lasting impact on physical and mental health for those people having to shield during the pandemic.

People have delayed seeking help or had difficulty accessing it during the pandemic and are now presenting later, with much more complex health issues often resulting in worsening comorbidities and prolonged illness.

9. Sensory Impairment

Overview and key messages

Sensory impairment is a normal part of ageing. As sensory impairment can be a significant life-limiting condition, the challenges associated with the condition are likely to grow over the coming decades.

People with sensory impairment are more likely to feel lonely and isolated. Research by RNID in 2000 found that 66% of deaf and hard of hearing people feel isolated due to their condition excluding them from everyday activities.

Sensory impairment is something that cuts across system wide services; it is important that sensory impairment awareness and services are embedded in the whole system of provision.

The combination of two sensory impairments can mean that a deafblind person will have difficulty, or find it impossible, to utilise and benefit fully from services for deaf people or services for blind people. Meeting the needs of deafblind people therefore needs a different approach.

Apart from the day-to-day difficulties, people with sensory impairment also have poorer health outcomes, higher rates of poverty and lower educational achievements than people free from disability.

- Both visual and hearing impairment are projected to increase in West Wales over the coming years
- Accelerating factors for sight loss include diabetes and obesity
- Sensory impairment is associated with increased risk of falls and fear of falling has a major impact on people's ability to remain independent.

Gaps and areas for improvement

- Improving awareness and understanding of sensory impairment
- Improving the accessible implementation standard and developing a process to audit implementation
- Improving provision of accessible information e.g., braille letters

- Extending provision of the interpretation service outside 9-5 and increasing availability of interpreters
- Enhancing record systems such as Welsh Patient Administration System (WPAS) to be able to record more than one impairment

The impact of COVID -19:

The COVID pandemic has contributed to communication difficulties for both hearing and visually impaired people. Access to information has been more difficult to obtain for the visually impaired e.g., reduced access to braille in surgeries. Where services have shifted from face to face to video consultations, they don't work for sight impaired people, who may prefer phone conversations.

The pandemic has also led to challenges for hearing impaired people around communication e.g., face masks make lip reading impossible. People with sensory impairment are more likely to suffer from isolation and loneliness, which has been exacerbated by the COVID pandemic.

10. Substance Misuse

Overview and key messages

Welsh Government has recently launched its new [Substance Misuse \(drug and alcohol\) Delivery Plan for 2019 - 2022](#). The new plan builds on the progress made during the lifetime of the 2008-2018 strategy and is a key reference for the Population Assessment.

Gaps and areas for improvement

- Improving prevention and harm reduction
- Reducing smoking prevalence levels
- Supporting individuals to improve health and aid maintain recovery
- Supporting and protecting families
- Tackling availability of substances and protecting individuals and communities
- Developing stronger partnerships, workforce development and service user involvement.
- Developing accommodation provision in response to care and support needs

The impact of COVID -19:

The effect of COVID-19 pandemic may have had a significant impact on substance misuse however, at present data is not available.

11. Violence against Women, Domestic Abuse and Sexual Violence (VAWDASV)

Overview and key messages

Violence against Women, Domestic Abuse and Sexual Violence (VAWDASV) is a major public health problem, a criminal justice issue, and a violation of human rights. It causes harm to individuals and families, and its impact can be felt across whole communities, societies, and economies and can impact on victims in many ways. For example, sexual violence can lead to a multitude of health consequences including physical, reproductive, and psychological harm.

The [Violence against Women, Domestic Abuse and Sexual Violence \(Wales\) Act 2015](#), together with the statutory guidance on commissioning sets the conditions and expectations for service developments in Wales, with [progress reported](#) annually.

Gaps and areas for improvement

- Increasing awareness of violence against women, domestic abuse and sexual violence
- Enhancing education about healthy relationships and gender equality
- Ensuring professionals are trained to provide effective, timely and appropriate responses to victims and survivors
- Providing equal access to appropriately resourced high quality, needs led, strength based, gender responsive services
- Improving prevention focussed initiatives e.g., IRIS/Ask Me.

The impact of COVID -19:

Emerging literature suggests that levels of VAWDASV have been impacted by the COVID-19 public health restrictions, including lockdown, shielding and social distancing regulations [3]. Whilst the full picture of how the pandemic has impacted on VAWDASV is still to fully emerge, it appears likely that both the scale and nature of VAWDASV may have worsened, with rising helpline contacts for all forms of VAWDASV and increased reports to emergency services for domestic abuse in some areas [4]. Many prevention strategies and programmes have been put on hold or been forced to adapt during the pandemic because of restrictions on movement, face to face interactions and public events. Given the increasing number of reports of VAWDASV during the pandemic, it is more important than ever to promote prevention through the transformation of norms, attitudes and stereotypes that accept and normalise violence.



References:

- [1] (Brugha et al., 2011, 2016; Chiarotti & Venerosi, 2020; Fombonne et al., 2021; Lyall et al., 2017).
- [2] Rodriguez J. Covid-19 in Wales: the mental health and wellbeing impact. Wales Fiscal Analysis. Available at https://www.cardiff.ac.uk/_data/assets/pdf_file/0010/2533762/COVID-19-Mental-health-FINAL-08-07-2021.pdf
- [3] [Bystander-Experiences-of-Domestic-Violence-and-Abuse-during-the-COVID-19-Pandemic.pdf](#) (violencepreventionwales.co.uk)
- [4] <https://committees.parliament.uk/writtenevidence/22280/pdf/>

2. Background and Scope

Regional Partnership Boards (RPBs) are required to produce a Population Needs Assessment (PNA) once every local government electoral cycle. They provide a clear and specific evidence base to underpin the delivery of their statutory duties and inform planning and operational decisions in response to the changing needs of people with care and support needs. This is the second PNA published by the West Wales Regional Partnership Board (WWRPB).

2.1 Purpose of the Population Needs Assessment 2022

The PNA provides an overview of the population demographics and distributions across the West Wales region and a detailed assessment of the care and support needs of 11 important population groups outlined by the Welsh Government, which include:

1. Older People (OP)
2. Dementia (D)
3. Unpaid Carers (UC)
4. Learning Disabilities (LD)
5. Autism (A)
6. Children and Young People (C&YP)
7. Mental Health (MH)
8. Health and Physical Disabilities (H&PD)
9. Sensory Impairment (SI)
10. Substance Misuse (SM)
11. Violence Against Women, Domestic Abuse and Sexual Violence (VAWDASV)

The PNA draws on a range of existing strategies in place across the region, providing an opportunity to review strategic intent at regional and local level and assess:

- the need for care and support
- the support needs of carers in the area
- the extent to which those needs are or are not being met
- the impact of Covid-19, including 'Long COVID' on care and support needs
- details of the range and level of services required to meet those needs
- details of the range and level of services required to deliver the preventative services required in section 15 of the Social Services and Wellbeing Act
- details of how these services will be delivered through the medium of Welsh

This PNA has been undertaken collaboratively by all partners in the West Wales region, agreed by the Regional Partnership Board (RPB) and has been endorsed by the three local authorities (LAs) and Hywel Dda UHB. It will inform the regional Area Plan, which sets out how partners aim to address the needs that are identified.

The first PNA published in March 2017 can be found here ([Layout 1 \(wwcp.org.uk\)](http://www.wwcp.org.uk)).



Figure 1: The West Wales and Hywel Dda University Health Board region, which includes the counties of Pembrokeshire, Carmarthenshire and Ceredigion (Hywel Dda University Health Board Pharmaceutical Needs Assessment, 2021)

2.2 Plan and Approach of the Population Need Assessment 2022

This report will include a detailed assessment of the care and support needs for each of the groups listed above. The results of these individual assessments are collated into thematic reports, which contain:

- an introduction and demographic profile
- a description of care and support needs
- an overview of current and future care and support provision
- special note of Welsh language and Covid-19 implications
- identification of gaps and areas for development
- recommendations

This information was collated in several ways, through survey data, direct engagements with residents and through focus groups and discussions with expert clients. Wherever possible, stakeholders, such as providers in the third and independent sectors, were engaged.

The following questions were considered as part of the assessment of each of the population groups:

1. Do the core data sets (*as used in the 2017 assessment, updated and provided for consideration*) provide a comprehensive basis for assessing projected need for care and support among this population group?
2. Are there additional data sets that are used for this population group and which would be useful in assessing need? How can these be sourced?
3. Are there any further gaps in data which need to be addressed in order to give a comprehensive picture?
4. What data is available to evidence sufficiency of current services to meet the identified need and where are some of the gaps?

This approach ensured that a comprehensive picture was generated for each of the population groups being assessed.

In addition, the following issues were considered for each of the population groups:

1. Are there any key issues to consider in relation to this population group, which will have an impact on need for care and support in West Wales? How can the impact be quantified?
2. What has / will be the impact of Covid-19, including 'Long COVID' on needs moving forwards?



3. Cross Cutting Themes

This section provides an overview of cross-cutting themes which apply across population groups. This also builds upon the themes identified within the 2017 Population Assessment.

There are a range of population stakeholder groups in West Wales which support our approach to continuous engagement, consultation and planning. These groups help us to reflect the lived experience of people within our Population Assessment.

3.1 Access to services

The 2017 Population Assessment identified the challenge that many disadvantaged groups face in accessing services to meet their care and support needs. A range of actions have taken place and will be an ongoing priority for the RPB. These include:

- The development of policies to ensure that it is as easy as possible for people to access support within their communities.
- Services should take account of language of choice, economic and cultural needs and additional needs such as physical, sensory and learning disabilities, neurodiversity, cognitive impairment and poor mental health
- The development of a single point of contact in each area, across the health and care system to make it easier to access relevant advice, information and support.
- The need to continue to develop technological solutions such as Assist My Life app, telehealth and virtual day-centres which assist people in accessing services

3.2 Assessment and diagnosis

Waiting times for assessment, diagnosis and treatment, as well as availability of support have been significantly impacted in Wales as the result of the COVID-19 pandemic. In West Wales, there is a need to continue:

- Improving availability of information available in relation to accessing community-based services for diagnosis
- Providing people with information regarding waiting times
- Increasing the range of support offered following diagnosis

3.3 Communication

There is a need to:

- Improve the consistency of information, advice and assistance across the region
- Ensure information, including care plans, are available in a range of formats such as easy read, sign language and braille and in the language of choice

- Continue to improve communication between organisations and professionals in relation to care planning to avoid people having to repeat their story.
- Increase the use of integrated information systems where all the information about a person is in one place and can be accessed by the right people across the different systems when it is needed

3.4 Use of Digital Technology

During the COVID-19 pandemic digital solutions were used by health and social care services to keep in touch with people, provide support, advice and information. This highlighted the potential and accelerated the use of digital technologies.

However, not everyone is able to access services in this way in West Wales. This is in part due availability of high-speed broadband or 4G coverage in some areas, access to suitable devices, as well as the confidence or skills to access support in this way. We must address this deficit.

We should also build on the experience during the pandemic to:

- Ensure a wide spectrum of people can access virtual services when and where appropriate
- Make better use of social media channels to engage with, inform and support communities
- Maximise the potential of digital and virtual support and telehealth to help people to manage certain conditions, address social isolation and reach those living in isolated communities
- Increase the use of assistive technology to enhance our direct care services such as domiciliary care and supported living

3.5 Embedding Co-production

There is more to do to ensure co-production is integral to our work by:

- Ensuring co-production is a key principle in developing sustainable community-based, user-led services
- Ensuring commissioners and providers co-produce services with those that use them
- Ensuring people needing care and support, their families and unpaid carers are involved in the decisions made about their care

3.6 Prevention & Wellbeing

In West Wales there are a range of 'preventative' services already available. The pandemic has led to increased isolation and a disruption of normal life. This could have short term effects on mental health and other conditions, as people may have been unable, or too concerned to access the support they would normally have. It is a priority for us to:

- Regain the momentum of community initiatives across the region that were paused during the pandemic
- Re-establish engagement activities and events that supported people to meet, share information and support and contribute to the development of services.
- Ensure preventative services are able to 'step up' to statutory services when people's needs increase and they require more support
- Further develop community-based services, that prevent isolation and support people to become more resilient and manage their own conditions
- Strengthen links with schools to identify groups of children, young people, families and unpaid carers, who may need additional support
- Improve access to mental health services at an early stage for both children and adults, thus preventing escalation and the need for referral to statutory services

3.7 Supporting our Workforce

Supporting and developing our workforce in health and social care remains a priority for us. Areas for attention include:

- Improving awareness and recognition of hidden conditions including, sensory and cognitive impairment, language and communication needs, neurodiversity and autism, Violence against Women, Domestic Abuse and Sexual Violence.
- Ensuring staff are aware of the range of services which are available within their community.
- Ensuring all staff have an awareness of safeguarding of adults and children

3.8 Transition

The time of transition from childhood to adulthood can be challenging. It can mean changes in arrangements for education, health, care and support and other aspects of a young person's life. To support a smooth transition, we should:

- Develop a regional transition policy that provides seamless and integrated support of families rather than a start/stop process
- Improve transition when accessing multiple services, particularly for children and young people who have complex needs

3.9 Voice and control

Putting the individual and their needs, at the centre of their care is a guiding principle of the Social Services and Wellbeing Act. It remains a priority for us to:

- Ensure assessment and care planning processes focus on what is important to people
- Ensure people have a choice in how their support needs can be met.

- Improve the range and choice of accommodation so people can continue to live independently in their communities
- Increase opportunities for volunteering, work experience, employment opportunities and networking for people living with a range of disabilities and conditions

3.10 Welsh language

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. A key principle of the original Framework – is that of the 'active offer', which places the onus on service commissioners and providers to deliver a service in Welsh without someone having to ask for it, is a continuing priority for those needing care and support in West Wales where, according to the Office for National Statistics in 2011, 37 % of the population over 3 years of age are Welsh speakers



4. West Wales Population Profile

The latest population estimates for the West Wales region are 389,719 (mid-2020) [1], an increase of 1.34% since the 2017 population assessment. This comprises of 191,368 males (49.1%) and 198,351 females (50.9%).

48.8% of the population in the region live in Carmarthenshire, 18.7% in Ceredigion and 32.5% live in Pembrokeshire.

Current population projections suggest the total population of West Wales will increase to 396,000 by 2043, with a rise in those aged over 65 from 94,336 in 2018 to 124,587 by 2043 [2]. This increase in the older population will be a key challenge.

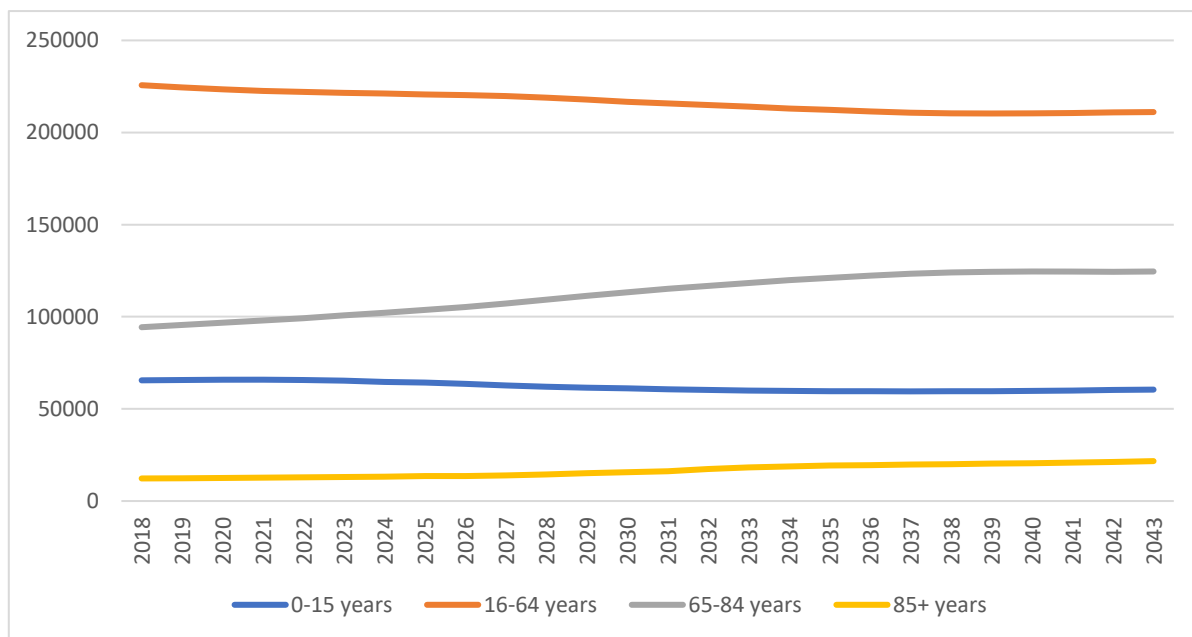


Figure 2: Population projections by age cohort in Hywel Dda University Health Board 2018 – 2043 (Welsh Government, 2018)

The following figures below show the population profiles for Wales and West Wales.

Figures 3 and 4 show that West Wales has an older population than Wales in general, with more people in the age groups of 55 and over, and less people in the 20 – 49 age range.

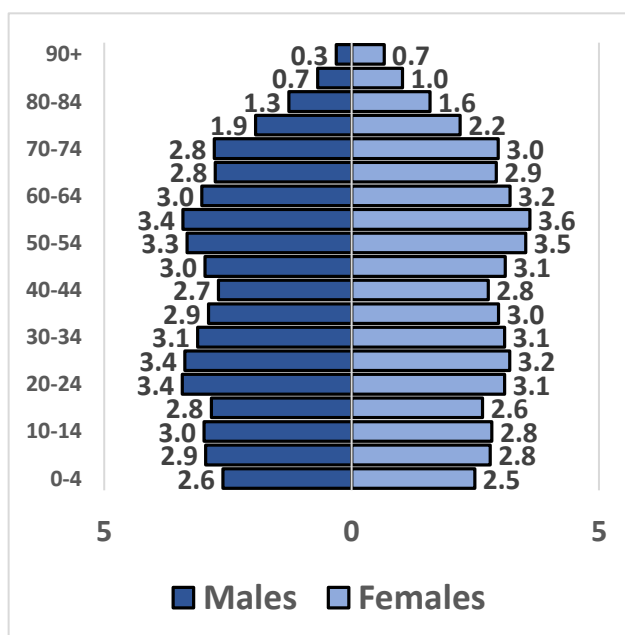


Figure 3: Population of Wales by gender and age group, mid-2020 (values presented as percentage of total population) (ONS, 2021)

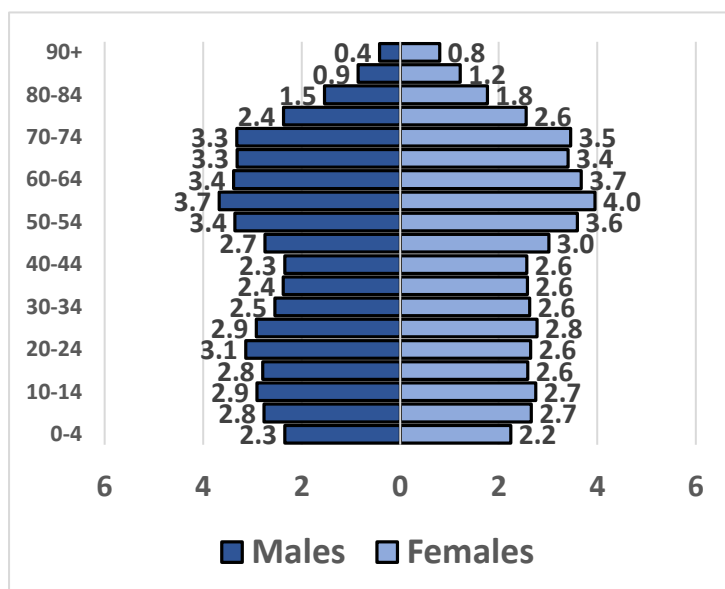


Figure 4: Population of West Wales by gender and age group, mid 2020 (values presented as percentage of total population) (ONS, 2021)

Table 1 below sets out key population statistics for West Wales, compared with Wales overall. It shows that West Wales has a higher proportion of people aged 75+ than Wales as a whole. West Wales also has a slightly lower proportion of adults who are overweight or obese when compared to Wales, as well as a slightly higher incidence of smokers and those who drink above guidelines.

The birth rate in West Wales is slightly lower than the national average.

Key Statistics	Wales	West Wales
Total Population	3,169, 586	389,719
Population aged 75 and over (%)	9.7	11.5
Adults who are overweight or obese (%)	60	59
Adults who smoke (%)	18.4	18.7
Adults who drink above guidelines (%)	19.0	20.0
Birth Rate (per 1,000 population)	10.3	9.0

Table 1: Key population statistics (HDdUHB Pharmaceutical Needs Assessment, 2021)

Table 2 below shows the life expectancy and healthy life expectancy for males and females in each of the three local authorities. Carmarthenshire has both a lower life expectancy, and less percentage of life expectancy in good health when compared to Ceredigion and Pembrokeshire.

	Males			Females		
	Life Expectancy	Healthy Life Expectancy	Percentage Life Expectancy in Good Health	Life Expectancy	Healthy Life Expectancy	Percentage Life Expectancy in Good Health
Ceredigion	80.1	67.9	84.7	83.9	69.7	83.1
Pembrokeshire	79.5	66.9	84.1	82.9	69	83.3
Carmarthenshire	78.6	65	82.7	82.6	66	79.9

Table 2: Life expectancy and healthy life expectancy in the three local authorities (HDdUHB Pharmaceutical Needs Assessment, 2021)

Differences in the composition of the populations for each of the three local authorities are illustrated in figures 5, 6 and 7 below.

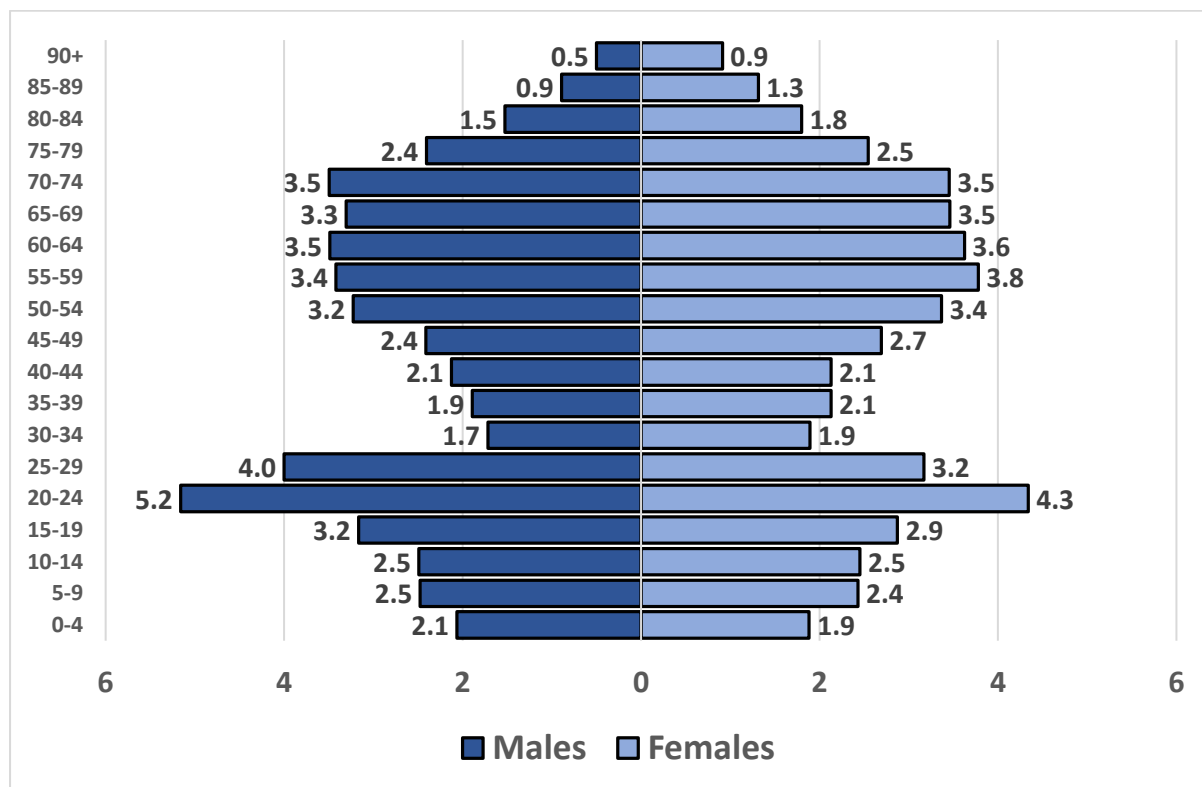


Figure 5: Population of Ceredigion by gender and age group, mid 2020 (values presented as percentage of total population) (ONS, 2021)

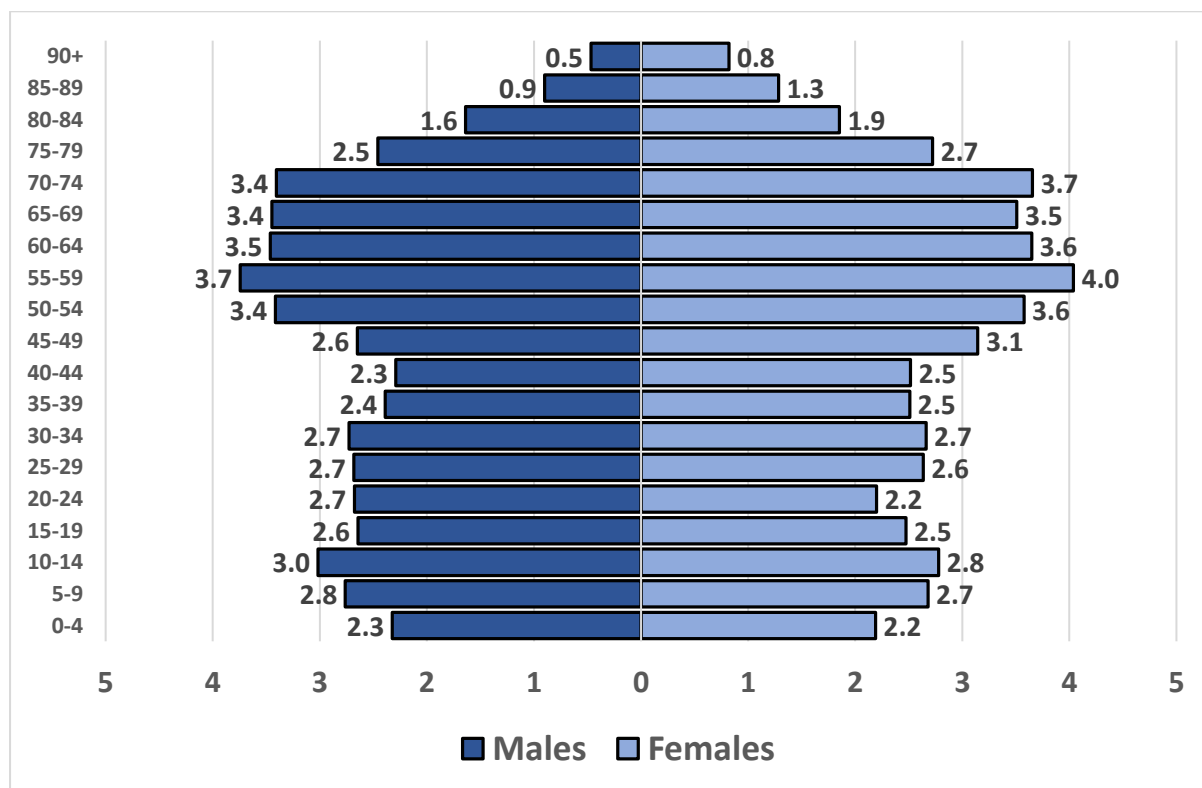


Figure 6: Population of Pembrokeshire by gender and age group, mid 2020 (values presented as percentage of total population) (ONS, 2021)

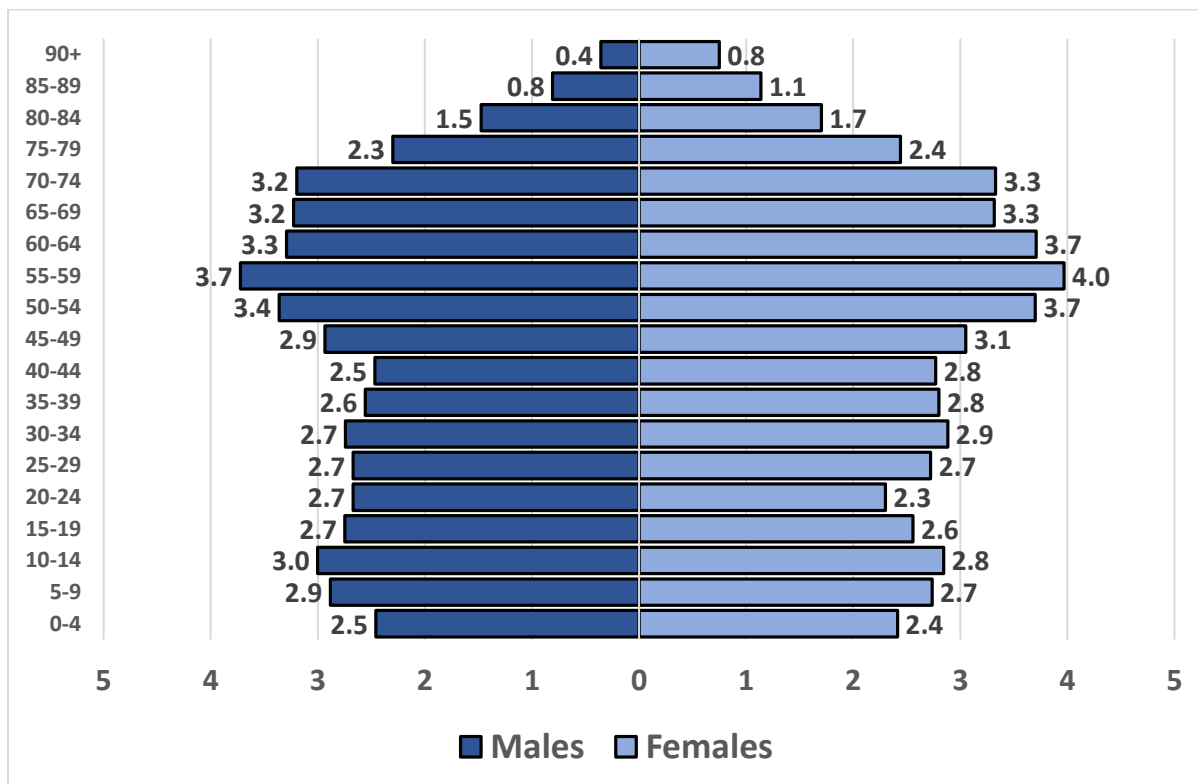


Figure 7: Population of Carmarthenshire by gender and age group, mid 2020 (values presented as percentage of total population) (ONS, 2021)

Ceredigion has a larger population of young adults aged 20-24 and 25-29 when compared to Carmarthenshire and Pembrokeshire due to its large University town.

4.1 Deprivation and Lifestyle Factors

Geographically based deprivation measures can be used to show inequalities in health. The Welsh Index of Multiple Deprivation (WIMD) is the Welsh Government’s official measure of relative deprivation for small areas in Wales. Figure 8 below shows there are some areas of deprivation in West Wales, mainly in less rural areas such as Llanelli, Pembroke Dock, Haverfordwest and Cardigan.

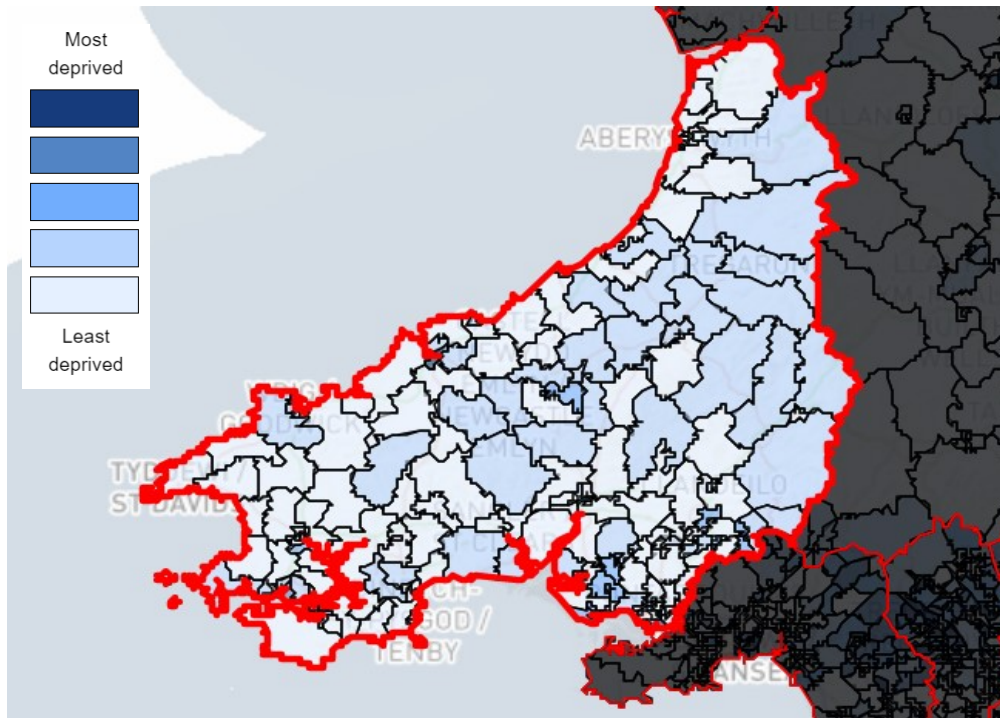


Figure 8: Welsh Index of Multiple Deprivation (WIMD) for the West Wales region (2019)

Generally, WIMD implies that deprivation is lower in West Wales than in the rest of Wales.

Of the 10% most deprived Lower Super Output Areas (LSOAs) in Wales, 10 are located in West Wales, which accounts for 4.4% of the LSOAs in the local health board. Furthermore, using the health metric of the WIMD, only 5 LSOAs are in the 10% most deprived for Wales (2% of those in the local health board).

Despite this, there are still some challenges to address. In Hywel Dda, 20% of residents drink more than the recommended guidelines, which is one of the top three health boards for this category, and higher than the Welsh average of 19%. This is due to Carmarthenshire (20.9%) and Pembrokeshire (19.8%) figures, whereas in Ceredigion only 18.4% of residents drink more than the recommended guidelines. Alcohol consumption among adults for each of the local health boards in Wales is shown in figure 9 below:

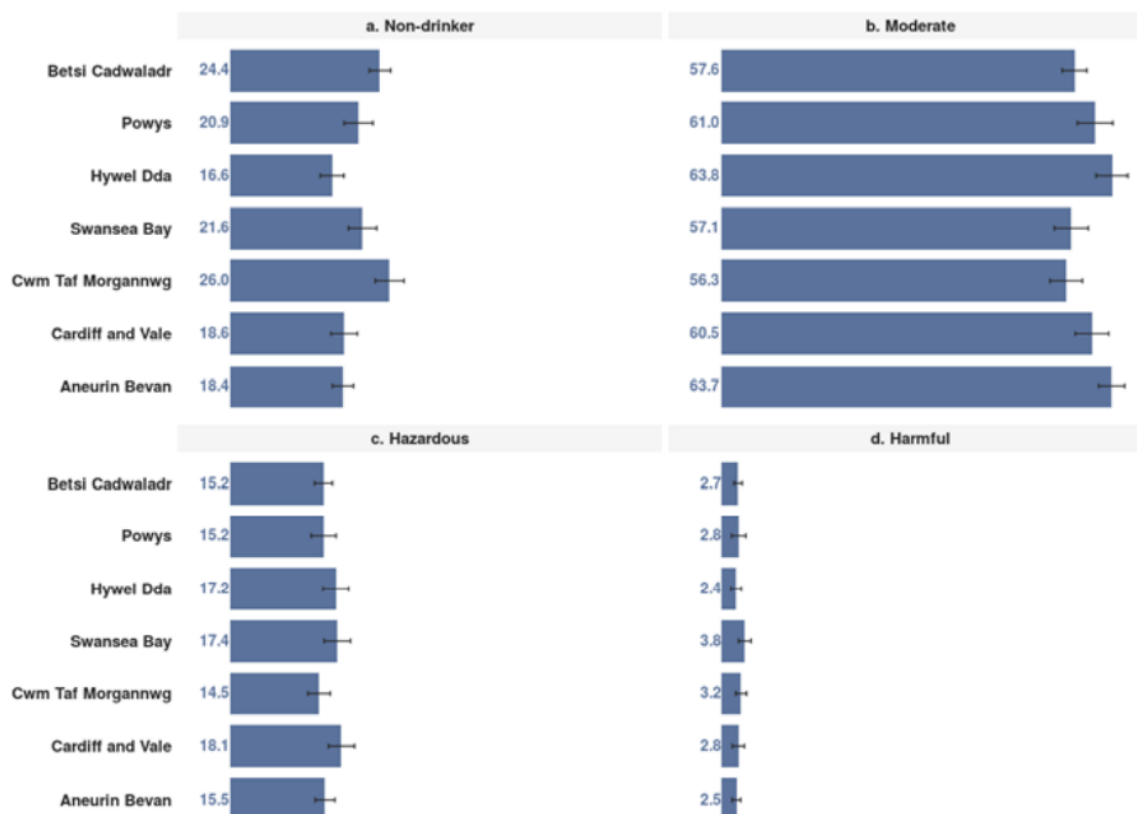


Figure 9: Alcohol consumption among adults for each local health board, 2016/17-2017/18 (HDdUHB Pharmaceutical Needs Assessment, 2021)

Obesity is a major challenge in Hywel Dda and across Wales, where more people are struggling to maintain a healthy weight. In Wales, currently 60% of adults are classed as overweight or obese, which compares to 59% in the Hywel Dda region. If current trends continue, it is predicted that 64% of adults in Wales will be overweight or obese by 2030 [3].

Prevalence of smoking is also slightly higher in Hywel Dda (18.7%) than the Welsh average (18.4%). Prevalence of smoking is highest in Pembrokeshire (20.3%), followed by Carmarthenshire (18.8%) and Ceredigion (16.6%) [3].

4.2 Further Information

More information on the West Wales population profile is available in the Hywel Dda UHB Pharmaceutical Needs Assessment [3], which provides further details on the demographic profile, lifestyle factors and other determinants that impact upon health in West Wales.

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

References:

[1] Office for national statistics Population estimates for the UK, England and Wales, Scotland and Northern Ireland - Office for National Statistics (ons.gov.uk)

[2] Welsh Government. Available at <https://statswales.gov.wales/Catalogue/Population-and-Migration/Population/Projections/Local-Authority/2018-based/populationprojections-by-localauthority-year>

[3] Hywel Dda UHB Pharmaceutical Needs Assessment. Available at <https://hduhb.nhs.wales/about-us/consultation-and-engagement/pharmaceutical-needs-assessment/>

5. Older People

5.1 Introduction

The Strategy for Older People in Wales 2013-2023 was published by the Welsh Government in 2021, with the following vision:

- that all people in Wales feel valued and supported whatever their age
- that all older people in Wales have the social, environmental and financial resources they need to deal with the opportunities and challenges they face

The strategy aims to improve the wellbeing of older people around social, financial and environmental factors. Building well-being and resilience is a key aim of the strategy, helping people to have a sense of control and purpose in life, reducing dependence and improving overall health.

The population of West Wales has a higher proportion of older people than the Welsh Average, and it is predicted that the elderly population will continue to increase in the coming decades.

High levels of inward migration contribute to the elderly population of West Wales and is an accelerating factor, especially in Pembrokeshire, which has an older population than Ceredigion or Carmarthenshire.

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 [2]. 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 [14].

5.2 Demographic Profile

It is estimated that the total number of people aged 65 and older in England and Wales will increase by 19.4% between 2015 and 2025, with the number with a disability increasing by 25%. [1]

There is an increasing number of older people in West Wales. Current population estimates for 2021 suggest that people over 65 make up 24.1% of the population in Carmarthenshire, 26.2% in Ceredigion and 26.7% in Pembrokeshire. The population by age group and gender in West Wales is shown in figure 10 below.

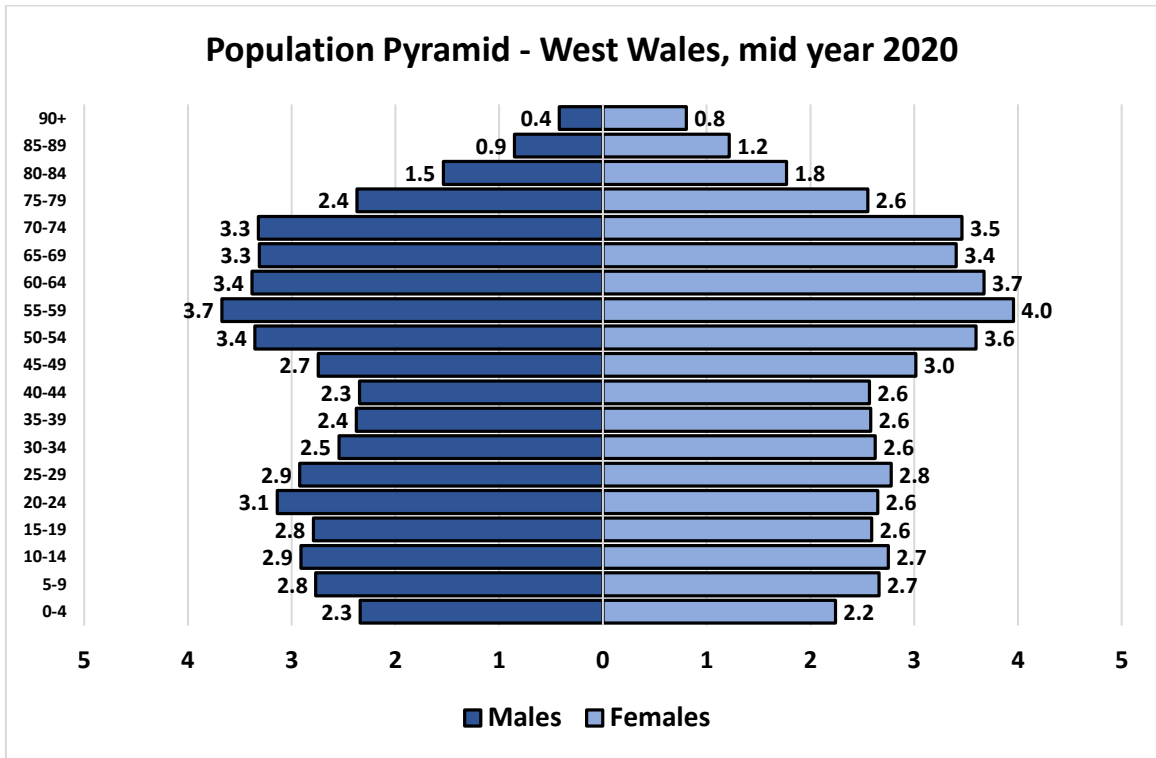


Figure 10: Population of West Wales by gender and age group, mid 2020 (values presented as percentage of total population) (ONS, 2021)

As large parts of West Wales are both rural and coastal, the area attracts high levels of inward migration of people over 65. The highest levels are found in Pembrokeshire, with a 31% migration rate, 87% of which are over 65. [3]

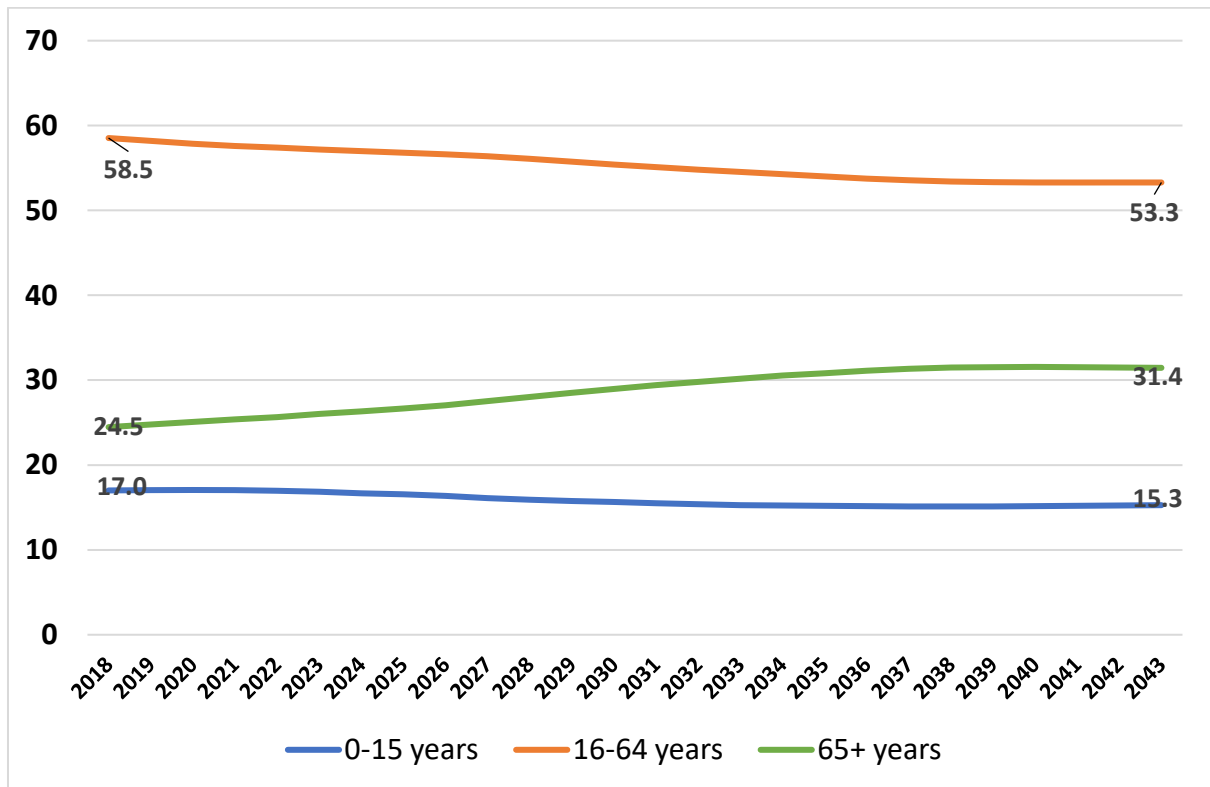


Figure 11: Population Projections by percentage of the total population in West Wales (Welsh Government, 2018)

As in the previous population assessment, the projected number of people aged over 65 is predicted to increase in each of the three local authority areas from until 2043 (Figure 12).

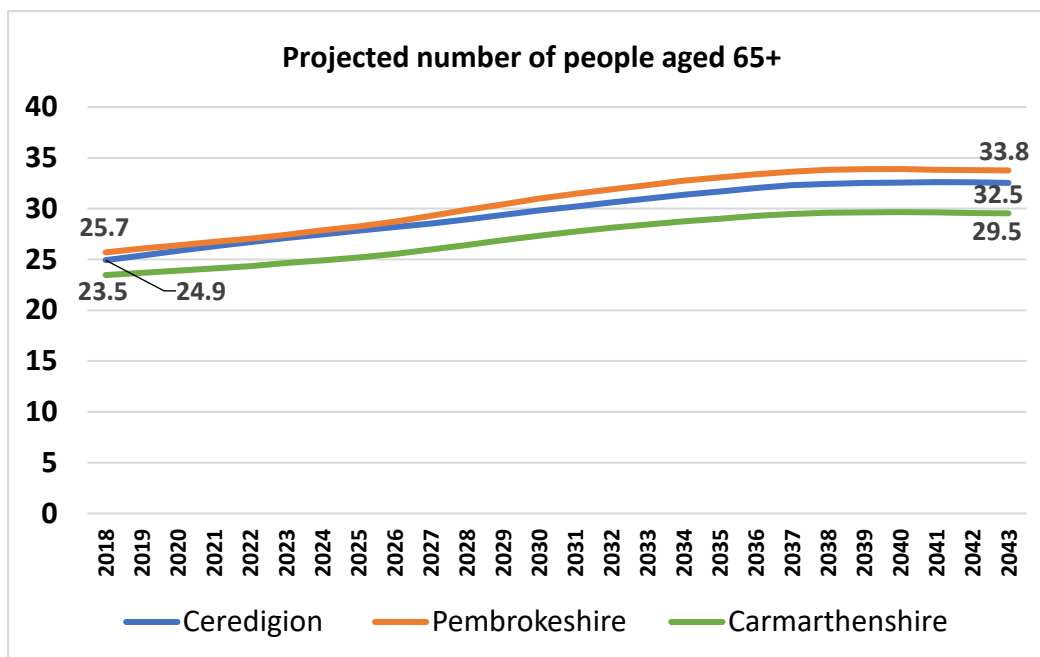


Figure 12: Projected number of people aged 65+ for each local authority (Welsh Government, 2018)

As shown in figure 12 above, Pembrokeshire is predicted to have a slightly larger proportion of its population in the 65+ age bracket, whereas Carmarthenshire is predicted to continue to have a slightly lower proportion of its population in the 65+ age bracket.

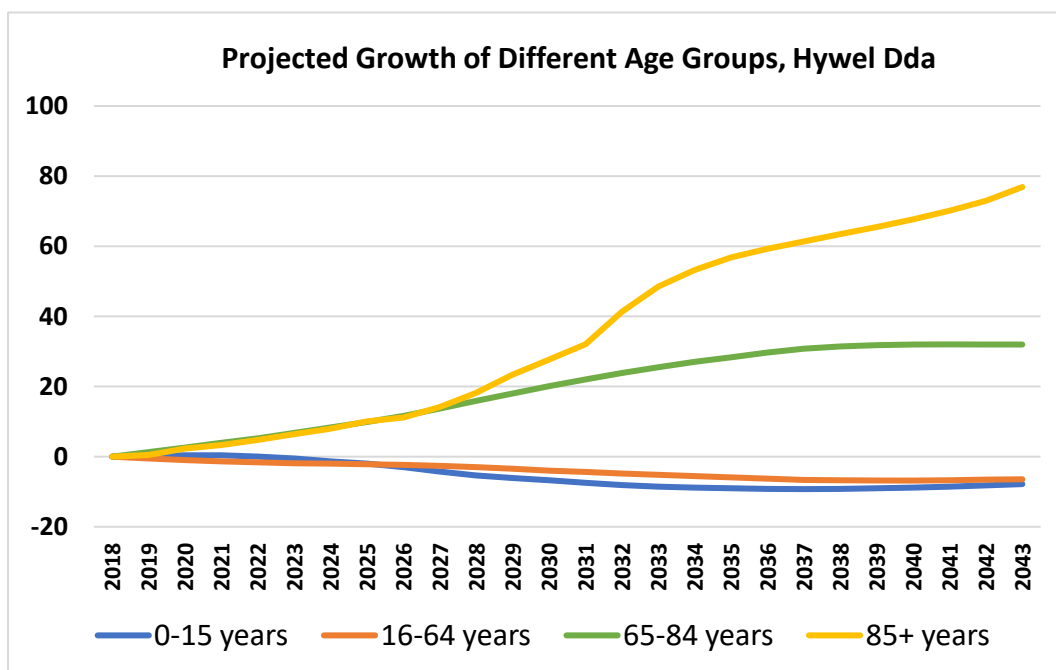


Figure 13: Projected growth for different age groups, HDdUHB (percentage growth compared to 2018 values)

As per the 2017 population assessment, the projections continue to predict an increasingly aging population in all three local authorities of the HDdUHB region.

Pembrokeshire is projected to be the local authority with the biggest percentage increase in people aged over 85, with the group almost doubling in size by 2043 (93% increase). This can be seen in Figure 14 below. This is likely due to the migration of pensioners to Pembrokeshire due to the access to countryside and coast.

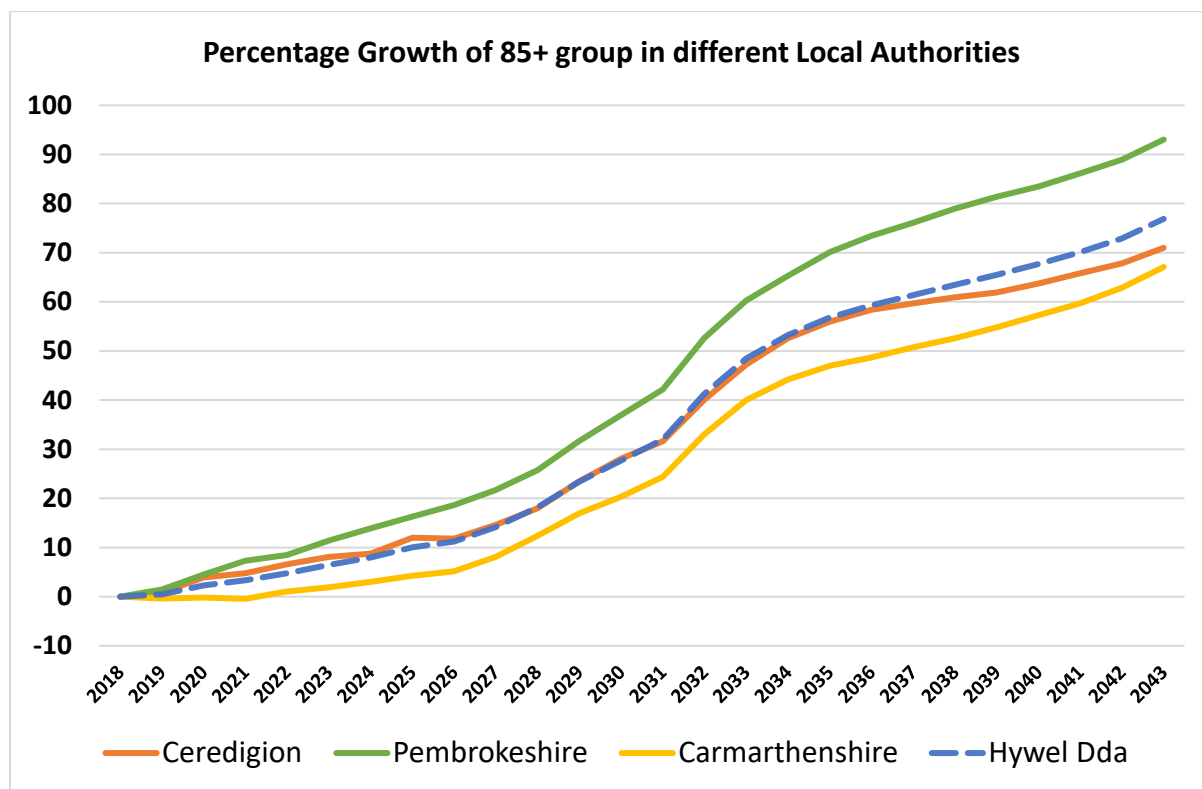


Figure 14: Percentage growth of 85+ group in different local authorities (Welsh Government, 2018)

5.2.1 Falls

Falls are a common problem amongst the older population. Current projections by suggest a modest increase in hospital admissions due to falls in people over 60 of just 10% towards 2043 [4].

Recent research has shown that falls prevention exercise programmes are effective at reducing falls in people aged 60 and over, with a reported reduction in falls of 23% for those who took part in any form of regular exercise [6]. Measures should be taken to encourage exercise in older people where possible, possibly the implementation of exercise programmes for older people should be considered.

5.2.2 Rurality

The West Wales region has a high proportion of rural areas. This could contribute to the ageing population due to migratory factors – the average age of rural areas was found to be increasing faster in 2013 [7]. Rurality also has impacts on housing,

deprivation, access to services and levels of physical and social isolation. Deprivation also has a big impact on health in older age – people living in the least deprived areas of Carmarthenshire can expect to live 14 years longer than those living in the most deprived areas [8].

5.2.3 Loneliness and Isolation

In West Wales, 45% of the aged 65+ group are living alone. Although historically, loneliness and isolation has been a problem that is thought to be more prevalent in older people, most recent data taken from 2019-20 suggests that people in Wales overall, the percentage of adults who are lonely according to the De Jong Gierveld loneliness scale is lower in the older age groups, with loneliness appearing to be a growing problem in younger adults [10].

The number of people aged over 65 in West Wales that struggle with activities of daily living is predicted to increase by almost 40% towards 2043 [4]. This could lead to further increased demand for carers.

In summary, West Wales has a higher proportion of older people than Wales, and the overall percentage of older people is predicted to rise over the coming decades. The demand for care is increasing however, people want to remain in their own homes with care provided, or in alternative settings such as extra care schemes. This demand has been accelerated by the COVID pandemic, which has negatively impacted people's views on residential care.

5.3 Care and Support Needs

The 2017 report emphasised the need for a holistic approach to care and support, able to respond to wide and varied levels of need and support the development of resilience and independence.

All partners in the region have continued to move towards a consistent model of care for older people based on the principles of wellbeing and prevention, encapsulated in the [Social Services and Wellbeing \(Wales\) Act 2014](#) and informed locally by a range of plans and strategies, including Ageing Well plans, the Health Board's Integrated Medium Terms 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) [17].

5.4 Current and Future Care and Support Provision

There is an increasing demand for extra care housing in Wales [15]; likely because it allows people to remain in housing accommodation, with the potential for extra care and support should they need it. This type of care allows for greater flexibility to maintain independence when compared to traditional residential home model.

Although technology enabled care has been increasingly utilised in response to the pandemic, this needs to be evaluated and a clear plan developed to realise the full

benefits of technology across the region. Although technology has improved the availability of care and support across the region, some of the older population are not confident in using technology. This needs to be considered when using technology in the future, so that care and support can be delivered effectively and appropriately.

A response to the lack of transport links within very rural regions that impacts on access to services also needs to be considered.

Older people spend 70-90% of their time at home, which means it is crucial for this environment to be conducive to supporting their wellbeing. The importance of housing quality for older people could have an impact on their care and support needs. The 2018 Housing and Ageing report [18] highlighted the need to place housing at the heart of service integration.

"Housing should be at the centre of attempts to support older adults, not on the edges, which is how the current situation is often perceived within health and social care integration."

For current care and support provision, please see Appendix 5B.

5.5 Gaps and Areas for Improvement

- Fewer people are choosing long-term residential care, creating a greater demand for community-based care and an increased need to develop alternative accommodation
- Whilst recognising that technology does not provide solutions for everyone, the evaluation, standardisation and development of services such as telehealth and telecare across the region could mitigate increasing demand for care and support where appropriate
- If current trends continue, 160,000 more people in England and Wales will need palliative care by 2040 [16]. In addition to improving palliative and end of life provision, increasing implementation of advance care planning would allow people to make informed choices before reaching crisis point and inform future development of services

5.6 The impact of the Covid-19 Pandemic

- COVID has had a significant effect on quality of life for older people. A UK wide survey conducted in April/May 2020 showed that being unable to access social support services due to COVID contributed to worse quality of life and increased anxiety in older adults and those with dementia [11]. Social support services need to continue to adapt to provide support services to those potentially affected by COVID in the future

- COVID has been responsible for the deaths of thousands of older people in Wales. During the first wave of COVID, there were an estimated 47,243 excess deaths in England and Wales, of which 41,608 were aged over 65. This includes an estimated 1,757 excess deaths in Wales [12]. In March and April of 2020 alone, there were an estimated 20,000 more deaths in the care sector of England and Wales than would normally be expected [13]. Additional exacerbating factors of the pandemic on the older population include the negative effect on mental health that come with the social isolation caused by lockdown, and possibly increased care needs due to the longer-term impact on health to survivors of COVID

5.7 Recommendations

- There is an increasing demand for older people needing care but wanting to remain in their own environment. Future support needs to focus on providing care and support for older people in their homes, allowing them to remain as independent as possible for as long as possible
- There is a need to further develop alternatives to residential care such as extra care. These changing demands have been fuelled by the COVID pandemic, which has negatively altered people's perceptions of residential care
- Pembrokeshire has an older population than Carmarthenshire and Ceredigion. This could mean there are greater demands for services for older people such as community-based care
- Continue to develop technology enabled care initiatives such as telehealth and telecare across the region, which will improve access to care especially in very rural areas, and potentially help people to remain independent in their homes for longer
- Consider the impact of fuel poverty on overall health and well-being, which is projected to increase over the coming years
- Ensuring that services are available through the medium of Welsh

For current legislation and regulations see Appendix 5A

For current care and support provision see Appendix 5B

For additional data see Appendix 5C

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6. Dementia

6.1 Introduction

The dementias are a group of disorders, characterised by a continual and progressive dying of brain cells, that leads to a deterioration in physical and cognitive functions that are beyond what might be expected from the usual consequences of biological ageing. It affects memory, attention, sensory changes, language, thinking and problem-solving skills.

The impairment in cognitive function is occasionally preceded by, or commonly accompanied by, changes in an individual's psychological wellbeing. Behaviour Expression of Unmet Need (BEUN) can also become more apparent when the wellbeing of the individual becomes compromised in some way, leading to carer stress and placement breakdown.

Young onset dementia is defined as those under 65 that are diagnosed with dementia. People living with dementia (PLWD) include those who are pre-diagnosis, post diagnosis, their families and carers.

The Dementia Action Plan for Wales (DAP) 2018 – 2022 sets out a clear vision for *"Wales to be a dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities."*

In response, the west Wales region has commissioned the development of a [Regional Dementia Strategy](#) to support implementation of best practice focussing on:

- Considering dementia as everybody's business
- Improving diagnosis rates and subsequent care planning and management, including those for young onset dementia
- Enhancing community preventative services
- Implementing best practice within social care, domiciliary care, care homes and specialist services
- Ensuring advance care planning for end-of-life care is fully embedded in wider inclusive, personalised care and wellbeing planning
- Improving access to support for carers

6.2 Demographic Profile

Dementia is becoming increasingly prevalent in ageing populations of high-income countries across the world. As life expectancy and inward migration of older people impacts on the percentage of older people in West Wales, the number of people living

with dementia in the region is expected to continue to increase over the next couple of decades. It is therefore important to identify what services we will need to invest in to support people to maintain their independence, live as well as possible following diagnosis and remain living in their residence of choice for as long as possible.

Dementia is a condition that cuts across system wide services and is therefore everybody's business. It is important to recognise that dementia services need to be embedded in the whole system of provision.

West Wales has the highest proportion of people over the age of 85 in Wales, due in part to inward migration, the popularity of West Wales as a retirement destination, and the outward migration of young people unable to find employment in their own communities.

As the incidence of dementia is strongly linked with age, it is therefore very likely that we will see an increase in the number of people living with dementia.

The previous Population Assessment carried out in 2017 included dementia within the 'older people' population group, with young onset dementia included as a mental health issue. This assessment however requires a separate section outlining the care and support needs of PLwD.

- The older adult population in West Wales is set to increase, whilst the child and working age adult population is set to decrease:
- By 2025 the population of over 65s is expected likely to increase by 6% (over 80s by 11%)
- By 2040 the population of over 65s is predicted likely to increase by 27% (over 80s by 55%)
- The over 65s currently make up a quarter of the population and the over 80s make up just over 6%
- By 2040 nearly a third of the population is expected to be made up of over 65s, with the over 80s predicted to increase to over 10% (from just over 6% currently) (ONS)
- The incidence of dementia on the Quality Assurance and Improvement Framework (QAIF) disease register in Hywel Dda in 2019-20 was 0.7%, in keeping with the Welsh national average of 0.7%
- As there is thought to be a diagnosis gap of around 50% in west Wales, actual prevalence is likely to be closer to 1.4%
- In 2015, dementia became the leading cause of death in the UK and has continued to displace other causes of death; pre-COVID, dementia was the leading cause of death in the UK, representing 12.7% of all deaths
- Over thirty genetic, medical, lifestyle, cultural and societal factors have been identified that impact the risk of cognitive decline differently, depending on gender. Because of the unique aspect of the female brain, some of these factors increase risk more dramatically in women than in men. Importantly, hormonal changes in the years leading up to and after the menopause have been shown to act as key underlying mechanism that can activate these risks as well as existing predispositions

Predicted number of people with dementia in Hywel Dda Regions, 2020 – 2040 (Attain, WWCP).

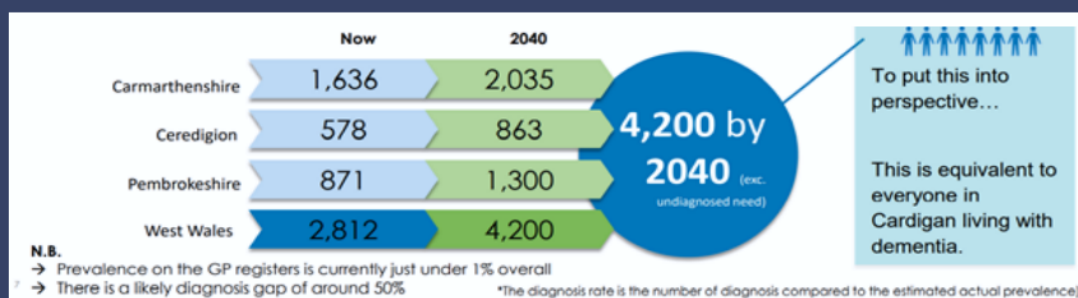


Figure 15: Predicted number of people with dementia in HDdUHB 2020-2040 (Attain, WWCP)

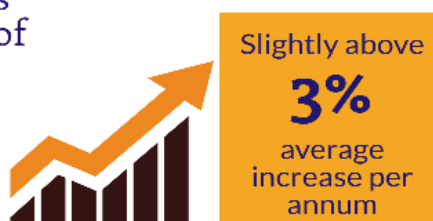


Alzheimer's society UK estimates dementia affects **one in six** people **aged 80+**
*West Wales records suggest dementia affects **1 in 10** of those over 85

Dementia Action Plan for Wales says Health Boards should aim to improve diagnosis rates by.....

3% per annum

In 2016-17 dementia diagnosis rates in the Hywel Dda region were one of the lowest in Wales at 45.6%. The numbers of those diagnosed with dementia in the Hywel Dda region have increased from 2499 per annum in 2016 to 2947 in 2020



62% of those diagnosed with dementia in West Wales are women.



In West Wales...
50% of female dementia patients are over 85
36% of male dementia patients are over 85

Figure 16: Dementia statistics (Alzheimer's Society UK)

6.3 Care and Support Needs

A [Regional Dementia Strategy](#) has been commissioned in collaboration with a range of partners across West Wales. The aim of the strategy was to identify current and future care and support needs, to ensure that the support provided for people living with dementia in West Wales is co-produced, person-centred and based on best practice.

6.4 Current and Future Care and Support Provision

The new pathways that are being developed demonstrate the continuing shift towards a more integrated approach to service delivery, whilst continuing to refine best practice in existing services within West Wales.

There is much to be commended in current service delivery. However, the co-productive approach taken to developing the dementia strategy and the engagement activity undertaken to develop the needs assessment has confirmed the gaps in services and have identified areas for improvement.

In addition, a new wave of data suggests that dementia is preventable, leading to a drive to deliver direct clinical care to improve brain health, with a focus on both risk assessment and early intervention.

For current care and support provision, please see Appendix 6B.

6.5 Gaps and Areas for Improvement

The list below identifies gaps and areas of improvement that have become apparent during our engagement process. The list however is not exhaustive; it is to be expected that as the strategy and new pathways are developed, further gaps and areas for improvement will be identified and the strategy will be amended accordingly.

The gaps and areas for improvement identified have outlined the need for the following actions:

- Continuing to improve awareness, identification and diagnosis of dementia, so that people with dementia have a timely diagnosis and can access appropriate care and support and long-term care when and where required
- Improving co-production of services by including PLwD in service design.
- Agreeing a set of delivery principles to underpin development of pathway models
- Building on the dementia training framework, the learning and development requirements of those supporting PLwD in communities should be reflected and addressed through organisational workforce strategies.
- Increasing diagnosis rates in non-specialist community settings by:
- Improving training and awareness of new dementia models within primary care, based on the Good Work Framework
- Supporting GPs, allied health professionals (AHPs) and nurses to make assessments
- Improving quality of referrals into specialist care for those that require it

- Continuing improvements in community support, training and help for PLwD to discuss their diagnosis, navigate/co-ordinate services, to build resilience and maintain balance across all aspects of their life
- Developing more consistent person-centred care across the region.
- Ensuring equal access to physical health services and treatment for PLwD, as poor physical health is an inevitable consequence of dementia
- Ensuring any health issues are factored into person-centred planning and end of life care
- Continuing improvements in awareness of and implementation of advance care planning and end of life care, so that PLwD die with dignity in a place of their choosing
- Improving research into dementia by involving care homes in the region in research opportunities
- Building on emerging data and intelligence to inform future service development
- Continuing the development of a “hub” or single point of contact approach for PLwD to access information and support for:
 - Support staff, including dementia support workers, admiral nurses etc
 - Support groups for PLwD and their carers
 - Access to local dementia services
 - Training programmes for carers
 - Activities for PLwD
 - Dementia cafes
 - Memory clinics
 - Finance/legal/benefits advice
 - Involvement in research opportunities

6.6 The impact of the Covid-19 Pandemic

The COVID-19 pandemic has had a disproportionately negative impact on PLwD ([The Impact of COVID-19 on People Affected By Dementia \(alzheimers.org.uk\)](https://www.alzheimers.org.uk)) and dementia has also been shown as an age-independent risk factor for severity and death in COVID-19 patients [1].

Although the exact impact of COVID on the diagnosis and incidence rate of dementia is unclear, stakeholders have identified that COVID has impacted timely diagnosis due to late presentations.

There is also some concern that in some cases, COVID causes damage to the brain and long-term, this could lead to increased risk of developing dementia ([How Covid-19 can damage the brain - BBC Future](https://www.bbc.com/future)). However, full information on the impact of COVID upon those with dementia and their carers is not yet available.

Technology has been shown to contribute to patient and carer resilience during COVID. Just being able to communicate has benefits in allowing to sustain contact with previous activity groups and hobbies [2]. However, not all PLwD are able to adapt well to using technology and may require others present to support them in using technology, as they may be unable to do this independently due to their dementia.

6.7 Recommendations

- Further refinement of integrated service model in line with the West Wales Dementia Strategy.
- Further development of initiatives to encourage early diagnosis and improve diagnosis rates by 3% per annum
- Implementation of care pathways as agreed in the regional strategy, particularly post-diagnostic support and coordination for PLWD and their carers
- Enhancing support for those caring for family members with dementia.
- Expanding support for care homes to care for residents with dementia

For current legislation and regulations see Appendix 6A

For current care and support provision see Appendix 6B

For additional data see Appendix 6C

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7. Unpaid Carers

7.1 Introduction

The Social Services and Well Being (Wales) Act 2014 defines an unpaid carer as a person, of any age, who provides or intends to provide care for an adult or child.

An unpaid carer can be anyone, of any age, who provides unpaid care and support to a relative, friend or neighbour who is disabled, physically or mentally ill, or affected by substance misuse. Unpaid carers are the single largest provider of care to people with support needs in our communities, saving the NHS and Social Services millions of pounds a year [1].

Over recent years there has been progress towards recognising and supporting unpaid carers through legislative changes. These include adoption of the Social Services and Wellbeing (Wales) Act 2014, the Well-being of Future Generations (Wales) Act 2015 and the long-term plan for health and social care "A Healthier Wales".

It is important that we can identify unpaid carers, or assist them to self-identify, to enable them to access the right help and support, at the right time, to help them to fulfil their role.

It is also important to provide unpaid carers with support to maintain their own health, well-being and independence. The 2019 GP Patient Survey (England) found that unpaid carers are more likely than non-carers to report having a long-term condition, disability or illness (63% of unpaid carers compared to 51% of non-carers).

Support for unpaid carers in West Wales is overseen by the West Wales Carers Development Group* (WWCDG), which is a sub-group of the West Wales Regional Partnership Board (RPB).

**The West Wales Carers Development Group includes representatives from Hywel Dda University Health Board, the three Local Authorities of Carmarthenshire, Ceredigion and Pembrokeshire, as well as Third and Voluntary sector organisations and representatives of service users and Carers in West Wales"*

7.2 Demographic Profile

The following points outline some key facts that are relevant to unpaid carers in West Wales:

- In Wales, more than 370,000 unpaid carers, of all ages, provide care that is estimated to be worth around £8.1 billion to the Welsh economy each year [2]
- It is estimated that 3 in 5 people in Wales will become an unpaid carer at some point in their lives [3]

- Carers Wales' 'Missing Out' report noted that, in Wales, 55% of unpaid carers took more than a year to recognise their caring role, while 24% took more than five years to identify as a carer [4]
- Research from Carers Trust Wales (2015) suggests that Young Carers have significantly lower educational attainment at GCSE level and are significantly more likely to become NEET (not in education, employment or training) between the ages of 16 and 19, than those without caring responsibilities [5]
- Problems with school attendance or attainment can have an impact on the future of Young Carers, often resulting in unemployment, reduced earnings, poor health and depression
- Estyn in 2019 reported that many secondary schools, colleges and pupil referral units do not know which learners have a caring role at home and identified the importance of improving provision and outcomes for Young Carers. [6]
- Census data (ONS, 2011) records more than 47,000 unpaid carers in West Wales, with 3,436 of these falling into the Young Carers category (5-17 years old); this equates to 12.5% of the residents of West Wales, with a large number of 'hidden' carers not included in these figures [7]
- Based on a national calculation (Carers UK and Sheffield University, 2015; Buckner and Yeandle, 2015), the cost of replacing unpaid care in West Wales would be around £924m. This exceeds the total NHS annual budget for the region, which is almost £727m [8]

7.3 Care and Support Needs

In January 2020, the WWCDG engaged with unpaid carers, with input from relevant support organisations, to find out 'what mattered to them'. Engagement was primarily undertaken via a survey, with the aim of the exercise being to improve outcomes for unpaid carers in West Wales. Some of the survey results are listed below:

- Only 38% of respondents to the West Wales Carers' survey indicated that they recognised their role immediately, or within 6 months of becoming a Carer; 49% agreed that they had missed out on support as a result
- 26% of those who responded to the WWCDG Carers survey indicated that they were in employment, with 91% of these aged 35-64
- Survey respondents in the 35-44 age group felt that being a Carer had impacted negatively on finances, work, physical and mental health, as well as on relationships
- 64% of people commented that caring has had a negative impact on their own physical health and mental wellbeing
- Only one-fifth of respondents to the WWCDG Carers survey indicated that they had spoken to a health, social care or third sector organisation about what to do if the condition of the person they care for deteriorates, or they are no longer willing to provide care
- We identified that some things matter more to younger people - or have a greater impact on them; this means we need to plan action that takes account of the different needs of unpaid carers across the different age groups

The information that was gathered from the engagement was used to develop a long-term strategy for unpaid carers called 'Improving lives for Carers' ([Carers-Strategy-Final-20.10.20-Eng.pdf \(wwcp.org.uk\)](#)).

7.4 Current and Future Care and Support Provision

A report by the Social Care Institute for Excellence (SCIE) (2018) reported that Wales has the highest proportion of older unpaid carers and those providing more than 50 hours' unpaid care a week.

A 'Track the Act' report by Carers Wales (October 2019) predicted that the number of unpaid carers across Wales will increase significantly in the coming years. By 2037, it is estimated that the unpaid carer population will rise from 370,000 to over half a million.

West Wales has an ageing population that is expected to increase in magnitude over the next 5 years. People are living longer, often with limiting health conditions. Inevitably, this will increase the number of people requiring additional care and support from both unpaid and paid carers.

The experience of lockdown during the COVID-19 pandemic recognised the need to safeguard vulnerable people who are more at risk, many of whom rely on unpaid carers and community support.

The COVID-19 pandemic has seen an increase in the self-identification of unpaid carers. A National Survey for Wales report (June 2020) showed a 35% increase in the number of people recognising they look after or give help and support to family members, friends and neighbours.

The Carers Information and Support Service across West Wales reported an increase of 2,073 in unpaid carers during 2020/21 (from 8,008 to 10,081):

- Carmarthenshire, Carers Trust Crossroads Mid and West Wales reported a 31%, from 4,613 to 6,071
- Hafal Crossroads, who provide information and support in Pembrokeshire, reported an increase in numbers from 2,570 to 2,918
- Ceredigion Carers Unit reported the number increased by 267 from 825 to 1,092

For current care and support provision, please see Appendix 7B.

7.5 Gaps and Areas for Improvement

The Gaps and Areas for improvement are comprehensive and reflect the engagement work undertaken to develop the West Wales Improving Lives for Carers Strategy published in 2021.

7.5.1 Impact of being a carer on well-being and mental health

Being an unpaid carer, whilst being inspiring and rewarding, can leave them feeling:

- Exhausted, isolated and in need of emotional support and counselling
- Concerned over the financial burden of being an unpaid carer and its effect on their employment
- They have lost the ability to maintain a balance between the caring role and work-life balance
- They have lost their identity beyond that of being a carer
- Their 'voice' is not well enough recognised
- The WWCDG Carers survey revealed that 75% of former unpaid carers who took part in the survey felt that they had experienced a negative impact on their physical health and mental well-being due to their caring role

7.5.2 Supporting the needs of carers

Self-identification of unpaid carers and identification and recognition of their role by health and social care professionals is vital to ensure that they access the right help and support at the right time, as well as maintain their own health, well-being and independence. Unpaid carers report:

- There should be an improvement in the consistency of approach, information, advice and assistance provided across the region, within a more integrated system
- Information provided to carers needs to be reviewed to ensure it is current and relevant, more accessible and easier to find. Having a single point of contact to navigate the system would help people to identify relevant information and access the support to which they are entitled
- Access to appropriate respite should ensure that it fits the needs of both the carer and the looked after person
- Support is particularly difficult to source in rural areas
- The statutory carers assessment process can be challenging, often takes too long and carers needs are not always properly considered. Whilst it is recognised that not all unpaid carers need or want a statutory carers assessment, it is important that those that do, know how to apply and outcomes are reviewed to reflect changing needs or circumstances
- Response to the WWCDG Carers survey indicates that 81% of people had not had a Carer's assessment or review of their assessment within the last 12-months
- 62% of those surveyed who had an assessment or review during the transition from children to adult services, felt that the assessment process and subsequent consideration of the care and support needs did not consider their needs properly

7.5.3 Digital Inclusion and Technology

Digital connectivity has become even more important since the Covid-19 pandemic. Engagement events identified:

- Most people are using technology but not all. Efforts must be made to ensure technology is available to all and that digital inclusion (and training) as well as non-digital alternatives are offered
- Better use could be made of social media channels to identify and provide information to carers, particularly for young carers
- Technology could be used to make it easier for support staff to keep in regular contact with the carer to make sure they do not burn out

7.5.4 Young People

Many young carers and young adult carers fed back that their caring responsibilities mean:

- They struggle to have a break, are not seeing their friends and do not have their own space
- They find it difficult to balance schoolwork, homework and their caring role and can feel stressed, worried and anxious at school, as they are away from the person that relies on them for care
- They may need extra support especially for their mental health and wellbeing

7.6 The impact of the COVID-19 Pandemic

During the COVID-19 pandemic the role of unpaid carers has become more prominent. The experience of lockdown during the COVID-19 pandemic, and the need to safeguard people who are more at risk of the disease, has further highlighted the important role that unpaid carers play within our communities [9].

Hywel Dda University Health Board (HDdUHB) has been proactive in supporting unpaid carers to access COVID Testing and, more recently, identifying unpaid carers through eligibility checks for COVID-19 vaccinations. This resulted in over 3,000 unpaid carers self-identifying between April - May 2021, who had not registered previously as an unpaid carer with their GP practice [10].

As part of HDdUHB action to make every contact count, the Health Board Carers Team provided follow up information to each newly identified carer including information about third sector support services and the Introduction to Looking After Me courses delivered by the Education Programme for Patients.

Many unpaid carers have felt increasingly isolated due to the COVID-19 pandemic. Some of the concerns expressed in engagement events and feedback from an on-line survey circulated as part of the process to develop the PNA highlighted the following:

- Many were very cautious of people coming into their homes due to the risk in virus transmission, with many choosing to suspend domiciliary care. This increased their isolation and put further strain on their wellbeing and mental health
- Many experienced financial pressure, as they had to take more time off work to support their cared for person
- A reduction in access to respite care as care homes closed their doors to new clients increased their isolation and put further strain on their wellbeing and mental health

- Many were concerned about the adverse effect on the well-being of loved ones, due to the strict visiting restrictions in hospitals and care homes
- Young carers missed the break from caring and social interaction with peers that schooling (suspended during lockdown) usually provides
- In some instances, unpaid carers reported they were able to access more support due to the increased availability of services on-line because of the pandemic

7.7 Recommendations

The recommendations below are an excerpt of those identified in the West Wales Carers Strategy 2020-2025 ([Carers-Strategy-Final-20.10.20-Eng.pdf \(wwcp.org.uk\)](#)).

The recommendations are:

- Ensure that staff in health, social care, education (schools and colleges), and other public, private and third sector organisations are “carer aware” and have robust systems in place to proactively identify unpaid carers, including Young Carers and Young Adult Carers
- Ensure that statutory partners, working with the third-sector, commission sufficient capacity to enable staff to signpost to support and respond proactively to the unprecedented increase in carers identified during the pandemic
- Continue to increase the number of settings achieving an Investors in Carers award, recognising the contribution this scheme makes to ensuring that people have greater awareness of what care and support services are available to them locally, and are supported to have a voice and control over their care and support needs
- Deliver a programme of carer awareness campaigns linked to national days and events e.g. Carers Week, Young Carers Day, Carers Rights Day to promote the identification and self-identification of Carers
- Develop a Carers ID Card scheme across the region that supports unpaid carers to self-identify and access Carer-based support / benefits
- Promote and identify opportunities for unpaid carers of all ages to be involved in the co-production of services to ensure they are given the opportunity to shape and influence services
- Raise awareness of unpaid carers with employers, including small and medium enterprises, through the Employers for Carers Scheme. It would also be helpful to look at a way of ensuring consistency in the use of the term ‘Carer’ across all public bodies and departments. It may help to identify an agreed name for Care Workers in Health and Social Care which differs from the term ‘Carer’
- Review the support offered to Young Carers in West Wales and engage Young Carers in the process to ensure a best practice innovative service is recommissioned.
- Rollout the Resilience and Well-being facilitator training, to extend the support offered to those in employment with a caring role
- Actively promote the regional Employers for Carers membership, focusing on working collaboratively with other public sector services as well as small and medium size enterprises (SMEs)

- Continue to encourage involvement in the Investors in Carers accreditation scheme and support progression through the award levels
- Work with others, including commissioned services to maximise the potential of digital services

For current legislation and regulations see Appendix 7A

For current care and support provision see Appendix 7B

For additional data see Appendix 7C and the carers strategy [Carers-Strategy-Final-20.10.20-Eng.pdf \(wwcp.org.uk\)](#)

References:

- [1] <https://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>
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- [9] <https://phw.nhs.wales/publications/publications1/voices-of-carers-during-the-covid-19-pandemic-messages-for-the-future-of-unpaid-caring-in-wales/>
- [10] WWCDG-Annual-Report-2021-21-FINAL <https://www.wwcp.org.uk/wp-content/uploads/2020/11/Carers-Strategy-Final-20.10.20-Eng.pdf>

8. Learning Disabilities

8.1 Introduction

People with learning disabilities (PwLD) have a reduced ability to understand new or complex information and learn new skills. In addition, PwLD often have a reduced capacity to live independently.

In the West Wales region there are approximately 2,588 adults (16+) living with moderate or severe learning disability (LD). Some people with a severe learning disability can also have a complex range of other difficulties or disabling conditions requiring a high amount of specialist care and support. This group are referred to as people with Profound and Multiple Learning Disabilities (PMLD). There are a significant number of people with PMLD in West Wales, some of whom continue to experience significant inequalities in the services they receive.

8.1.1 Classification of a learning disability

PwLD are not one singular homogenous group, they have diverse needs and goals. LD is often classed in terms of its severity: mild (a person able to live independently with minimal help), moderate (able to live independently in appropriate accommodation with the right support), or severe (unable to live independently and reliant on carers). In addition, it is not uncommon for people with LD to also have other diagnoses/conditions such as: Down's syndrome, autism, physical disabilities, sensory impairment, communication impairment etc.

Some people with LD may always need full assistance with every activity of living because of their diagnosis and prognosis, but that should not impact on, or detract from, their right to have a fulfilling life. Others with more moderate impairments should have the choice to manage with less support.

8.1.2 Health facts and inequalities associated with LD

Learning disabilities are not always apparent and can sometimes be difficult to identify, which can lead to PwLD not having the care and support they need or would choose.

PwLD face many health inequalities. They are more likely than other people to experience poorer health with poorer self-rated health; physical health; psychological distress; or multiple morbidities. Behavioural risk factors are more common such as poor diet, low levels of physical activity, smoking, alcohol use and resistance to access health services.

They are less likely to be employed for 16 hours or more per week; live in a high-quality neighbourhood or feel safe outside in the dark. They are more likely to experience financial hardships; social isolation; being threatened; actual violence or being a victim of hate crime.

8.2 Demographic Profile

Results from the 2019-2020 Quality and Outcomes Framework (QOF) register indicates an incidence rate of people with LD in the West Wales region of about 0.5%. The value is the same as that recorded for the whole of Wales.

At a local authority level, the incidence is higher in Carmarthenshire (0.6%) compared to Pembrokeshire (0.5%) and is lowest in Ceredigion (0.4%). The QOF register is based on data collected from Local authorities who submit numbers of all persons identified as having LD currently known to the authority and included in a register of records for the purpose of planning or providing services. The register of PwLD data may be an underestimate as registration is voluntary and does not account for people undiagnosed.

8.2.1 Children and Young People

The total number of children and young people with LD (aged 0-17) in West Wales is currently predicted at 2,978 in 2021. The total number of children with LD is expected to remain consistent over the next 10 years (see Appendix 8C) for all categories of severity. The current prediction of the number of children and young people (aged 0-17) with LD in each of the LA is:

- Moderate LD: 1,206 in Carmarthenshire, 770 in Pembrokeshire, and 395 in Ceredigion
- Severe LD: 241 in Carmarthenshire, 154 in Pembrokeshire, and 79 in Ceredigion
- PMLD: 68 people in Carmarthenshire, 43 in Pembrokeshire, and 22 in Ceredigion

8.2.2 Adults

A current estimate of the number of people (aged between 17 and 65) with LD in West Wales, is provided by people claiming financial support in West Wales through Personal Independence Payments (PIP) and DLA.

The number of people claiming PIP in November 2020 is 2,264 (1,160 in Carmarthenshire, 770 in Pembrokeshire and 334 in Ceredigion). Figure 17 shows a steady increase, over the last 5 years, in that number coinciding with a significant reduction in the number of claims for DLA. From Nov 2020 only 162 adults (17 to 65 years old) are entitled to DLA (42 in Carmarthenshire, 49 in Pembrokeshire and 71 in Ceredigion).

There has also been a steady increase in people with LD aged 65+ claiming personal independence payments rising to 94 [Nov 2020] (52 in Carmarthenshire, 28 in Pembrokeshire and 14 in Ceredigion). Coinciding with a reduction in claims for DLA in over 65s to just 68 (34 in Carmarthenshire, 16 in Pembrokeshire and 18 in Ceredigion).

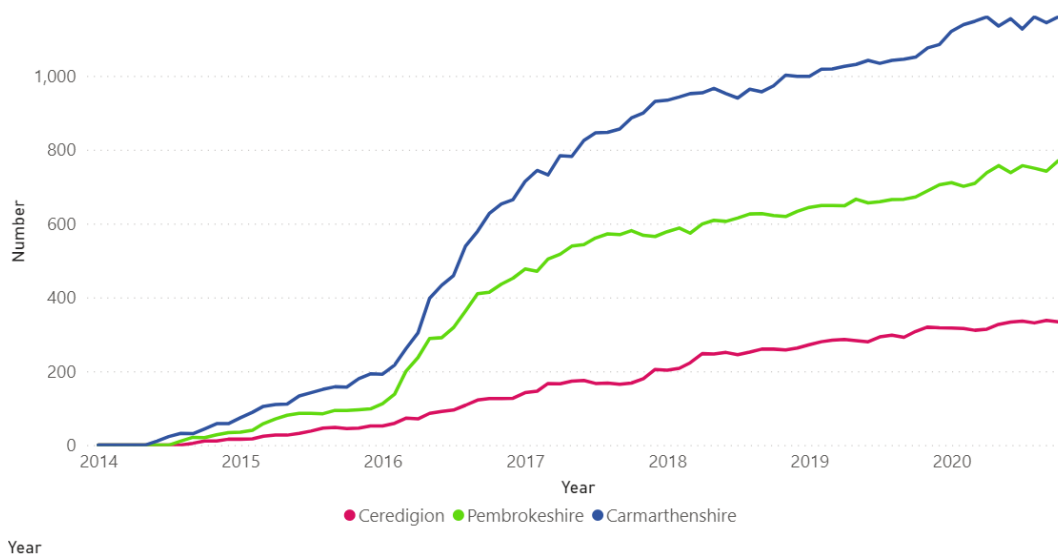


Figure 17: Number of adults (aged 16 to 64) claiming Personal Independence Payments in West Wales [data collected from the department of works and pension, <https://stat-xplore.dwp.gov.uk>]

8.2.3 PMLD

An important consideration in planning for care and provision in people with LD are those with the most needs. The prevalence of PMLD in the general population is 0.05 per 1,000.

Due to medical advances the total number of children and adults with PMLD is expected to grow by about 1.8% each year. This estimate would lead to a figure of 77 people with PMLD in Carmarthenshire, 32 in Ceredigion and 51 in Pembrokeshire in 2021. Within the Hywel Dda catchment area the figure is thought to be around 160.

8.2.4 Placements and Provision

One of the key challenges in supporting PwLD is providing safe and supported accommodation relevant to their life stage and care needs. As they transition into adulthood and age, the choice of accommodation should reflect their changing needs, promoting independence whenever possible and appropriate.

The greatest proportion of PwLD live with their families. This is illustrated in Figure 18 which shows the breakdown of accommodation type for 1,854 people living in West Wales.

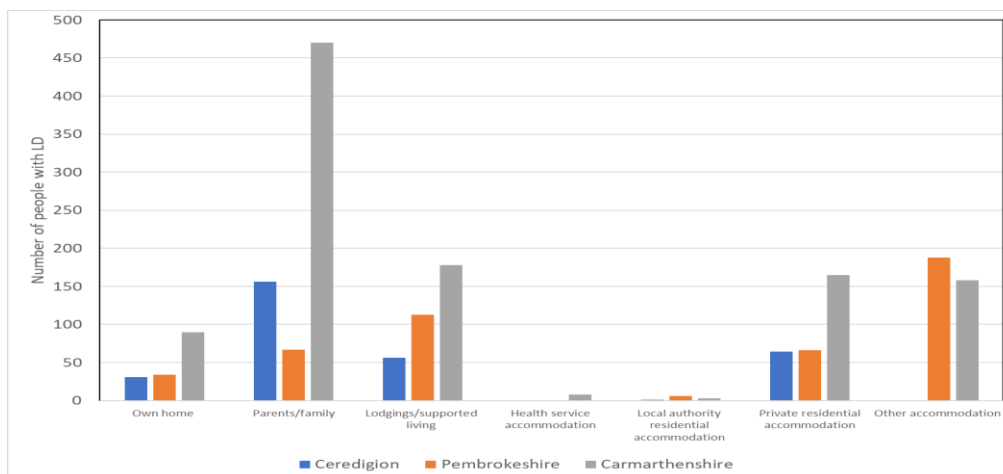


Figure 18: Placements for PwLD in West Wales
 [data collected from WAG, <https://statswales.gov.wales>]

8.3 Care and Support needs

To provide an assessment of the current services and to determine the gaps and areas for improvement, several engagements were undertaken, both through interviews and workshops that captured the views of PwLD and those who provide and deliver their care. These groups include:

- **Services Users:** Engagement with the LD community has been through workshops and responses with members of the Dream Team. The Dream Team primarily consists of people with moderate LD and tend to be more independent. In addition, parents and carers involved in support and caring for people with LD with more complex needs were also invited to provide their views on their behalf
- **Service providers:** Opinions from a range of different specialities, services, and commission bodies across the three local authorities

Engagement activity with PwLD and those providing care and support has demonstrated that although there is some way to go, lessons learned from the previous PNA in 2017 have resulted in several improvements and developments in the approach to supporting PwLD, which include the development and implementation of the [LD Charter](#) and the work of the Dream Team.

8.4 Current and Future Care and Support Provision

A range of care and support services are in place across the region to support adults with LD to live fulfilled lives within the community, which are summarised in Appendix 8B.

There is a noticeable increase in the number of people with PMLD and an increase in complex cases. This will require a multiagency approach across West Wales to address.

8.5 Gaps and Areas for Improvement

The main gaps and needs identified in the chapter are covered by 6 main themes, some of which are also common to other population groups:

- Improved Communication
- Improved Access, Support and Planning of Peoples Care
- Better Training and Education for All
- Changes to How Placements and Accommodation is managed
- Improvement in how Transition between Services & Specialities are Managed
- Improved Services and Education for Children & Young People with LD and their families

8.5.1 Children and Young People

The following areas were identified in respect of services and provision for children and young people with LD. These included:

- A need to focus on children with LD to ensure they are getting the support required
- Implementation of the Additional Learning Needs Act
- A need to provide specialist training and support to foster carers who look after children with learning disabilities.
- Ensuring that parents of children and young people with LD can access information, advice and support if they need it.
- There needs to be an overall strategy and better links between health, education, children's and adult social care to ensure there is a joined-up way of meeting the care and support needs of children and young people

8.6 The impact of the Covid-19 Pandemic

Coronavirus has had a continued profound effect on PwLD in Wales. According to Phase 2 of a 2021 Disability Wales study, during the pandemic almost 30% of PwLD paid for a direct payment service they were not receiving and around 70% of PwLD had restrictions on visitors [1]. PwLD rely on contact with their GP, community or learning disability nurse and / or social worker to maintain their health and well-being. During the pandemic, PwLD had more difficulty accessing GPs, social workers and day / community services, leading to increased social isolation, a negative impact on their mental health, general health and well-being and increased stress for their carers and support network.

A report published in February 2021 by Improvement Cymru, shows that in Wales, PwLD are 3 to 6 times more likely to die from Coronavirus than the rest of the population, due to inherent health inequalities.

"This report is an essential piece of on-going work to highlight the health inequalities we so often find with people with learning disabilities. This report is vitally important in maintaining the focus on improving the lives of people with a learning disability both now and in the future."

Dr Rachel Ann Jones, Learning Disabilities programme Lead at Improvement Cymru

The pandemic has impacted on the implementation of continuous improvements planned for LD services in the region, including a buddying programme between PMLD and members of the Dream Team.

8.7 Recommendations

Ongoing improvements in care and support should include the development of a comprehensive set of standards co-produced by PwLD and adopted by commissioners and all providers of LD services. This should and underpin innovation in design and delivery of:

- Accessible community-based accommodation that promotes independence
- Appropriate care for PMLD
- Awareness of LD and how to support PwLD and PMLD
- Communication with and for PwLD and between care and support services
- Multi-disciplinary approaches for providing care and support
- Support for transition between services for children and adults
- Access to primary and secondary health care, day-services and respite care

For current legislation and regulations see Appendix 8A.

For current care and support provision see Appendix 8B.

For additional data see Appendix 8C.

References:

[1] <https://www.ldw.org.uk/project/covid19-learning-disability-study/>

9. Autism

9.1 Introduction

Autism is a developmental disorder which affects the way a person communicates with and relates to other people and the world around them. The way in which people are affected varies from one individual to another and by age and intellectual functioning.

The term 'autistic people' rather than 'people with autism', reflects the language preferences expressed by autistic people. The term 'people' refers to children, young people and adults. This language will be used throughout this chapter.

Estimates of the prevalence of autism spectrum disorders suggest rates of around 1% in the general population, but there is much debate and the suggestion that not all individuals are identified (Brugha et al., 2011, 2016; Chiarotti & Venerosi, 2020; Fombonne et al., 2021; Lyall et al., 2017) [1][2][3][4][5].

New services for adult diagnosis have been set up across Wales at a time of rising awareness of the spectrum of autism experiences; however, until recently no studies have examined adult autism prevalence in Wales

Increased rates of diagnosis and more prevalent autism in the community necessitate increased funding for specialist services to enable autistic adults to receive any support they require. As an alternative to a separate Autism Bill, The Welsh Government developed a Code of Practice for Autism which highlights and reinforces existing duties of the Social Services and Wellbeing (Wales) Act 2014 and the NHS (Wales) Act 2006 in respect of Autistic people.

9.2 Demographic Profile

Estimates suggest that 1 in every 100 people in a population will have a diagnosis of Autism. This would mean that there are in the region of 4,000 autistic people in West Wales (about 2,000 in Carmarthenshire, 1,500 in Pembrokeshire and 750 Ceredigion)

Local authorities are required to keep data by Special Educational Needs (SEN) category. In 2020-21 there were 945 children in West Wales in the Autism category - 375 in Carmarthenshire, 420 in Pembrokeshire and 150 in Ceredigion.

However, these estimates are likely to be underplaying the true prevalence rates in West Wales. Currently Hywel Dda University Health Board reports that there are 900 adults on the waiting list waiting to be assessed for an autism diagnosis and over 1,000 children.

9.3 Care and Support Needs

Since the 2017 Population Needs Assessment the needs of Autistic people have been recognised as a separate requirement to Learning Disabilities. This recognition of the needs of Autistic people, be they children or adults, is also reflected within the Welsh Government's Autism Code of Practice.

The Code of Practice sets out what autistic people, their parents and carers can expect from public services in Wales and how Welsh Government intend to adapt the way we organise society to be more aware and more attuned to neurodiversity.

The Code of Practice recognises that whilst some autistic people may have a co-morbid learning disability or mental illness, many will not, yet will still at times require specific advice, help and support.

9.4 Current and Future Care and Support Provision

In March 2016, as part of the refreshed Autistic Spectrum Disorder Strategic Action Plan the Welsh Government announced that it would be funding a new national Integrated Autism Service (IAS)

The West Wales Integrated Autism Service (WWIAS) was then established in 2019. This is a joint service delivered by Hywel Dda University Health Board in partnership with the local authorities of West Wales.

The service was developed across Wales following consultation with autistic people, carers and professionals which highlighted the lack of support available for autistic people who did not meet the criteria for mental health and learning disability services.

WWIAS offer adult autism diagnostic assessment for adults who do not have a significant learning disability or mental health problem. They also offer a range of support for autistic people, their families, including carers and advice for professionals.

In 2020-2021:

- They received 420 referrals to the service were made for autistic adults with 41% of these self-referrals from adults
- They undertook 1,944 interactions were made with autistic adults
- 68% of referrals for autistic adults were requesting autism diagnostic assessments and 32% were requesting support
- 118 adults received a full diagnostic assessment
- 109 interactions were made with parents/ carers
- 38 referrals to the service were made for parents/ carers with 21% referrals by professionals and 79% of these self-referrals
- 1,061 interactions were made with professionals
- 280 new contacts with professionals

9.5 Gaps and Areas for Improvement

To provide an assessment of the current services to determine the gaps and areas for improvement, engagements have been completed with autistic people, parents, carers and professionals.

In West Wales a regional strategic group of all key partners meets to oversee the implementation of services for Autistic people, including the Integrated Autism Service

(IAS). This strategic group is chaired by the Head of Service within Hywel Dda University Health Board with the responsibility for Autism.

In each local authority there is an 'Autism Lead' a named contact responsible for overseeing and coordinating the activity in their area. This includes the coordination of local steering and stakeholder groups (with autistic people and their families) as well as training and awareness raising for staff.

Our engagement activities have been limited during the COVID 19 pandemic. However, our agreed approach for the future is set out below.

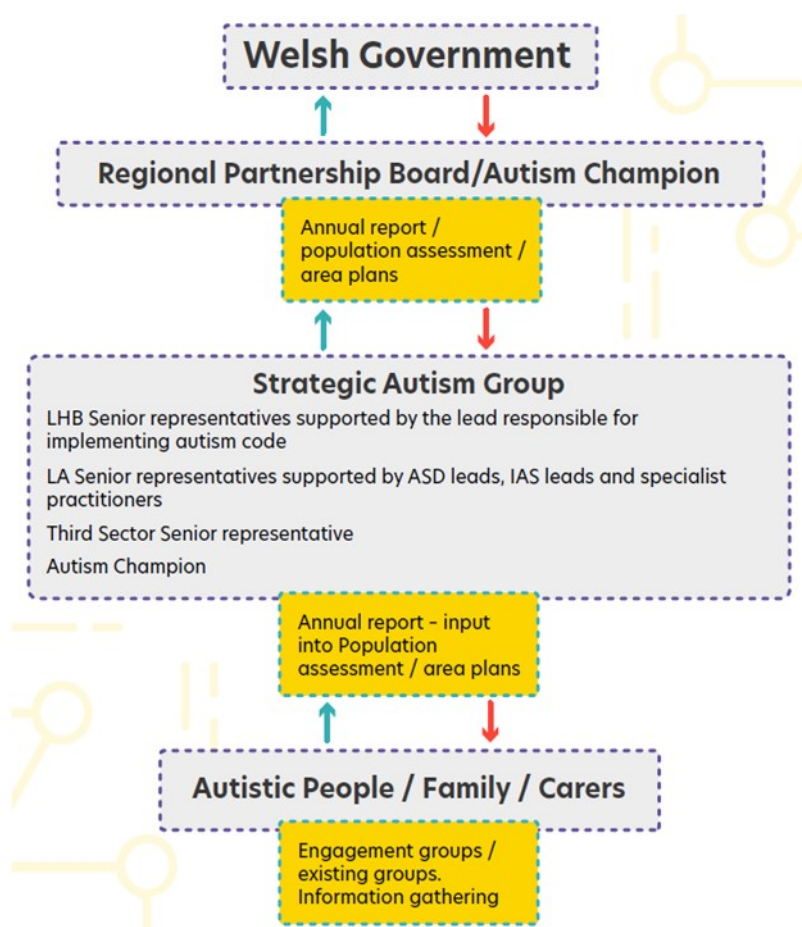


Figure 19: Diagram illustrating the role of the Autism Champion in collating and sharing information to inform the Regional Partnership Board (Welsh Government, 2021)

Engagement through the strategic groups has allowed us to reflect what matters to autistic people in West Wales including the impact of the COVID-19 Pandemic on their wellbeing and care and support needs.

In addition, a virtual meeting was held with 10 parents of children and young people with complex needs, including autism.

9.6 The impact of the Covid-10 Pandemic

The pandemic has impacted on the care and support available for autistic people as many support services were paused. In addition, the uncertainty and frequent changes to routines and rules will, in some cases have had a significant impact upon people's mental-health and wellbeing. This has placed increased pressure on family members and carers.

For Autistic People the resumption of and reintegration to activities such as education following prolonged periods of lock down has also presented significant challenges.

9.7 Recommendations

The overarching themes and recommendations for improvement, taken from our engagements, include the following:

- A need to Improve waiting times for diagnosis and diagnosis rates for both children and adults
- Improve access to information and advice for Autistic people and their families, including the autism strategy and the associated support services available in West Wales
- Improve awareness of Autism and the Autistic Spectrum Conditions across health, social care services, education and all public services
- Greater emphasis on user engagement and coproduction in service development
- Improving the transition for Autistic Young people when they leave school
- Increasing opportunities for volunteering, work experience, employment opportunities and networking for autistic people

For current legislation and regulations see Appendix 9A

For current care and support provision see Appendix 9B

For additional data see Appendix 9C

References:

- [1] Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., Bebbington, P., Jenkins, R., & Meltzer, G. C. W. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*, 68(5), 459–465. <https://doi.org/10.1001/arch-genpsychiatry.2011.38>
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10. Children and Young People

10.1 Introduction

Children and Young People can be grouped into three categories:

- Up to the age of 18
- Up to the age of 21 if they are in care
- Up to the age of 25 if they are in care and are still in education

10.2 Demographic Profile

- There are over 82,000 children and young people (0-19) in the West Wales Region (StatsWales), making up approximately 22.2% of the population
- 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 to early intervention, multiple needs and remedial intervention
- All three local authorities are currently below the national average for the number of young people as a percentage of the population
- Projections for 2043 show that young people aged 0-15 will account for 16.54% of the national population, whereas only 16.22% of the population in Carmarthenshire, 14.67% of the population in Pembrokeshire, and 13.64% of the population in Ceredigion will be made up of people aged 0-15
- In 2020 there were an estimated 6,105 children and young people with a long-term illness/disability in West Wales – 3,105 in Carmarthenshire, 1,983 in Pembrokeshire, and 1,017 in Ceredigion; projections for 2043 show a decrease to 5,652, with 2,986 in Carmarthenshire, 1,784 in Pembrokeshire, and 882 in Ceredigion



Number of children looked after					
	31 Mar 2017	31 Mar 2018	31 Mar 2019	31 Mar 2020	31 Mar 2021
Ceredigion	75	60	65	75	85
Pembrokeshire	125	135	155	185	225
Carmarthenshire	205	195	180	160	150
Wales	5,960	6,405	6,855	7,150	7,265

Figure 20: Number of looked after children in West Wales 2017-2021(Welsh Government)

Local Authority	Children with a Disability	Children with no Disability	All Children receiving care and support
Ceredigion	195	220	410
Pembrokeshire	65	230	295
Carmarthenshire	145	435	580

Table 3: Children receiving care and support by local authority and disability (StatWales)

	Carmarthenshire		Ceredigion		Pembrokeshire	
	Received	Accepted	Received	Accepted	Received	Accepted
2017-2018	999	638	308	218	646	445
2018-2019	1267	826	352	252	773	497
2019-2020	1268	937	362	273	775	559
2020-2021	1178	826	342	249	632	449
2021-2022	1463	1016	455	324	820	546

Table 4: Referrals received and accepted to S-CAMHS (CAMHS)



Figure 21: Number of young people not in education, employment or training

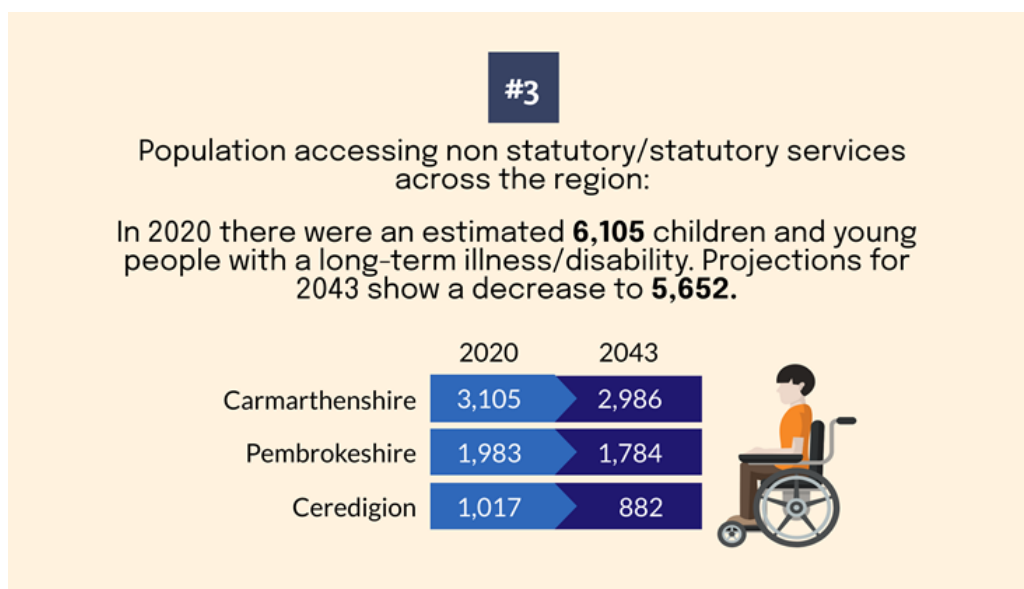


Figure 22: Population accessing non statutory / statutory services in West Wales
 Source: <http://www.wwcp-data.org.uk/children-and-young-people>

10.3 Care and Support Needs

Care and support needs for children and families span a wide range from universal, through early intervention, multiple needs and remedial intervention. Children and families will require different levels of care and support depending upon their presenting need and strengths. In West Wales we have developed 'The Right Help at the Right Time' Framework which details the care and support available in each locality. The document also provides guidance on the thresholds of need acknowledging that children's situations and circumstances can vary across the spectrum of need and professional judgement should always be used in partnership with the family.

10.4 Current and Future Care and Support Provision

As outlined in Appendix 10B the range and level of care and support currently being provided offers a range of interventions at varying levels of intensity, with the aim of preventing escalation to more restrictive interventions and delivering positive outcomes to children and young people.

10.5 Gaps and Areas for Improvement

There are several areas in which further improvement can be made. These are set out below against the core principles of the [Social Services and Wellbeing \(Wales\) Act 2014](#).

10.5.1 Voice and control

- Enhancing assessment and care planning processes to ensure that children, young people and their families have a voice in relation to what is important to them and the support they need.

10.5.2 Prevention and early intervention

- Continue 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.

10.5.3 Wellbeing

- Reducing the number of placement moves for children looked after by local authorities (CLA) and reducing reliance on residential care
- Improving access to mental health services at an early stage, thus preventing the need for referral to Child and Adolescent Mental Health Services (CAMHS).
- Improving joint planning between CAMHS and learning disability services to ensure equitable service provision for children with neuro-developmental conditions

10.5.4 Co-production

- Improving engagement opportunities with Children, Young People and their Families to ensure their voice is heard and services are designed with them in mind.

10.5.5 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 to ensure best outcomes and improve financial efficiency
- Incorporating of the [NEST \(Nurturing Empowering Safe Trusted\) framework](#), bringing services together to support children and young people’s mental health at every opportunity

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.

10.6 The impact of the Covid-19 pandemic

The coronavirus pandemic (Covid-19) has presented new and difficult challenges for everyone. Many households have been put under strain or have faced adversity because of the social, psychological and economic impact of lockdown.

Services have done everything they can under difficult circumstances, but it is likely children will have suffered harm during this period that will not have been identified by professionals.

Providing time and space to listen directly to children is integral to a child-centred system and promotes good safeguarding practice. Children’s Social Services have maintained face-to-face contact for children known to be at risk. However, many children will have only had virtual contact via video, telephone or online with services from their home with family members present. This is likely to have impacted on the opportunities for practitioners to identify abuse and for children to disclose harm. Although many practitioners are very experienced in safeguarding practice, others may not feel as confident in this area of practice.

10.7 Recommendations

- Continue with the development of policies and practice that recognise the importance of the family in decision making processes
- Develop an ‘Information Sharing Protocol’ and integrated case management system that assists professionals to maintain and share records and reports to support the “No Wrong Door approach”
- Build on the success of one stop shop models of community-based family support such as Flying Start.
- Improve targeted support for families of disabled children
- Extend availability of Family Support Workers

For current legislation and regulations see Appendix 10A

For current care and support provision see Appendix 10B

For additional data see Appendix 10C

11. Mental Health

11.1 Introduction

According to the World Health Organisation, mental health is defined as "a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community". [1]

Our mental health affects how we think, feel and act. A healthy outlook can reduce both the intensity and duration of illnesses, whereas poor mental health can have the opposite effect. It has been shown that depression and its symptoms are major risk factors in the development of coronary heart disease and death after myocardial infarction. Mental illness generally refers to conditions that affect cognition, emotion and behaviour. [2] Many factors contribute to mental health problems, including:

- Biological factors, such as genes or brain chemistry
- Life experiences, such as trauma or abuse
- Family history of mental health problems [3]

11.1.1 Classification of Mental Health

There are many different mental health disorders, which can generally be characterised by a combination of abnormal thoughts, perceptions, emotions, behaviours or relationships with others. Different mental health disorders include depression, bipolar disorder, schizophrenia and other psychoses. [4]; [5]

11.1.2 Health facts and inequalities associated with Mental Health

Stigma surrounding mental illness is common. This can be defined as the formation of stereotypes or negative expectations around the identity of an individual with mental illness. The presence of these stereotypes and negative expectations can lead to prejudice and discriminating behaviour. Stigma can also play a role in determining health-seeking behaviour, leading to people potentially hiding issues surrounding their mental health rather than seeking help [6]. Stigma can be reduced through increasing the information, education and public awareness surrounding mental illness.

11.2 Demographic Profile

The following are statistics around mental health in Wales:

- 1 in 4 adults experience mental health problems or illness at some point in their lifetime
- 1 in 6 adults are experiencing symptoms at any one time
- 1 in 10 children between the ages of 5 and 16 has a mental health problem, and many more have behavioural issues
- Approximately 50% of people who go on to have serious mental health problems will have symptoms by the time they are 14 and many at a much younger age

As can be seen in figure 23 below, the total number of people registered on the mental health Quality and Outcomes Framework (QOF) register has been increasing in both Wales and the West Wales region from 2009 to 2019. This implies that mental health issues are a growing problem across Wales.

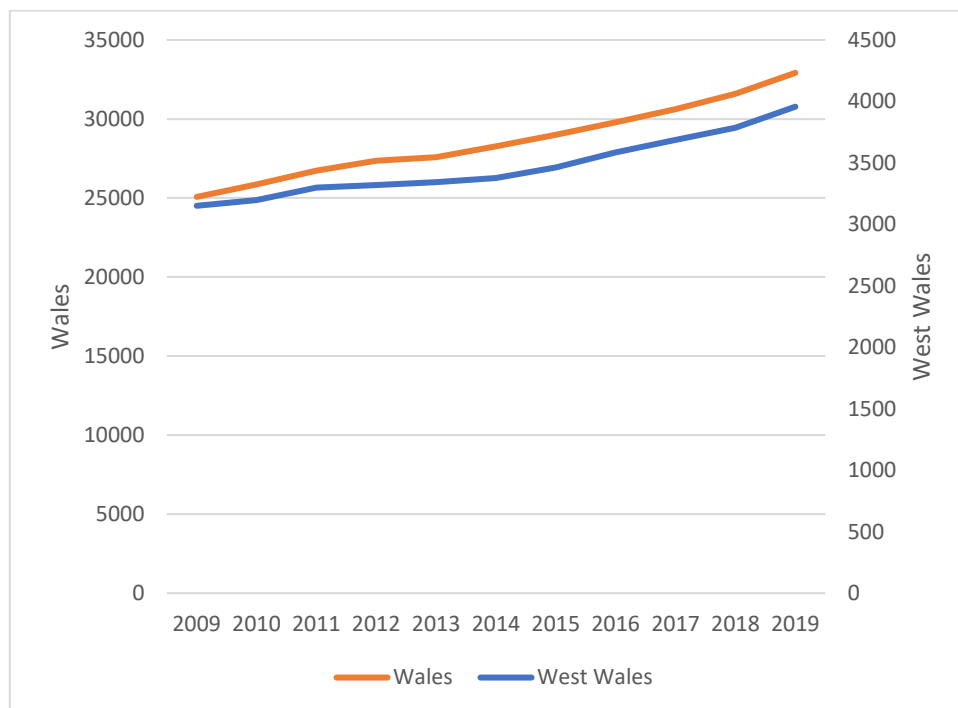


Figure 23: Total number of patients on the mental health Quality and Outcomes Framework (QOF) registered in HDdUHB and Wales

11.2.1 Admissions to Mental Health Facilities by Local Health Board

Figure 24 below shows total admissions to mental health facilities in Wales and the West Wales region covering a ten-year period from 2010 to 2019. Admissions have been steadily decreasing in Wales over the past 10 years, from around 11,000 in 2010-11 to just over 8000 in 2018-19. Despite this overall reduction in Wales, numbers in West Wales have remained steady, and have actually increased from 2017 to 2019, with 768 admissions in 2016-17 and 902 admissions in 2018-19.

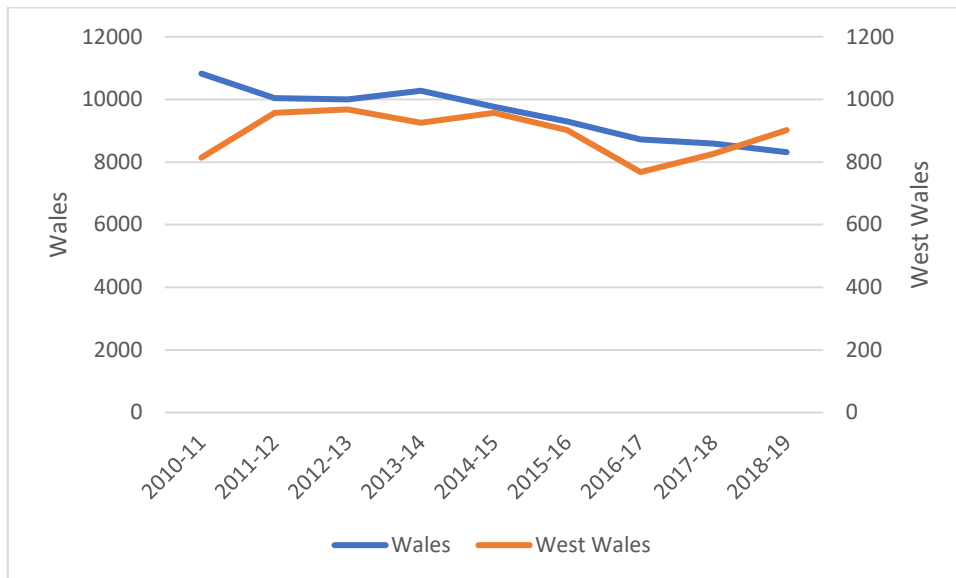


Fig.24: Total admissions to mental health facilities in Wales and West Wales from 2010 to 2019

11.2.2 Specialist Child and Adolescent Mental Health Services (sCAMHS) waiting for a First Appointment

The waiting times for specialist child and adolescent mental health services (sCAMHS) under 4 weeks and over 4 weeks in Wales and West Wales are shown in Appendix 11C. Waiting times on the sCAMHS pathways have generally been less in West Wales than in Wales overall, with a larger proportion of patient in Wales having to wait over 4 weeks for this service. There appears to be a large spike in patients having to wait more than 4 weeks in Wales towards the end of 2020, with a smaller spike apparent in West Wales, which could be related to the COVID-19 pandemic.

11.2.3 Local Primary Mental Health Support Services

The total monthly referrals for local primary mental health support services for Wales and West Wales are presented in Appendix 11C.

There appears to be a steadily growing demand for these services from 2013 through to 2019 in both Wales and West Wales. A sudden sharp decrease in referrals occurred in early 2020 coinciding with the covid outbreak. This decrease was seen in the West Wales region and across Wales overall.

As can be seen in Appendix 11C, the total percentage of Local Primary Mental Health Support Service (LPMHSS) assessments that are carried out within 28 days is generally higher in West Wales than in Wales in general.

11.2.4 Predicted Change in Mental Disorder Prevalence

As shown in figure 25 below, whereas in Wales there is predicted to be an overall increase in the prevalence of mental health disorders, in West Wales the overall percentage of people with mental health disorders is generally predicted to decrease between 2020 and 2043. Although it is predicted that there will be an increase in

common mental disorders in Carmarthenshire and Pembrokeshire. Overall, the total number of people in Ceredigion suffering from a mental disorder is predicted to decrease the most out of the three local authorities.

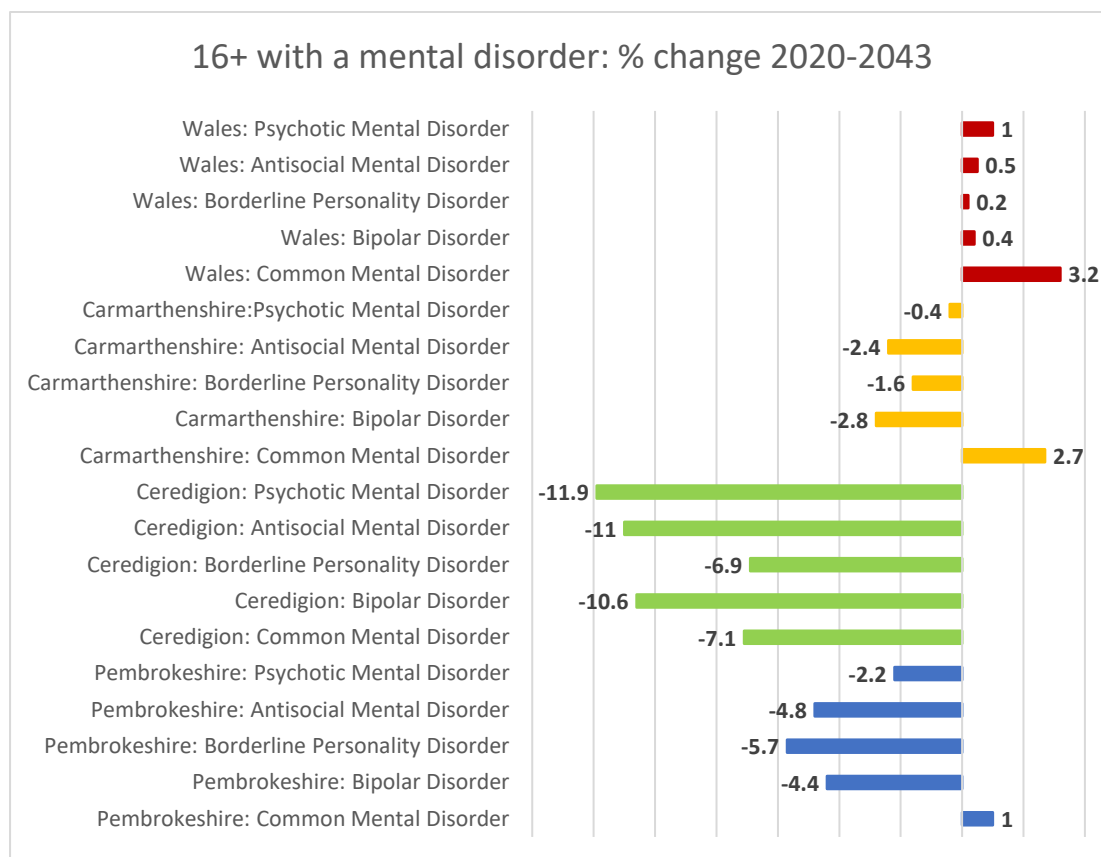


Figure 25: Change in percentage of people with different mental disorders from 2020 to 2043

11.3 Care and Support Needs

To provide an assessment of the level and range of current mental health services, determine the adequacy of these services, and identify future care and support needs and areas for improvement, virtual engagement sessions were carried out with both service providers and service users from West Wales Action for Mental Health (WWAMH) and Mind.

11.4 Current and Future Care and Support Provision

- As a result of COVID-19, demand for mental health services in West Wales over the coming years is expected to increase significantly. Future planning should reflect this and be based on co-production principles
- Secondary and primary care staff need more training to improve knowledge and understanding of mental health issues, especially surrounding crisis and suicide, to ensure they meet the complex issues and demands being presented and therefore are managed more effectively

- Services need to be community focussed and better integrated, so that patients managing multiple issues can get the full range of support they need from multi-disciplinary teams closer to home, which would also help mitigate access to services for those living in rural communities
- Follow up services need to be improved to educate and support people with lifelong conditions after they have been released from a service; this could help people to self-manage their condition better and avoid them returning in the future
- To keep up with the increasing demand for mental health services now and in the future, employers should consider how to make working within mental health services a more appealing opportunity for potential employees

For current care and support provision, please see Appendix 11B.

11.5 Gaps and Areas for Improvement

The following are some of the key issues identified during engagements:

- Follow up services need to be improved to educate and support people with lifelong conditions after they have been released from a service; this could help people to self-manage their condition better and avoid them returning in the future
- There needs to be a greater recognition and awareness of dual diagnosis and neurodiversity, with increasing numbers of people diagnosed on the autism spectrum
- Although progress has been made since 2017 in providing a 24/7 service, further work is still needed to achieve this. A twilight sanctuary has been set up in each of the three counties to provide support for people out of hours, but these do not offer around the clock support and are not always accessible for people in rural areas
- These services need to be reviewed to ensure that a 24-hour service is delivering support in response to need, in the most appropriate, smart and cost-effective way. For example, prioritising the service as a safe haven out of hours, with therapeutic support available there during the day
- Overnight accommodation associated with the sanctuaries is currently underutilised, which could suggest the threshold for admission is set too high
- Although some improvements have been made with regards to crisis management and intervention, there needs to be further consideration of effective alternatives to hospital attendance in response to crisis, to avoid A & E being the default option for situations where people are considered “too difficult to deal with”
- Access and referrals to Community Mental Health Teams (CMHTs) need to be improved

- Assessment processes need to be improved to avoid people being released prematurely without the appropriate post-discharge support, only to be re-admitted

11.6 The impact of the Covid-19 pandemic

The pandemic has led to increased isolation and a disruption of normal life and had a dramatic impact on people's access to services. With access to primary care services severely curtailed or becoming virtual, many people have been unable or too worried to access the support they would expect. People that were doing well before COVID often have been unable to access support needed because of it. [10]

Whilst some of the impact may be short-term and resolved by increasing the visibility and accessibility of services, it is not clear what the long-term impact might be on mental health and wellbeing.

In the period immediately before the pandemic, it was reported that 11.7% of Welsh people suffered from severe mental health issues. This reportedly climbed to 28.1% in April 2020. This deterioration in mental health was equivalent to someone who is employed becoming unemployed.

Young people reportedly experienced the largest deterioration because of COVID-19, with the average GHQ score among those aged 16-24 rising by 3 points, or 24% relative to pre-pandemic period.

Women also experience worse levels of mental health than men after the onset of the pandemic, with the gap in mental health between men and women reportedly increasing from 9.9% to 14.1%.

It is reported to have had a worse effect on those from black, Asian and minority ethnic (BAME) backgrounds – in June 2020 BAME individuals in Wales reported on average 4.1 problems associated with mental distress, whereas for white British individuals this was 2.7 (a 55% difference in relative terms).

Mental health between the lowest and highest income has also widened significantly during the pandemic. Average GHQ-12 score in November 2020 for the lowest income quintile increased by 39% compared to the pre-COVID level. The top quintile of earners, however, only experience an increase of 6.5% over the same period.

A common response from the engagement events suggests "COVID has highlighted cracks that were already there and made them worse".

11.7 Recommendations

Results from the engagements highlight several important gaps in the current services which give rise to several recommendations:

- Increase integration of services to support people with multiple co-occurring issues
- Improve recognition and awareness of neurodiversity and dual diagnosis
- Provide a safe place for people in crisis to go 24/7, as an alternative to A&E
- Improve the crisis referral process so that people experiencing crisis have access to immediate support
- Improve training for front line, primary and secondary care staff
- Improve follow up support for patients after they have been released from services, including education and self-management of conditions
- Increase co-production of services
- Increase staff retention and recruitment rates.

For current legislation and regulations see Appendix 11A

For current care and support provision see Appendix 11B

For additional data see Appendix 11C



References:

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12. Health and Physical Disabilities

12.1 Introduction

Latest population estimates state that there are 218,685 people aged between 18 to 64 years old living in the West Wales (HDdUHB) region (Office for National Statistics (ONS), 2021). This means that 69% of the population is aged between 18 and 64 years old, which is a fall of 1% from 2015 and is below the average for Wales (74%).

This percentage is slightly lower in Pembrokeshire at 68% (69,575 of the 102,744 residents), slightly higher in Carmarthenshire at 70% (106,117 of the 152,810 residents) and the same as the region average in Ceredigion at 69% (41,993 out of the 60,661 residents). This highlights that we have an ageing population in West Wales in comparison to Wales as a whole, particularly in Pembrokeshire.

Many of the people in the 18-64 age group are healthy adults, however, within this population there are considerable numbers with significant health concerns or physical disabilities, exacerbated by socio and economic risk factors that have a negative impact on their health and therefore on demand for services.

12.2 Demographic Profile

Socio-economic factors related to poor health in the region include:

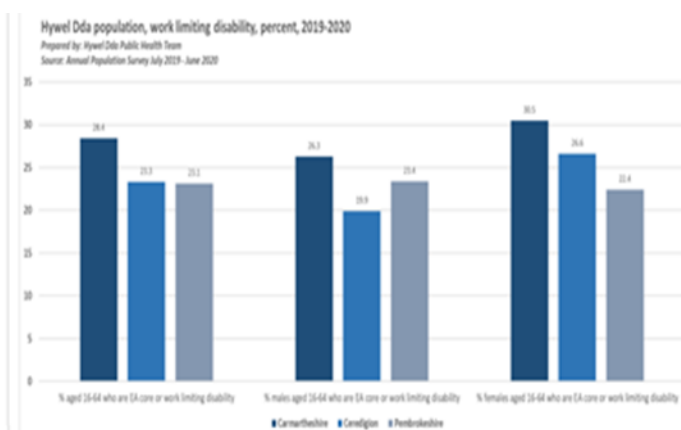
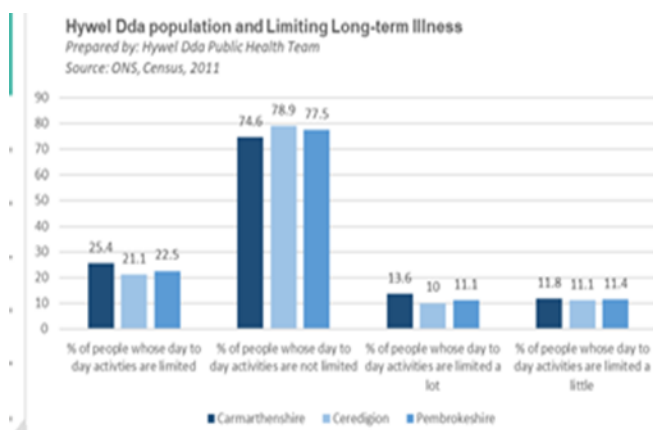
- 5.5% of people between 16 and 64 in Ceredigion do not have central heating, 3.5% in Pembrokeshire and 2% in Carmarthenshire (StatsWales)
- The National Survey for Wales (NSW) suggested that 36.9%, 27.6% and 25.3% of adults were active for less than 30 minutes a week in Pembrokeshire, Carmarthenshire and Ceredigion, respectively
- In Pembrokeshire, Carmarthenshire and Ceredigion it was estimated that 25.0%, 21.7% and 23.3% of people had eaten five portions of fruit and veg the day before the survey, respectively
- 5.8% of adults in Pembrokeshire were e-cigarette users, 6.7% in Carmarthenshire and 4.2% in Ceredigion
- In Wales currently 60% of adults are overweight or obese, this is compared to Hywel Dda UHB at 59%. If current trends continue, it is projected that 64% of adults in Wales will be overweight or obese by 2030
- Prevalence of being overweight and obesity in Wales is higher in men than women, but for obesity prevalence alone, it is slightly higher in women and in terms of age, prevalence is highest in the 45-64 age group

Census data, records of people on local authority registers or claiming certain benefits, provide a reasonable indication of the numbers in the region living with serious illness or disability as follows:

- In the West Wales (HDdUHB) region over 22,000 people between the ages of 18–64 are entitled to Personal Independence Payment (PIP); 10,000 people are entitled to Disability Living Allowance (DLA) and over 13,500 people are entitled to Attendance Allowance (AA)
- According to Welsh Government records, in 2019, there were 9,444 people with physical or sensory disabilities on local authority registers in West Wales,

5,190 of whom live in Carmarthenshire, 1,183 in Ceredigion and 3,071 in Pembrokeshire. 1,679 of those are aged between 18 and 64 and are registered with a physical disability and a further 1,744 aged between 18 and 64 are registered as having physical and sensory disabilities, which combined represents around 1.1% of the total 18-64 population and aligns broadly with the Welsh average of 1.02%

- Data from the 2011 census highlighted that Carmarthenshire had the highest percentage of people whose day-to-day activities were limited (25.4%) or limited a lot (13.6%), followed by Pembrokeshire (22.5% and 11.1% respectively) and then Ceredigion (21.1% and 10% respectively)
- As can be seen in the figures below, the percentage of those who are EA core or work limited disabled are mainly higher in females than males, except in Pembrokeshire where males (23.4%) are higher than females (22.4%). Percentages are higher in Carmarthenshire for both males and females (28.4%)



Figures 27 & 28: HDdUHB population and Limiting Long-term illness (fig. 27); HDdUHB population with limiting disability (fig. 28)

12.3 Care and Support Needs

Although a drop in the number of people is predicted within this group 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 well-being and independence and prevent escalation of need.

12.4 Current and Future Care and Support Provision

Engagement activity has been undertaken with people in the community, people with physical disabilities and those people who provide their care to identify the appropriate care and support required now and in the future. Whilst recognising that support for people with a disability continues to improve, they indicated areas where more could be done to ensure people with a disability are provided with appropriate person-centred support that allows them to lead full and fulfilling lives.

For current care and support provision, please see Appendix 12B.

12.5 Gaps and Areas for Improvement

Listed below are some of the recurring themes and issues identified:

- Improving infrastructure and information, to ensure people with a disability or limiting condition can access premises providing the care and support services they are entitled to
- Recognising the changing requirements of people with a disability or limiting condition. Many buildings were compliant with the 1995 disability legislation to be wheelchair accessible however, almost all people with disabilities now use scooters
- Increasing availability and choice of appropriate and accessible accommodation
- Involving people with different disabilities at the planning and design stage of new and refurbished premises, recognising their views and experience can ensure that any new development is easy to use and accessible
- Reducing restrictions around home improvements and modifications to help people manage in their own homes for as long as possible
- Identifying alternative solutions for people living in rural areas where public transport is not adequate
- Improving assessments and person-centred planning to ensure they reflect what really matters for individuals and can flex up and down in response to changing needs

12.6 The impact of the Covid-19 Pandemic

The pandemic has led to increased isolation and a disruption of normal life, having a dramatic impact on access to services generally and particularly for people with a disability or limiting condition, many of whom were shielding during the pandemic. With access to primary care and out-patient services severely curtailed or becoming virtual, many people have been unable or too vulnerable to access their regular support.

12.7 Recommendations

- Improving early identification and treatment of risk factors associated with health inequality
- Improving the early identification, treatment and management of preventable and chronic conditions including diabetes, heart disease and respiratory illness, to improve long term well-being and reduce complications
- Ensuring effective interventions and pathways for prevention, treatment and management of obesity and childhood obesity are routinely available and systematically implemented
- Strengthening transition arrangements between children and young people's services and adult services
- Developing community-based, user-led, co-produced services that prevent isolation, promote independence and support people to become more resilient and manage their own conditions
- Increasing use of assistive technology, such as telecare to transform domiciliary care and supported living services



For current legislation and regulations see Appendix 7A

For current care and support provision see Appendix 7B

For additional data see Appendix 7C

13. Sensory Impairment

13.1 Introduction

Sensory impairment is the common term used to describe blindness, deafness, visual impairment, hearing impairment and deafblindness. A person does not have to have a full loss of a sense to be impaired.

13.1.1 Visual Impairment and Sight Loss

Visual impairment is a severe reduction in vision that cannot be corrected with standard glasses or contact lenses and reduces a person's ability to function at certain or all tasks. A person can be registered as either partially sighted or severely sight impaired (blind). It can be caused by several conditions, such as cataracts, diabetes, genetic defects, trauma, glaucoma, macular degeneration, visual cortex disorder.

People living with visual impairment can experience different levels of sight loss – some might be able to only determine lights or shapes, whereas others might experience blurred vision. Likewise, visual impairment might lead to a loss of sight in the centre of the eye, or no side vision. It is uncommon for someone to have complete sight loss, even if they are registered blind.

13.1.2 Hearing Impairment and Deafness

Hearing impairment can be temporary or permanent and can affect all age groups. It can be caused by factors such as: old age, genetics, exposure to noise, infections, trauma, birth complications, certain medications or toxins. Hearing loss can be gradual, such as people who are later in life. Another common symptom of hearing loss is continual ringing in the ear which is caused by conditions such as tinnitus.

13.1.3 Dual Sensory Impairment

Dual sensory impairment or deafblindness is the loss of sight and hearing to the point where communication, mobility and ability to access information are impacted. Many people with dual sensory impairment can still see or hear to some extent, with the effects varying greatly. The department of health describes four groups of people who experience dual sensory impairment:

- Those who are hearing and sight impaired from birth or early childhood
- Those who are blind at birth or early childhood, and subsequently acquire hearing loss
- Those who are profoundly deaf from birth or early childhood, and subsequently lose their sight
- Those who acquire hearing and sight impairment later in life, which has a significant functional impact

The combination of two sensory impairments can mean that a deafblind person will have difficulty, or find it impossible, to utilise and benefit fully from services for deaf

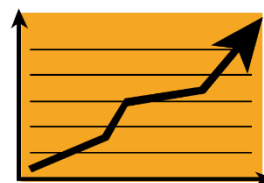
people or services for blind people. Meeting the needs of deafblind people therefore needs a different approach.

Apart from the day-to-day difficulties, people with sensory impairment also have poorer health outcomes, higher rates of poverty and lower educational achievements than people free from disability [1].

13.2 Demographic Profile

There are over 22,000 people who are entitled to Personal Independence Payment (PIP), 10,000 people who are entitled to Disability Living Allowance (DLA) and over 13,500 people who are entitled to Attendance Allowance (AA) in the Hywel Dda University Health Board footprint.

People over 65 in west wales registered with a visual impairment is forecast to rise from **13,014 in 2020** to **19,423 in 2043**



People over 61 in west wales registered with a hearing impairment is forecast to rise from **69,558 in 2020** to **92,945 in 2043**.

Figure 29: Sensory impairment in West Wales

13.3 Care and Support Needs

The accessible information standard states that patients, service users, carers and parents with a disability, impairment or sensory loss should:

- Be able to contact, and be contacted by services in accessible ways, for example email or text message
- Expect letters and information in formats they can read and understand, for example audio, braille, email or easy read
- Be supported by a communication professional at appointments if this is needed to support conversation, for example a British Sign Language interpreter
- Expect support from health and care staff and organisations to communicate, for example to lip-read

People with sensory impairment are more likely to feel lonely and isolated. Research by RNID in 2000 found that 66% of deaf and hard of hearing people feel isolated due to their condition excluding them from everyday activities. Sufficient support in the

community is needed to address the issues of isolation and loneliness facing those with sensory impairment, along with improvements to identification and diagnosis, so that appropriate and timely support can be implemented.

It has been found that 40-50% of older adults with visually impairing eye disease limited their activities due to fear of falling [6]. Evidence suggests that around 10% of falls can be attributed to sight loss [7]. Injuries from falls have detrimental effects on individuals and require costly interventions. Appropriate support and adaptations to help prevent falls and increase confidence of visually impaired people could improve quality of life and avoid further social isolation and loneliness.

13.4 Current and Future Care and Support Provision

For current care and support provision, please see Appendix 13B.

13.5 Gaps and Areas for Improvement

To provide an assessment of the current sensory impairment services, and to determine adequacy of these services and identify areas which can be improved, a series of engagements were carried out.

The following are some of the key issues identified:

- Improving awareness and understanding around sensory impairment and the corresponding needs across primary, secondary and social care
- Developing services to meet predicted demand
- Improving identification and diagnosis
- Improving community support to address loneliness and isolation
- Improving accessibility, so that patients are not turned away inappropriately or give up because of the difficulties of navigating the health and social care systems
- Improving audit of the accessible implementation standard to ensure a person's needs are fully recognised e.g., someone with complex needs also may have sensory impairment, which may be missed
- Considering alternatives for those with sensory impairment to avoid having to use public transport to access services, which can be particularly challenging, especially in rural areas

13.6 The impact of the Covid-19 pandemic

Due to the Covid-19 pandemic, services have shifted from face-to-face to virtual delivery, such as video consultations. The pandemic has contributed to communication difficulties for both the hearing and visual impaired, as certain technologies may not be appropriate for communicating with people of differing sensory needs.

Although convenient, remote video consultations do not work for blind or visually impaired people, telephone conversations are more appropriate. The pandemic has also led to communication challenges for deaf people e.g., face masks making lip reading impossible and information in braille has been more difficult to obtain.

13.7 Recommendations

Results from the engagements highlight several important gaps in the current services which give rise to several recommendations:

- Addressing system limitations when it comes to recording impairments. Currently, the Welsh Patient Administration System (WPAS) only allows for one impairment to be selected. Systems should be updated to record multiple impairments
- Improving community support and diagnosis
- Raising the profile, awareness and understanding of sensory impairment across the whole care and support system
- Improving accessibility and communication for people with sensory impairment to support independence and increase confidence in using services e.g., improved signage, increased use of braille on doors and lifts, use of appropriate colour schemes etc.
- Developing patient support services, such as interpretation, translation and lip-reading, to ensure they are accessible, available and equitable across the region

For current legislation and regulations see Appendix 13A

For current care and support provision see Appendix 13B

For additional data see Appendix 13C

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14. Substance Misuse

14.1 Introduction

Substance abuse or misuse is formally defined as the continued misuse of any mind-altering substance that severely affects a person's physical and mental health, social situation, and responsibilities. The World Health Organisation website (accessed 2019) notes that, "*Substance abuse refers to the harmful or hazardous use of psychoactive substances, including alcohol and illicit drugs. Psychoactive substance use can lead to dependence syndrome - a cluster of behavioural, cognitive, and physiological phenomena that develop after repeated substance use and that typically include a strong desire to take the drug, difficulties in controlling its use, persisting in its use despite harmful consequences, a higher priority given to drug use than to other activities and obligations, increased tolerance, and sometimes a physical withdrawal state.*"

The UK has a higher prevalence of drug misuse than any other country in Europe.

Drug and Alcohol (Substance) Misuse contributes considerably to the overall burden of disease and social need in the UK, such as communicable diseases, mental health issues, physical health, accidental harms, and the associated service pressures. Substance misuse is a complex issue that touches young people, families, communities, and societies, affecting a wide range of health and social outcomes for individuals and communities.

In Wales, there is a joint strategic approach to tackling harms related to both drugs and alcohol. The Welsh Government Drug and Alcohol Strategy "Working Together to Reduce Harm" has recently ended and Welsh Government has recently launched its new Substance Misuse (drug and alcohol) Delivery Plan for 2019 - 2022. The new plan builds on the progress made during the lifetime of the 2008-2018 strategy.

14.2 Demographic Profile

Generally, West Wales has an older population than the rest of Wales with 9.8% of West Wales residents aged over 75, compared to the Welsh average of 8.6%. It is estimated that 59% of Hywel Dda adults are overweight or obese (above all Wales average of 57%) but only 23% of Hywel Dda residents smoke compared to 24% across Wales. It is self-reported that 40% of the adult population of Hywel Dda drink above the alcohol guidelines compared to 45% for all-Wales. Other indicators are presented in Table 6 below.

Hywel Dda HB	
Total population	374,600
% aged 75 and over	9.8%
Life expectancy at birth - males	77.5 years
Life expectancy at birth - females	82.0 years
% overweight or obese adults	59%
% adults who smoke	23%
% adults drinking above guidelines	40%
MMR uptake	92.2%
Live births per 1000 women aged 15-44	57.9
Emergency hospital admissions (European age standardised rate per 1,000 population)	59.4

Table 5: Summary Statistics Description of Hywel Dda University Health Board's population (Public Health Wales, 2019)

14.3 Care and Support Needs

The current care and support needs focuses on addressing 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 because of drug and alcohol misuse and make communities safer through tackling issues created by drug and alcohol misuse within communities

14.4 Current and Future Care and Support Provision

The following have been identified as key priorities moving forward:

- Prevention and harm reduction
- Support for individuals – to improve health and aid maintain recovery
- Support and protection families
- Tackling availability and protecting individuals and communities
- Stronger partnerships, workforce development and service user involvement

For current care and support provision, please see Appendix 14B.

14.5 Gaps and Areas for Improvement

Future service development plans, care and support provisions and needs should focus on the following interventions:

- Turn the curve and reduce the inequalities gap in smoking prevalence through prioritising specific groups who are at high-risk of tobacco related harm. High-risk groups include inpatients, people with mental ill-health, people with conditions made worse by smoking, people with smoking related illness and pregnant women who smoke
- Support pregnant smokers to quit
- Continue to target smoking cessation interventions in those areas with the highest smoking prevalence
- Use social marketing to maximise reach
- Use asset-based approaches to work with local communities to assess barriers and facilitators to prevent uptake and reduce prevalence
- Treat smoking at the point of diagnosis for a wide range of diseases to improve outcomes. The evidence suggests that smoking quit attempts in healthcare settings are effective as smokers are overrepresented in the population of people who use NHS services
- Support the development of digital or electronic aids to cessation
- Support the development of opt-out models across secondary care settings and maternity
- Work with partners to ensure full implementation of public health and wellbeing legislation
- Work with partners (Local Authority, Education, Housing, Emergency Services) to reduce exposure to environmental tobacco smoke through supporting smoke free legislation, maximising the delivery of brief advice as support smoking cessation
- Work in partnership to improve the strategic alignment of policy and services across the health and wellbeing continuum for tobacco control
- Ensure evidence-based smoking cessation services are available for everyone who smokes, including brief advice, behavioural support
- Implement the recommendations of the NHS Future Forum which emphasises the value of having brief opportunistic 'healthy lifestyle chats' including raising the issue of stopping smoking. Providing Very Brief Advice to every smoker is recommended by the Department of Health is effective in general care settings and can be adapted to mental health settings
- Support staff in primary and secondary care settings who already have the necessary therapeutic skills to engage patients in conversations about behaviour change. We know that offering support to stop smoking, rather than mealy asking a smoker if they are interested in stopping or telling them they should stop, leads to more people making a quit attempt. Raising the issues of smoking can be done opportunistically with patients, such as during protected engagement time; at the end of a home visit or during clinical visits. It can also be helpful to link these brief interventions to a current health problem such as a cough, breathlessness or something that is of personal relevance to the patient

- Support the implementation of harm reduction approaches for those smokers who may not be able to stop in one step (NICE Guidance, 2013)

14.6 The impact of the Covid-19 pandemic

The effect of COVID-19 pandemic may have had a significant impact on substance misuse group, however this effect remains unknown.

14.7 Recommendations

To reduce exposure to drugs and tobacco misuse, the recommendations are as follows:

- Co-ordinate Leadership for Drugs Control
- Reduce the uptake of smoking
- Reduce smoking prevalence levels
- Reduce exposure to smoking

To reduce exposure to alcohol misuse, the recommendations are as follows:

- Improve prevention and harm reduction
- Support for individuals to improve health and aid recovery
- Support and protect families
- Tackle availability and protect individuals and communities
- Develop stronger partnerships, workforce development and service user involvement

For current legislation and regulations see Appendix 14A

For current care and support provision see Appendix 14B

For additional data see Appendix 14C



15. Violence Against Women, Domestic Abuse and Sexual Violence

15.1 Introduction

Violence against Women, Domestic Abuse and Sexual Violence (VAWDASV) refers to acts of violence or abuse that are disproportionately expressed toward women.[3]

Types of VAWDASV include:

- Gender based violence (GBV)
- Intimate partner violence (IPV)
- Domestic violence and abuse (DVA)
- Sexual violence and abuse (SVA)
- Coercive control
- Forced marriage
- Child marriage
- So-called honour-based abuse (HBA)
- Female genital mutilation (FGM)
- Human trafficking
- Sexual harassment
- Cyber harassment
- Adolescent dating violence (ADV)

Violence against Women, Domestic Abuse and Sexual Violence (VAWDASV) is a major public health problem, a criminal justice issue and a violation of human rights. It causes harm to individuals and families [2], and its impact can be felt across whole communities, societies and economies (WHO, 2021).

Living without fear of violence and abuse is a fundamental requirement for health and wellbeing. The National Institute for Health and Care Excellence (NICE, 2014) states that: "The cost, in both human and economic terms, is so significant that even marginally effective interventions are cost effective".

The true impact of VAWDASV cannot be adequately quantified. However, these types of violence can impact on victims in many ways. For example, sexual violence can lead to a multitude of health consequences including physical, reproductive and psychological harm. Female genital mutilation (FGM) can lead to both immediate health risks as well as a variety of long-term complications which can affect the person's physical, mental, and sexual health and well-being throughout their life.

15.2 Demographic Profile

A Home Office report estimating the economic and social costs of VAWDASV in England and Wales, placed the annual cost at £66 billion, with 71% of that being attributed to addressing the physical and emotional harm experienced by victims (Oliver et al., 2019).

VAWDASV can have fatal outcomes. Every day, 137 women are killed worldwide by a family member. It has been estimated that more than half (50,000) of the 87,000 women who were intentionally killed in 2018 were killed by family members or intimate partners. More than a third of these women (30,000) were killed by a current or ex intimate partner (United Nations Office on Drugs and Crime, 2019).

Between March 2018 and 2019, Welsh police forces recorded 80,924 VAWDASV related incidents (ONS, 2020a), yet recorded police data only highlights a fraction of the real picture, as incidents often go unreported.

It is estimated that a total of 2.3 million adults aged 16-74 living in Wales and England have experienced VAWDASV in the past year (ONS, 2020a). Anyone can experience VAWDASV, regardless of gender identity, age, sexuality, ethnicity, occupation, and income. However, understanding VAWDASV requires an appreciation that it is part of a social pattern of male violence towards women (Hester and Lilley, 2019), with data illustrating that it is predominantly women and girls who are victims and survivors of VAWDASV perpetrated by men and boys (ONS, 2020b).

Women and girls are significantly more likely to experience severe forms of abuse, including physical and sexual violence, which result in injury or death (Hester, 2018). Furthermore, they are more likely to experience repeated physical, emotional, or psychological abuse.

Between 2016 and 2018, 270 out of 366 domestic homicide victims, in Wales, who were killed by a current or ex intimate partner were female (ONS, 2019).

As required by the VAWDASV Act, the Welsh Government published its five-year national strategy in 2016. This was followed by publication of its national delivery framework and in 2019, the Welsh Government published national indicators for measuring progress against the Act.[10] The Welsh Government has published several guidance documents and national standards to help deliver commitments within its five-year strategy including:

- Whole Education Approach to Violence Against Women, Domestic Abuse and Sexual Violence in Wales Good Practice Guide
- Violence Against Women Domestic Abuse and Sexual Violence – Guidance for Governors
- National Advisers Annual Plan [4]
- Information and guidance on domestic abuse and sexual violence: Safeguarding older people (60+) in Wales
- National Training Framework Statutory Guidance
- Ask and Act Training Guidance
- Local Strategies Statutory Guidance
- Commissioning Violence against Women, Domestic Abuse and Sexual Violence Services Statutory Guidance
- National Standards for working with Perpetrators

15.3 Care and Support Needs

- There is a lack of understanding amongst professionals of the nature, effects and long-term consequences of Violence against Women, Domestic Abuse and Sexual Violence, leading to reduced confidence in professional contacts
- Both recognition and concern over the preventative and pastoral role of education in dealing with issues of Violence against Women, Domestic Abuse and Sexual Violence
- The lack of consistency and availability of safe interventions across the region aimed at holding perpetrators to account and providing opportunities to change behaviours
- The lack of specialist provision for children and young people who are experiencing Violence against Women, Domestic Abuse and Sexual Violence
- The persistent challenge to prioritise and resource early intervention and prevention
- Inconsistency of commissioning practices and sustainability of funding
- Complexity of current referral pathways resulting in confusion, response “overload” and duplication of services
- The lack of coordinated approaches to service provision and the need for an integrated referral pathway into services
- Lack of awareness amongst individuals experiencing Violence against Women, Domestic Abuse and Sexual Violence, their friends, families and professionals of what services are available and how to access information and support
- The inconsistency of service availability across the region leading to a “postcode lottery” of provision
- The lack of “whole family” approaches across the region
- The critical role of leadership and accountability for Violence against Women, Domestic Abuse and Sexual Violence across the region
- Recognition that what seem like opposing views are often a product of parties with a variety of roles seeing things through a different lens; a need to utilise and harness these ‘differences’ to work creatively and collaboratively cross sector in a solution focussed manner to best meet individual and family needs
- The need to maintain and sustain equal and respectful partnerships with professionals who are experts in their field, in particular agencies in the third sector who have a wealth of specialist knowledge, strategic expertise and operational skills
- The value of involving partners at an early stage and to work in partnership with service providers to co-produce the regional approach to addressing gaps in provision, avoiding duplication and maximising resources

15.4 Current and Future Care and Support Provision

- The Violence against Women, Domestic Abuse and Sexual Violence (Wales) Act 2015, together with the statutory guidance on commissioning sets the conditions and expectations for service developments in Wales

- There are several changes to centrally co-ordinated funding streams which aim to encourage multi-disciplinary collaboration in order to develop more innovative, cross cutting and service user orientated responses. They also lay the foundations for regional activity
- Through the MWW VAWDASV Strategy [5] the region has taken the first step to establish an agenda for commissioning and developing a range of services which can respond more fully to the spectrum of need [6]
- Services and resources in the region are insufficient to meet the full range of needs articulated in the Strategy and there is agreement that that it will be necessary to work collaboratively and innovatively to address gaps and to respond to unmet need [7]
- The strategy highlights the need for a fundamental change in understanding the cross-cutting nature and impact of VAWDASV to enable public services and the specialist VAWDASV sector to think differently about how resources can be maximised to support the implementation of the strategy [8]

For current care and support provision, please see Appendix 15B.

15.5 Gaps and Areas for Improvement

The following gaps and areas for improvement have been identified as being required:

- Adopt commissioning models that allow for flexibility and development to meet changing needs rather than prescriptive funding that limits creativity / innovation and results in services that are restricted in the services they can provide
- Development of a service model whereby any eligibility criteria associated with accessing service provision is based solely on a need to access rather than a level of risk, complexity, or the availability of services
- Involvement of survivors as integral to the commissioning process
- The need for increased regional collaboration across the public and third sector to identify and secure additional resources
- Recognition of the diversity of communities across Mid and West Wales and the importance of equality and diversity to be integral to commissioning of services
- The challenges of rurality to be recognised when commissioning services – acknowledgement of the true cost of delivering services in rural areas
- The need for equitable investment of resources across the region

15.6 The impact of the Covid-19 pandemic

During the COVID-19 pandemic in 2020-2021, a rapidly emerging literature suggests that levels of VAWDASV have been impacted by the COVID-19 public health

restrictions, including lockdown, shielding and social distancing regulations (Snowdon et al., 2020). Whilst the full picture of how the pandemic has impacted on VAWDASV is still to fully emerge, it appears likely that both the scale and nature of VAWDASV may have worsened, with rising 55 Wales Violence Prevention Unit VAWDASV Systematic Evidence Assessment [1] helpline contacts for all forms of VAWDASV and increased reports to emergency services in some areas for domestic abuse (Hohl and Johnson, 2020).

Calls to helplines have increased fivefold in some countries as rates of reported IPV have increased because of the COVID-19 pandemic. This is referred to as the shadow pandemic, as COVID-19 continues to strain health services, and violence is exacerbated in the home, essential services such as domestic violence shelters and helplines have reached capacity (United Nations, 2021).

Many prevention strategies and programming have been put on hold or been forced to adapt during the pandemic because of restrictions on movement, face to face interactions and public events. However, given the increasing number of reports of VAWDASV during the COVID-19 crisis, it is more important than ever to promote prevention through the transformation of norms, attitudes and stereotypes that accept and normalise violence. Also, while traditional avenues of prevention, such as face to face interactions are limited, new opportunities have emerged, multiple forms of media, online communications and many community mobilisation programmes involve delivering activities virtually (UN General Assembly, 2020), a number of interventions included in this report utilise online platforms (Real Consent and mHealth screening tools); these interventions may have particular relevance where face to face interactions may be limited.

COVID-19 has further exposed VAWDASV as a global emergency requiring urgent action. The pandemic has exposed the failure of efforts to prevent and respond to violence but also the deeply entrenched and systemic nature of VAWDASV.

As the pandemic continues, growing economic and social stress has an impact on everyone, but particularly women who often bear the additional burden of caring responsibilities, are more likely to hold insecure employment, in addition to being at increased risk of violence victimisation in the home. At the same time, restrictions on movement and social isolation measures increase women's vulnerability to violence and since lockdown measures were introduced, restricted access to support services, friends and family reduce survivors' access to support thus increasing the risk of harm (UN General Assembly, 2020).

15.7 Recommendations

The current commissioning landscape for VAWDASV in West Wales has recognised six key areas for development and improvement:

- i. Principles for Commissioning VAWDASV Services in the Region
- ii. Establishing a Shared Understanding of the Big Picture within the Region
- iii. Local and Regional Commissioning activity

- iv. Joint Commissioning and Pooled Budgets
- v. Gaps and Priorities
- vi. Governance, Leadership and Collaboration

For current legislation and regulations see Appendix 15A

For current care and support provision see Appendix 15B

For additional data see Appendix 15C

References:

- [1] REPORT (violencepreventionwales.co.uk)
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OLDER PEOPLE: Current Legislation and Regulations

The Strategy for Older People in Wales 2013 – 2023 was published by the Welsh Government in 2012, with the following vision:

- That all people in Wales feel valued and supported whatever their age.
- That all older people in Wales have the social, environmental and financial resources they need to deal with the opportunities and challenges they face.

The strategy aims to improve the wellbeing of older people around social, financial and environmental factors. Further information can be found here: <https://gov.wales/sites/default/files/publications/2019-06/the-strategy-for-older-people-in-wales-2013-2023.pdf>

Acknowledging that life experiences and daily reality vary greatly for people in their 50s to those in their 80s and over, in 2021 the Welsh Government published **Age friendly Wales: our strategy for an ageing society**

With one vision of:

- An age friendly Wales that supports people of all ages to live and age well.
- A Wales where everyone looks forward to growing older.
- A Wales where individuals can take responsibility for their own health and well-being whilst feeling confident that support will be available and easily accessible if needed.
- A Wales where ageism does not limit potential or affect the quality of services older people receive.
- A nation that celebrates age and, in line with the UN Principles for Older Persons, a nation that upholds the independence, participation, care, self-fulfilment and dignity of older people at all times.

Further information can be found here: <https://gov.wales/age-friendly-wales-our-strategy-ageing-society-html>

OLDER PEOPLE: Current Care and Support Provision

All partners in the region have continued to move 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 is based around the three levels of service, which includes three 'offers' to individuals depending on their needs:

Offer 1: Help to Help Yourself

Provision of services to build resilience and independence of older individuals, helping people to help themselves and prevent the need for ongoing care.

Offer 2: Help When You Need It

Provide care and support to people so they can regain their previous level of independence after an illness or injury. Includes reablement and rehabilitation at home.

Offer 3: Ongoing Support

Includes services for people who require longer term care or support. Usually delivered through integrated assessment, providing multi-disciplinary professional support. Care support plans are based on the question 'What matters to you?' with outcome plans delivered accordingly.

Technology Enabled Care

Currently various technology enabled care programmes are being utilised across West Wales. These vary from using telehealth to monitor and support people with chronic conditions such as COPD and heart failure, to using telecare to monitor and prevent falls. Various technology enabled care programmes can help people to manage their conditions, increase confidence, and help people to live independently in their own homes for longer.

Current support services

Information, Advice and Assistance

A wide range of information and advice is available, to help people to achieve their outcomes by directing them to support available in the community.

Third Sector

There is a wide range of third sector services available, which promote independence, social engagement and inclusion.

Domiciliary Care and Support

There is rapid access to domiciliary care to provide care and support when it is needed, or on a longer-term basis.

Residential and Nursing Care

There are several residential and nursing care options available across the region, from extra care to EMI nursing. A significant proportion of older people living in the residential care setting in West Wales currently fund their own placement but may need financial support at a later date.

OLDER PEOPLE: Additional Data

Attendance Allowance

Total number of people aged over 65 receiving attendance allowance in Hywel Dda in November 2020 was 12,719 (6,490 in Carmarthenshire, 3,880 in Pembrokeshire and 2,354 in Ceredigion). As the likelihood of receiving attendance allowance increases with age, this will incur further costs with an aging population in the future.

Age Band	Carmarthenshire	Pembrokeshire	Ceredigion	West Wales
65-69	274 (4.22)	129 (3.32)	87 (3.70)	489
70-74	907 (13.98)	466 (12.01)	274 (11.64)	1,650 (3.84)
75-79	1,216 (18.74)	713 (18.38)	436 (18.52)	2,368 (12.97)
80-84	1,471 (22.67)	889 (22.91)	510 (21.67)	2,871 (18.62)
85-89	1,404 (21.63)	894 (23.04)	553 (23.49)	2,848 (22.57)
90+	1,215 (18.72)	786 (20.26)	493 (20.94)	2,497 (22.39)
Total	6,490 (100)	3,880 (100)	2,354 (100)	12,719 (100)

Table 6: Number of people receiving payment of attendance allowance for age groups in local authorities and West Wales (Nov 2020) [5]

Fuel Poverty

Fuel poverty is an increasing problem for many people and particularly older people. In addition to managing on a fixed income, the older the person is, the less likely they are to have central heating. This can have adverse effects on health and wellbeing and people diagnosed with respiratory diseases. Current data suggests that in future, older people will experience a much larger increase in fuel poverty than other age groups (as can be seen in figure 33 below) [4].

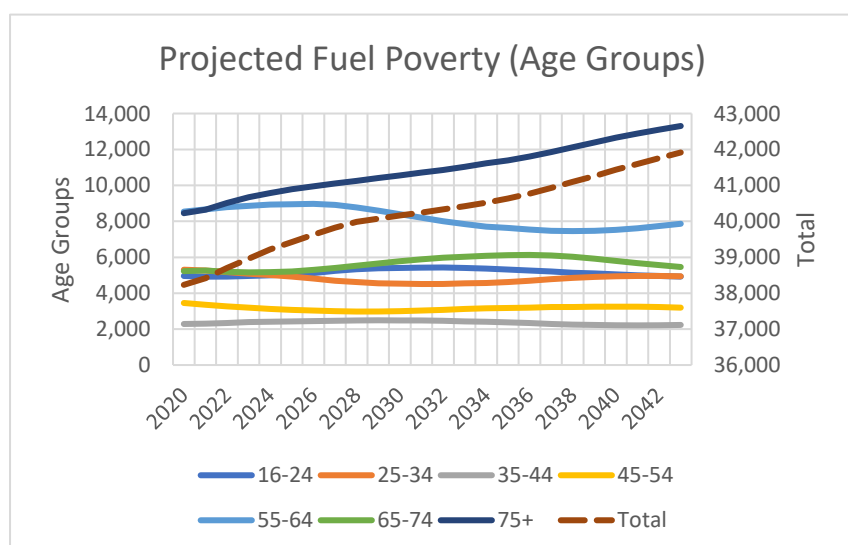


Figure 30: Total number of people projected to have fuel poverty in different age groups in HDdUHB

DEMENTIA: Current Legislation and Regulations

Listed below are plans, strategies, standards or good practice guides for implementing person-centred dementia support in Wales, rather than legislation:

Ageing well in Wales:

- Launched in 2014, Ageing well in Wales: An overview in a European perspective. Identified 5 priority areas to improve the health and wellbeing of older people in Wales:
 - Age friendly communities
 - Dementia supportive communities
 - Falls prevention
 - Loneliness and isolation
 - Opportunities for learning and employment
- Appropriate accommodation for older people can help to contribute to addressing all of the above.

Good Work Framework: A Dementia Learning and Development Framework for Wales:

- Passed in 2016, the overall aim is to support people to freely, creatively and responsibly identify and address their own specific learning and development needs within the context of their lives and circumstances.
- Intended to support what matters most to the people of Wales as well as the spirit and requirements of Welsh policy, legislation and guidance regarding the care, support and empowerment of people with dementia, carers and the health and social care workforce.

Dementia Action Plan for Wales:

- In February 2018 the Welsh Government published the Dementia Action Plan (DAP) 2018-2022. [Dementia action plan 2018 to 2022](#)
- The action plan sets out a clear strategy for Wales to be a 'dementia friendly nation that recognises the rights of people living with dementia to feel valued and to live as independently as possible in their communities'.
- The DAP is overseen by the Dementia Delivery Assurance and Implementation Group (DDAIG), members of which include people living with dementia and their families.

All Wales Dementia Care Pathway of Standards:

- In March 2021, Improvement Cymru published the All-Wales Dementia care pathway of standards. [The All Wales Dementia Care Pathway of Standards](#)
 - Directed by the requirements of the Dementia Action Plan for Wales

- Overseen by the Welsh Government Dementia Oversight Implementation and Impact Group (DOIIG).
- 20 standards have been designed to be dynamic by responding to evaluation and supporting evidence.
- The standards sit within 4 themes:
 - Accessible
 - Responsive
 - Journey
 - Partnerships and Relationship
- The standards have been developed using the Improvement Cymru Delivery Framework and it is anticipated that work will focus on developing a two-year Delivery Framework guide for the regions across Wales for the period April 2021 – March 2023.

THE NATIONAL HEALTH SERVICE (WALES) ACT 2006 The Primary Medical Services (Mental Health) (Directed Enhanced Services) (Wales) Directions 2017

(vii) early identification, effective management, advice and support for people with dementia and their carers; (viii) understanding the importance of timely diagnosis in dementia including advanced decision making and enduring or lasting powers of attorney;

<https://gov.wales/primary-medical-services-mental-health-directed-enhanced-services-wales-directions-2017-2017-no13>

DEMENTIA: Current Care and Support Provision

The Dementia Action Plan for Wales (DAP) sets out the Welsh Government's vision for creating a dementia friendly Wales, developed with those who know most about what needs to be done to improve truly person-centred dementia services – those with lived experience of dementia, their families and carers and service providers. As a result of views expressed in consultation and engagement processes the action plan is structured around outcomes which follow a pathway approach to dementia care to include the following:

- Risk reduction and delaying onset
- Raising awareness and understanding
- Learning and development
- Recognition and identification
- Assessment and diagnosis
- Living as well as possible, for as long as possible with dementia
- Care and support for increasing needs

As referenced in the main body of the chapter, to support implementation of best practice in alignment with the DAP, a Regional Dementia Strategy has been commissioned. Whilst recognising that the strategy will drive forward innovation and integration and identify gaps and areas for improvement, a range of services aligned with the aims of the DAP are available currently:

Risk reduction and delaying onset:

- Delta Connect – a telecare service providing individualised wellbeing assessment and personal stay-well plan

Raising awareness and understanding:

- A 3rd sector-led broad umbrella initiative – 'West Wales is Kind' campaign to incentivise random acts of kindness
- PAVS Dementia Supportive Communities Development Officer

Learning and development:

- Development of a dementia training framework

Assessment and diagnosis:

- Memory assessment services

Living as well as possible, for as long as possible with dementia:

- Fast Access Community Teams in all parts of West Wales providing multi-disciplinary support to people in their homes
- Admiral Nurse Team

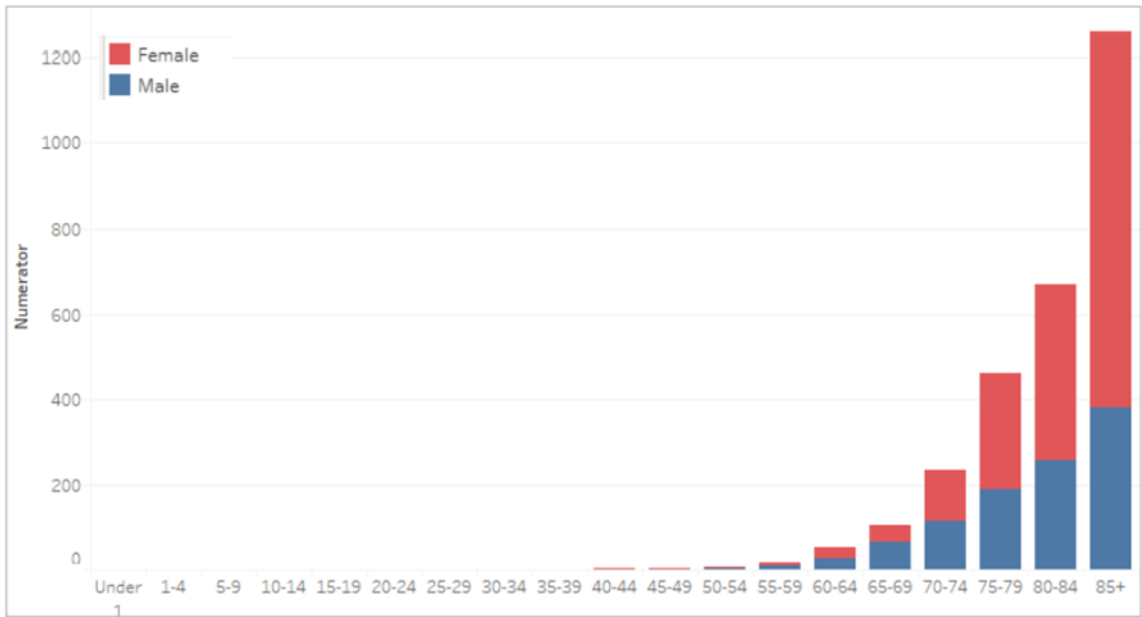
- Journey through dementia support groups

Care and support for increasing needs:

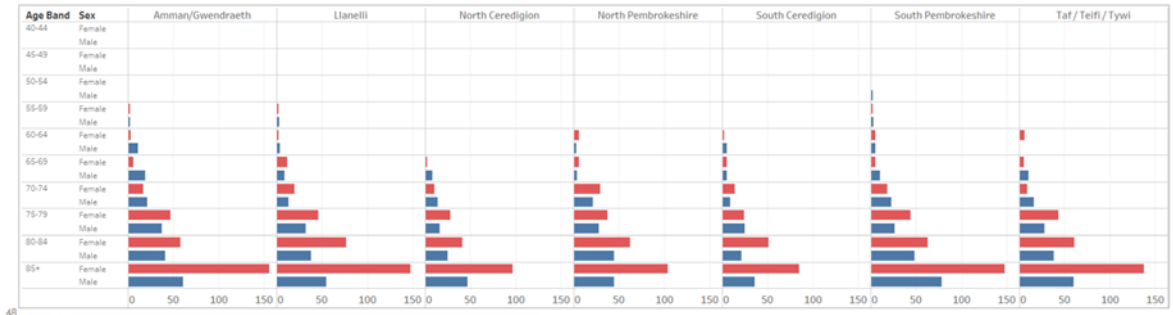
- Respite provision
- Dementia Well-being Community Team
- End-of-Life Care Service Provision including the following:
 - Paul Sartori and Marie Curie commissioned to deliver Advance Care Planning training
 - Marie Curie senior nurses help people with advanced dementia to access palliative and end of life care services in hospital, at home and in care homes across the region
 - Paul Sartori foundation provide education to a variety of audiences, including their own staff and others across the health board
 - Commitments from the DAP have been included in the Regional Palliative and End of Life Care strategy under development also

DEMENTIA: Additional Data

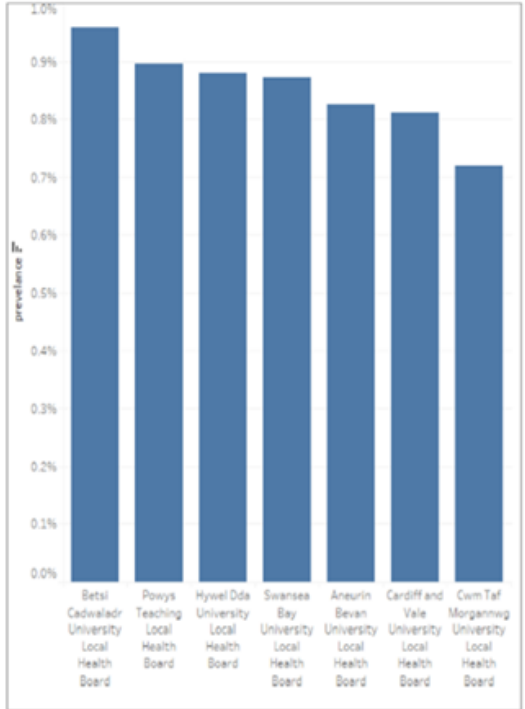
Dementia Data Charts and Graphs:



Source: GP QOF



Source: GP QOF and ONS



Figures 31, 32 and 33: Dementia Charts and Graphs (GP QOF)

UNPAID CARERS: Current Legislation and Regulations

There is a range of national legislation, policies and strategies in Wales aimed to support carers, including:

Welsh Government, Strategy for unpaid carers (2021)

The Welsh Government published a Strategy for Unpaid Carers in March 2021, which represents a renewed commitment to improving the recognition of and support to unpaid carers in Wales. It sets out revised national priorities for unpaid carers which have close alignment to the regional Carers strategy in West Wales. The 4 Welsh Government priorities are:

- *Priority 1:* Identifying and valuing unpaid carers
- *Priority 2:* Providing information, advice and assistance
- *Priority 3:* Supporting life alongside caring
- *Priority 4:* Supporting unpaid carers in education and the workplace

[Strategy for unpaid carers](#)

[Ministerial Advisory Group for Carers](#)

[Monitoring the implementation and progress of the delivery plan](#)

[Social Services and Well-being \(Wales\) Act 2014](#)

[Carers Wales Track the Act](#)

The Primary pillars of the act are:

- **Voice and control** – putting the individual and their needs at the centre of their care; 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.
- **Well-being** – supporting people to achieve their own wellbeing and measuring the success of care and support.
- **Co-production** – encouraging individuals to become more involved in the design and delivery of services.

Well-being of Future Generations (Wales) Act 2015

The Well-being of Future Generations (Wales) Act is about improving the social, economic, environmental and cultural well-being of Wales. It will make the public bodies listed in the act think more about the long term, work better with people and communities and each other, look to prevent problems and take a more joined-up approach. To make sure everyone is working towards the same vision, the act has 7 well-being goals:

- A prosperous Wales
- A resilient Wales
- A healthier Wales
- A more equal Wales
- A Wales of cohesive communities
- A Wales of vibrant culture and thriving Welsh language
- A globally responsible Wales

[Well-being of future generations act: the essentials](#)

Welsh Government, A Healthier Wales (2019)

<https://gov.wales/sites/default/files/publications/2019-10/a-healthier-wales-action-plan.pdf>

The strategy is focussed on changing five key areas of health and social care:

- i. The health and social care system will work together so that people using them won't notice when they are provided by different organisations.
- ii. Services will shift out of hospital into communities and services which stop people getting ill by detecting things earlier or preventing them altogether will be increased.
- iii. Systems to measure what really matters to people will get better and will be used to work out which services and support work well and which ones need to be improved.
- iv. Wales will be a great place to work in health and social care and more will be done to support carers and volunteers
- v. To make our services work as a single system, we need everyone to work together and pull in the same direction.

The National Outcomes Framework for people who need care and support and carers who need support (2019)

[National Outcomes Framework Indicator Report \(gov.wales\)](#)

The key objectives for the national outcome's framework are:

- To set the national direction to promote the well-being of people who need care and support and carers who need support in Wales.
- To describe the important national well-being outcomes that people who need care and support and carers who need support should expect in order to lead fulfilled lives.
- To provide greater transparency on whether services are improving well-being outcomes for people who need care and support and carers who need support in Wales using consistent and comparable indicators.

UNPAID CARERS: Current Care and Support Provision

1. Current work and important initiatives in the West Wales Region

A full breakdown of the work that is being carried out in West Wales under the guidance of the WWCDG can be found in Annual reports produced by the group. These annual reports provide full detail on all the actions and programmes delivered through the carers programme by WWCDG:

[WWCDG-Annual-Report-2021-21-FINAL.pdf \(wwcp.org.uk\)](#)

[WWCDG-Carers-Annual-Report-2019-20-FINAL.pdf \(wwcp.org.uk\)](#)

[WWCDG-Carers-Annual-Report-2018-19-final-version.pdf \(wwcp.org.uk\)](#)

2. Current support services

A range of care and support services are in place across the region to support carers. Some services are commissioned individually by statutory bodies and others are jointly commissioned on a county or regional basis. The WWCDG provides a key forum for partnership working between the commissioning bodies and ensures collaboration on the development of plans for utilisation of Welsh Government grant funding, e.g., Integrated Care Fund and Carers grants.

The West Wales Carers' Development Group (WWCDG) has been able to coordinate several important pieces of work, including:

- Providing young carers with access to a comprehensive information service and enabling them to notify supermarkets, pharmacies, teachers and others that they have caring responsibilities.
- Continued roll-out of the Investors in Carers' Scheme, increasing the awareness of professionals across sectors including primary, community and acute health care, schools, libraries, social care, Job Centre Plus and third sector organisations of the needs of carers. Over 120 settings are currently participating in the scheme and many more are working towards their award. The scheme also enables people to register as a carer with their GP, leading to the offer of a referral to the local Carers' Information Service which can provide additional information, advice and support
- Deployment of Carers Officers (employed by the third sector) within hospitals to support health professionals to identify unpaid carers, improve their involvement in the discharge process and provide information and support.
- Continued delivery of the Introduction to Looking After Me (I2LAM) programme for carers across West Wales, helping carers learn new skills and take care of their own health while looking after someone else.
- Roll-out of the Carers' Resilience and Wellbeing Programme, providing carers with a 'what matters' conversation and appropriate support including preventative interventions and respite

- Establishment of the regional Carers Support Innovation Fund offering third sector organisations with short-term funding to deliver support for carers. Initiatives supported include physical fitness sessions, sports reminiscence events, online craft and social sessions and targeted support for older carers
- Roll-out of the Employers for Carers (EfC) scheme in West Wales providing access to a range of resources for statutory and third sector partners. This has enabled organisations to review policies and procedures through a carers' lens and offer practical support to employees with caring responsibilities through the introduction of carers passports and staff networks
- Various digital inclusion initiatives to assist carers during the pandemic, including the Pembrokeshire Digital Connections Partnerships supporting people, including carers, to access digital equipment and technology

3. Support and Care Services

In addition to the programmes of work carried out under the WWDCG funded Welsh Government grant programmes, there are also several support and care services available to carers which are commissioned by Hywel Dda UHB and Local authorities. These can be broadly broken down into 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

4. Local Authority and Community

In addition to the specialised health support and services provided by Hywel Dda UHB, there are several other support mechanisms provided by local authorities:

- **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
- **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
- **Respite provision** - Short breaks/respite are 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. 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

5. Response to the COVID-19 Pandemic

In West Wales, the local authorities and third sector organisations have responded very well to the Covid-19 pandemic, quickly adapting their services and in some cases moving activities online.

For example, the Newport Carers group in Pembrokeshire went from meeting face-to-face to meeting on Zoom, supported by a Community Connector. As a result, the Carers group became more accessible to Carers across the County, attracting new Carers looking for online peer support.

Another example is Ceredigion Carers Unit who provided a full programme of workshops, training and discussions around Carers rights over the last six months of 2020-21.

All young Carers services have continued to operate and adapted ways of working, utilising Zoom, WhatsApp and Microsoft Teams.

Regular contact has been maintained with young Carers and their families to address issues.

All services have observed a decline in both young people's and parents' mental health over the year and services have responded by offering appropriate support.

UNPAID CARERS: Additional Data

The 2019 GP Patient Survey (England) found that unpaid carers are more likely to report having a long-term condition, disability or illness than non-carers (63% of unpaid carers compared to 51% of non-carers).

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 UHB, 2016a).

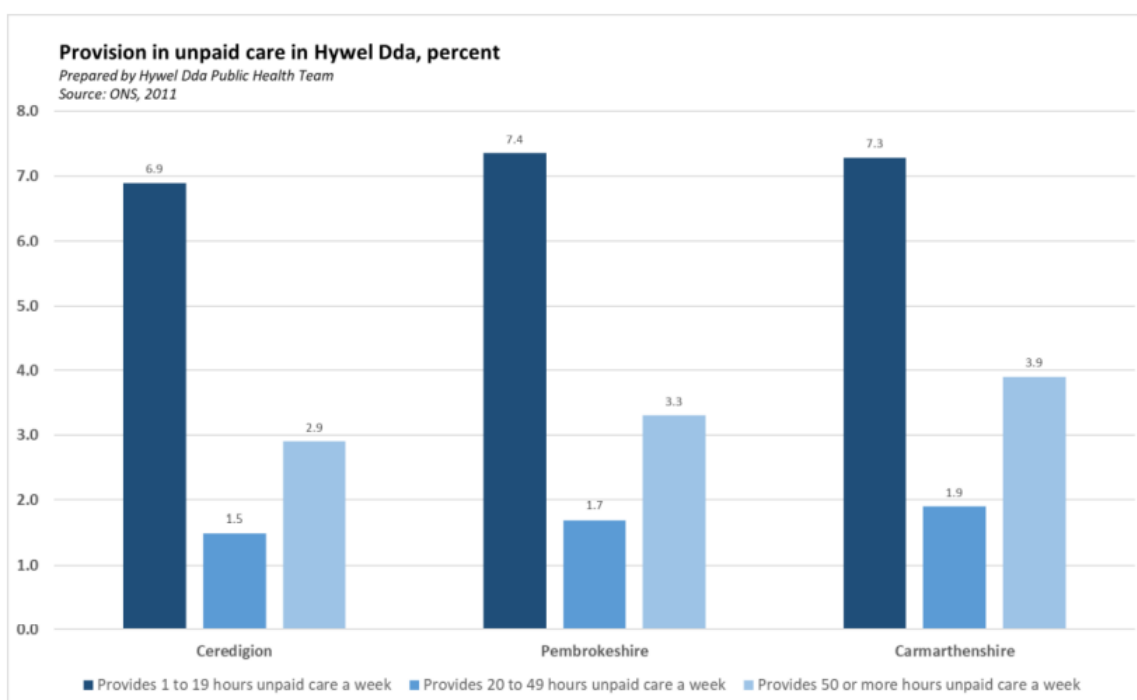


Figure 34: Provision of unpaid care in Hywel Dda UHB, ONS 2011

LEARNING DISABILITIES: Current Legislation and Regulations

There are many policies in Wales supporting how people with LD live their lives. We want to make sure we are part of creating and shaping how these policies support people with a learning disability to have the best lives. There are many generic policies that focus on the whole of the population, however, there are specific acts and programmes that are aimed at people with LD, these include:

Social Services and Well-being (Wales) Act 2014

The Primary pillars of the act involve:

- **Voice and control** – putting the individual and their needs at the centre of their care; 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.
- **Well-being** – supporting people to achieve their own wellbeing and measuring the success of care and support.
- **Co-production** – encouraging individuals to become more involved in the design and delivery of services.

Additional Learning Needs and Education Tribunal (Wales) Act 2018

The act provides a unified legislative framework to support all children of compulsory school age or below with additional learning needs. The act focuses on:

- An integrated, collaborative process of assessment, planning and monitoring that facilitates early, timely and effective intervention.
- A fair and transparent system for providing information and advice, and for resolving concerns and appeals.

Learning Disability – Improving Lives Programme 2018

A single cross-cutting strategy to inform all decision-making and to provide a framework for improving the lives of people with LD. The programme focuses on the strategies and evidence to improve five priority areas and address inequalities where they exist. The priority areas include:

- Early years and children
- Housing
- Social care
- Health and well-being
- Skills, education and employment

LEARNING DISABILITIES: Current Care and Support Provision

A range of care and support services are in place across the region to support adults with LD to live fulfilled lives within the community.

1. 'A Change in Approach': Coproduction and Involvement

Following the 2015 PNA particular focus has been placed on developing an ethos of co-production. The support and care services have aimed to include people with LD in all aspect of the care and support delivery plans in West Wales. The focus on co-production has led to the presence of service users on committees such as the RILP and the formulation of the 'Dream Team' and production of the West Wales LD Charter.

DREAM TEAM

The Dream Team is a collaboration of people and members from the Pembrokeshire and Carmarthenshire People First charities, together with representatives from Ceredigion. The members of the Dream Team consist of citizens with first-hand experience of living with a LD. The Dream Team are a group of individuals with an LD who advise care providers and the local authorities on what really matters, to hold the services to account and to ensure that the care and support needs that matter most to people with LD are being met.

LD Charter (<https://www.ldcharter.com/>)

Over the past 5 years, the LD community in Carmarthenshire, Pembrokeshire and Ceredigion have worked together to develop a Charter – a simple list of things they expect, and need, to live fulfilling lives.

"The West Wales LD Charter brings together our rights, our needs, and our wants, in a simple document aimed at everyone in our community. "It covers crucial areas like support, health and relationships, and brings them all together in a document anyone can – and should – sign up to. "I wasn't sure about using the words "we demand" – but we do! It's only fair that we demand to be treated like everyone else, to have a social life, to do things that fulfil us, and to be treated with dignity and respect."

James Dash, Co-Chair of the Learning Disability Programme Group

The West Wales LD Charter has been developed with support from the Welsh Government's Intermediate Care Fund, the West Wales Care Partnership, and Pembrokeshire College. It is supported by the County Councils of Carmarthenshire, Ceredigion and Pembrokeshire, and the Hywel Dda University Health Board. The Charter has been developed and led by the Dream Team, people with LD's, and not professionals, social services or even charities. The Dream Team are also involved in holding people to account. They visit businesses and organisations to get them to sign up – and checking that they really do follow through on their commitments.

The LD charter underpins all the future planning and provision for LD services in West Wales and has been designed by people with LD for people with LD.

2. Current work and important initiatives in the West Wales Region

In combination with the LD charter and co-production approach, several other initiatives have been put into action. These projects have had capital investment and are all designed to address the varying gaps and needs outlined by the previous PNA. The key to these initiatives is to ensure that citizen's voices are heard/listened to and ensure citizens can access the right information, when it is needed, in the way they want it and use this to manage and improve their well-being.

2.1 Health check champions

PwLD supporting their peers to access Annual Health Checks thereby, reducing prevalent health inequalities.

2.2 Tech apps

Co-producing accessible digital solutions to paper-based systems such as Health Passports and Care Plans and access to other on-line support, such as travel information.

2.3 Repatriation and Progression project

A virtual team reviewing residential care placements to develop appropriate alternatives to long-term institutional care in -line with individual assessed needs.

2.4 Regional LD Employment and training project

Support to address limited opportunities for people with LD to engage in volunteering or paid work as identified in the LD Strategies across the region, by scaling-up a successful pilot in Pembrokeshire.

2.5 Exercise buddies

Increasing the health and well-being of adults with a learning disability and their parents/carers, by developing a range of supported exercise and activity groups.

2.6 Supported accommodation

Improving access to supported accommodation through improved policies, systems, processes and engagement with Registered Social Landlord (RSL) partners.

2.7 Transformation of day opportunities

An engagement programme to develop a future model of day opportunities. Aimed at transforming day opportunities by developing alternative delivery models and piloting of new ways of working.

2.8 Prime of our lives

Developing partnerships, disseminating information, sharing experiences, providing mechanisms to ensure that the voices of older people with learning disabilities are heard and responded to.

2.9 Carms PBIS

Local services that support PwLD and their families, to reduce reported incidents of challenging behaviour, number of placement breakdowns and high cost of out of county placements.

2.10 LD Innovation Fund

Opportunities to test alternative service delivery models to support and empower those with learning disabilities by piloting innovative and co-produced services that meet gaps in provision.

3. Hywel Dda UHB Support and Care Services

Across Hywel Dda UHB there are a range of services and specialists that help to care and support people with LD, these include: Consultant psychiatry, psychology, community nursing, Speech and Language Therapy, Occupational Therapy and Physiotherapy. In addition, there are several services specifically available to the LD community across the Hywel Dda UHB to help ensure people with LD have access to the services and care they need and minimise any health inequalities. These include:

3.1 Community Team Learning Disability (CTLD) service

There are four Community Team Learning Disability (CTLD) services across the Hywel Dda area. The teams work together and are made up of learning disability nurses; occupational therapists; physiotherapists; speech and language therapists; psychologists; psychiatrists; behaviour practitioners; and social workers. The teams also work in the community supporting primary care, GPs and private providers, including clients in supported living and residential units, while also supporting individuals living on their own. The teams also support carers, families, and day services.

3.2 Learning Disability Health Liaison Service for adults and children

The Learning Disability Health Liaison Service is for adults and children with learning disabilities who are having or due to have hospital treatment and may need advice and support.

- Provides training to staff about the needs of people with LD.
- Provides advice about following the LD pathway and using the 'Care Bundle'
- Liaise with the hospital staff to ensure that reasonable adjustments are in place
- Provide advice and support to individuals and their carers during their hospital admission
- Provide support to ease communication between the patient, carers, and hospital staff

3.3 PMLD/Complex Health Needs Clinic

A new clinic due to be commissioned. The PMLD/complex health needs clinic aims to ensure that people with profound and multiple learning disabilities have access to consistent high-quality health support from the Learning Disabilities Service. Individuals are identified by members of the CTLD and referred to the PMLD Pathway. Aims and objectives of the clinic are:

- Identify individuals who require multiple specialist LD health professionals.

- Complete coordinated assessments and reviews in clinic setting
- Complete MDT care plan to meet complex needs and share with SU/carers/families
- Identify interventions required and training needs for carers/families
- Signpost to other professionals as required

3.4 Learning Disability Intensive Support Team (LDIST)

The Learning Disability Intensive Support Team (LDIST) is a pilot scheme. The LDIST consists of LD and MH nurses and health care support workers to provide intensive or additional support for adults with LD during a time of need. Support is available for a limited period to help manage or overcome a certain issue, problem or change. The support may include advice over the telephone, individually, in groups, by observational methods, assessments, via direct support, short term treatment, training to carers or through meetings. The LDIST work closely alongside CLDT and provide support that requires an increased level of input for a short and focused amount of time. The LDIST is community based, supporting people with LD/ their families or their care providers where they ordinarily live to continue delivery of care over the longer term.

The specific care and support options do vary across the different LA, with specifics available from: Carmarthenshire family information service, Pembrokeshire People First and Ceredigion Community Team for Learning

LEARNING DISABILITIES: Additional Data

Current data (Feb 2021) from the Department of Works and Pensions indicate that the number of families claiming financial support on behalf of a child or young person (aged 0 to 16), in terms of Disabilities Living Allowance (DLA), is 1,199 (202 in Ceredigion, 460 in Pembrokeshire and 533 in Carmarthenshire). Despite the prediction of the numbers of Children and Young people with LD remaining constant, West Wales has seen a steady increase in the number of people claiming DLA over the last 5 years (see figure 38).

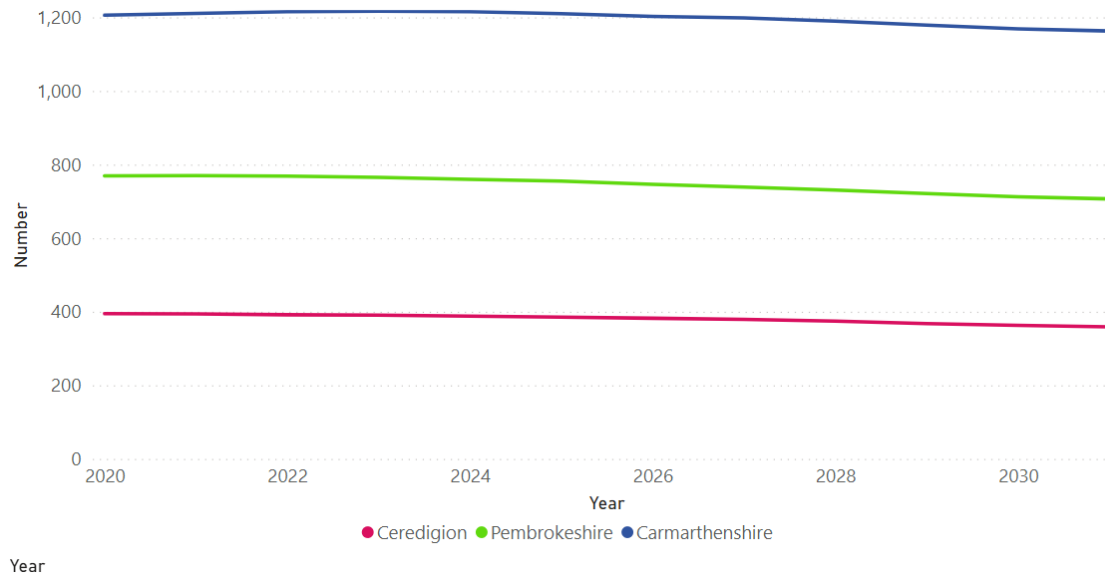


Figure 35: Projection of number of children and young people with moderate LD across the LA in West Wales [Projection based on models provided by Social Care Wales Population Projection Profile, www.daffodilcymru.org.uk]

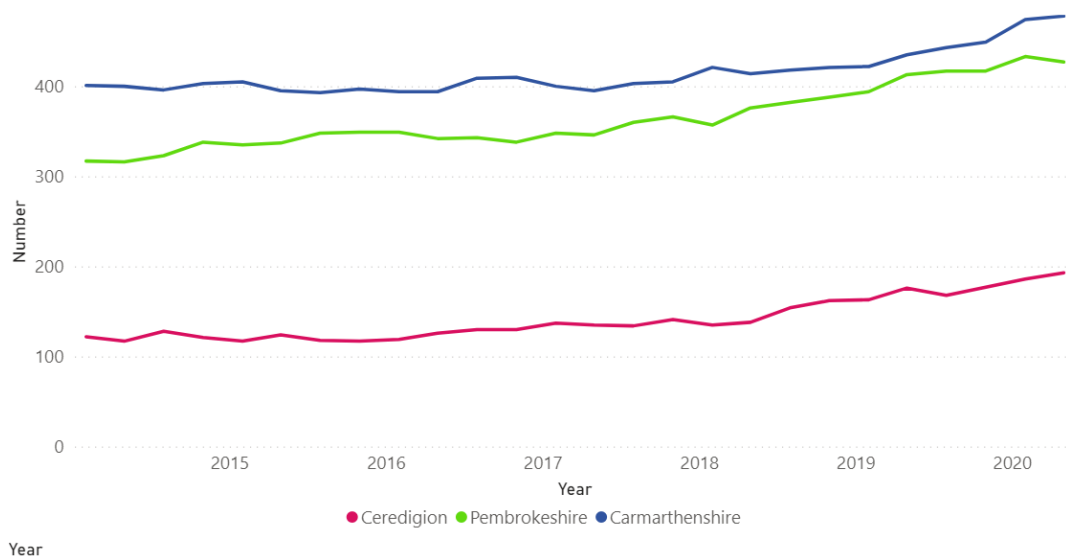


Figure 36: Number of children or young people (aged 0-16) entitled to Disability Living Allowance in West Wales [data collected from the department of works and pension, <https://stat-xplore.dwp.gov.uk>]

AUTISM: Current Legislation and Regulations

As an alternative to a separate Autism Bill, The Welsh Government developed a Code of Practice for Autism which highlights and reinforces existing duties of the Social Services and Wellbeing (Wales) Act 2014 and the NHS (Wales) Act 2006 in respect of Autistic people, which can be found here:

<https://gov.wales/code-practice-delivery-autism-services-0>

In 2019 the Welsh Government published a refresh to the original action plan published in 2008, which can be found here:

<https://gov.wales/sites/default/files/publications/2019-03/refreshed-autistic-spectrum-disorder-strategic-action-plan.pdf>

AUTISM: Current Care and Support Provision

In March 2016, as part of the refreshed Autistic Spectrum Disorder Strategic Action Plan the Welsh Government announced that it would be funding a new national Integrated Autism Service (IAS), information on which can be found here: <https://autismwales.org/en/integrated-autism-service/>

The service was developed across Wales following consultation with autistic people, carers and professionals which highlighted the lack of support available for autistic people who did not meet the criteria for mental health and learning disability services.

The West Wales Integrated Autism Service (WWIAS) established in 2019 and is a joint service delivered by Hywel Dda University Health Board in partnership with the local authorities of West Wales.

It offers diagnostic assessment for adults who do not have a significant learning disability or mental health problem and a range of support for autistic people, their families, including unpaid carers and advice for professionals. Further information can be found here: <https://fis.carmarthenshire.gov.wales/disability-autism/autism/>

AUTISM: Additional Data

The availability of data specific to autism spectrum disorders is limited, as its collation and disaggregation is in the early stages. As and when data is available, it will be added to the chapter.

CHILDREN and YOUNG PEOPLE: Current Legislation and Regulations

There is a range of legislation, policies and guidance relating to children, which include the following:

The Children Act 1989 (as amended):

<https://www.legislation.gov.uk/ukpga/1989/41>

The essentials of this piece of legislation are –

- To allow children to be healthy.
- Allowing children to remain safe in their environments.
- Helping children to enjoy life.
- Assist children in their quest to succeed.
- Making a positive contribution – to the lives of children.
- Achieving economic stability for our children's futures.

The Children and Social Work Act 2017:

<https://www.legislation.gov.uk/ukpga/2017/16/contents/enacted>

This Act intends to improve support for looked after children and care leavers, as well as promoting the welfare and safeguarding of children. It sets out corporate parenting principles for the local authority to be the 'best parent it can be' to children who are in its care. Local authorities are, under this Act, obliged to publish their support offer to care leavers and promote any educational attainment of children who have been adopted or placed in long-term care arrangements.

Keeping Children Safe in Education 2021:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1021914/KCSIE_2021_September_guidance.pdf

This document outlines statutory guidance for keeping children safe in schools and colleges. It is an update from the 2016 document. It is organised into five parts:

- Safeguarding information for all staff
- Management of safeguarding
- Safer recruitment
- Allegations of abuse made against teachers and other staff
- Child-on-child sexual violence and sexual harassment

The Education Act 2002: <https://www.legislation.gov.uk/ukpga/2002/32/contents>

The Education Act 2002 places a duty on educational settings such as schools and colleges to ensure that the safeguarding and welfare of children is paramount to the way in which their setting functions. Specific duties are placed on local education authorities and governing bodies under Section 175 of the Act, which maintains that:

- The local education authority must make arrangements for ensuring that their responsibilities in terms of safeguarding are exercised so that children are safe and that their welfare is promoted.

- The governing body of a school should make arrangements to ensure that their functions concerning the school's conduct are exercised with a view of safeguarding and promoting the welfare of children who attend the school.
- The governing body of a school should ensure that staff receive adequate training related to the safeguarding and promotion of the welfare of children.

The Equality Act 2010: <https://www.legislation.gov.uk/ukpga/2010/15/contents>

[The Equality Act 2010](https://www.legislation.gov.uk/ukpga/2010/15/contents) aims to protect people or groups of people who have one or more 'protected characteristics'. These protected characteristics are features of people's lives upon which discrimination, in the UK is now illegal. The protected characteristics listed in the Act are:

- Age
- Disability
- Sexual orientation
- Sex
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race
- Religion and belief

The Children and Families Act 2014:

<https://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

This Act aims to ensure that greater protection is available for children who have been classed as vulnerable. It includes children who may be in foster care and those who are looked after or have additional needs. The Act also ensures that an Education, Health and Care Plan is produced for any child who has been identified as having additional needs.

The Human Rights Act 1999:

<https://www.legislation.gov.uk/ukpga/1998/42/contents>

Human rights within the United Kingdom are protected by the Human Rights Act 1998, which means that if an individual believes that their human rights have been breached, they can take action against this in a court of law. Examples of rights that are contained within the Act, known as 'Articles' are:

- The right to freedom from torture and inhumane or degrading treatment or punishment
- The right to liberty and security
- The right to freedom of thought, conscience and religion
- The right to freedom of expression
- The right of access to an education

CHILDREN and YOUNG PEOPLE: Current Care and Support Provision

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

The Right Help at the Right Time Framework



Figure 37: Needs of Children, Young People and Families

CHILDREN and YOUNG PEOPLE: Additional Data

When developing the chapter, some data was awaiting release, such as that from the 2021 Census and some data had not been gathered during the pandemic to the level required. In some instances, data has been difficult to source, such as that on the impact of adverse childhood experiences (ACEs). As and when data is available, it will be added to the chapter including that for:

- Levels of and impact of deprivation
- Numbers in receipt of free school meals
- Levels of attainment
- Numbers receiving support from emotional and wellbeing services (Mental Health)
- Numbers and outcomes for care leavers
- Numbers of children in foster care
- Impact of ACES

MENTAL HEALTH: Current Legislation and Regulations

There are many policies in Wales supporting how people with mental health issues live their lives. Specific acts and programmes that are aimed at people with mental health issues include:

Together for Mental Health: A Strategy for Mental Health and Wellbeing in Wales

The Welsh strategy is outlined in [Together for Mental Health: A Strategy for Mental Health and Wellbeing in Wales](#). Together for Mental Health sets out the ambitions for improving mental health in Wales and sets out the vision for 21st century mental health services. This is the first mental health strategy for Wales to cover all ages; previously there have been separate strategies for children, adults and older people, but feedback has suggested that transition between services can break down, so combining the age groups aims to eliminate boundaries. A New Mental Health Partnership Board (NPB) is being established to oversee delivery of the strategy.

The Together for Mental Health Delivery Plan

The Together for Mental Health Delivery Plan 2019-2022 was produced as part of Welsh Governments strategy to improve mental health and wellbeing in Wales. In response to the COVID-19 pandemic, the Together for Mental Health Delivery Plan 2019-2022 was reviewed in 2020. The aim of the [review](#) was for the Welsh Government and partners to respond to the impacts of COVID-19 to ensure that the people of Wales have access to appropriate mental health support during the pandemic.

MENTAL HEALTH: Current Care and Support Provision

Care and support provision

Since 2010 and the introduction of the [Mental Health \(Wales\) Measure](#), the majority of mental health cases are treated at the primary care level. This is to promote early intervention, to reduce the likelihood of their condition deteriorating and needing further secondary mental health services.

Current support services

Care, services and support needs for people with mental health issues in West Wales are coordinated by Local Primary Mental Health Support Services (LPMHSS) and Community Mental Health Teams (CMHTs).

Local Primary Mental Health Support Services and Community Mental Health Teams

The introduction of Local Primary Mental Health Support Services (LPMHSS) aimed to increase the availability and uptake of mental health services at the primary care level, as well as improving integration of services, and working with GPs and practice staff to provide support and training.

Community Mental Health Teams (CMHTs) in West Wales are a partnership between Hywel Dda University Health Board and Social Services and provide the point of referral for those requiring access to secondary mental health services. CMHTs have a duty to assess anyone experiencing mental health issues which are affecting their ability to lead their life.

Third Sector

The health board and local authorities continue to commission a range of third sector organisations to support people with mental health issues such as advocacy services, information and advice, activities, healthy lifestyles and a range of supported accommodation and tenancy related support services.

Mind is a mental health charity that operates throughout West Wales. They provide advice and support to empower anyone experiencing a mental health problem. They also campaign to improve services, raise awareness and promote understanding. Mind services operating in West Wales are Pembrokeshire Mind, Carmarthenshire Mind and Mind Aberystwyth.

Other third sector organisations operating in West Wales include Hafal, which works with individuals recovering from mental health problems, with a special emphasis on those with serious mental illness, and FRAME, which provides around 80 people a week the opportunity practice work and train new skills.

West Wales Action for Mental Health (WWAMH) is a mental health development organisation in West Wales. It provides a range of services to voluntary groups, carers and individuals who require support around mental health in the West Wales region and seeks to improve the services and opportunities available to people with mental health problems, their families and carers.

Twilight Sanctuaries

Twilight sanctuaries are part of the service provided by Mind. They are designed to offer support to people at risk of deteriorating mental health outside of normal office hours. Currently in West Wales, there are twilight sanctuary services in Llanelli and Haverfordwest, with plans for 3rd Twilight sanctuary to be implemented in Ceredigion soon. This will mean a twilight sanctuary in each of the three local authority areas by December.

MENTAL HEALTH: Additional Data

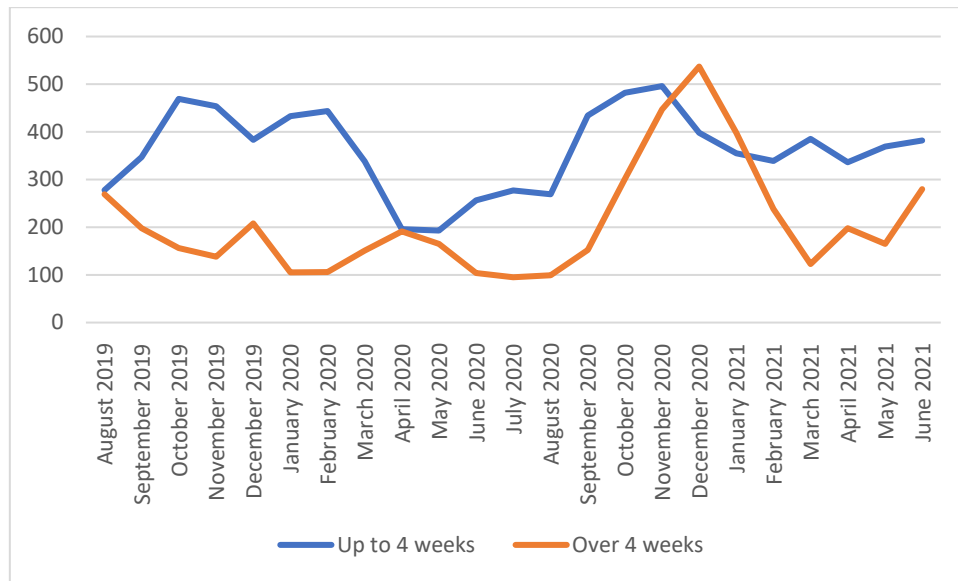


Figure 26: sCAMHS pathways waiting time for first appointment (up to 4 weeks, compared to over 4 weeks) in Wales.

Figure 41 below shows the percentage of people aged 16+ years free from common mental disorders in each of the counties compared to Wales and West Wales. The prevalence of common mental disorders is around 16% in each of the local authorities and in Wales according to the data, with slightly lower prevalence in West Wales than in Wales as a whole. [7]

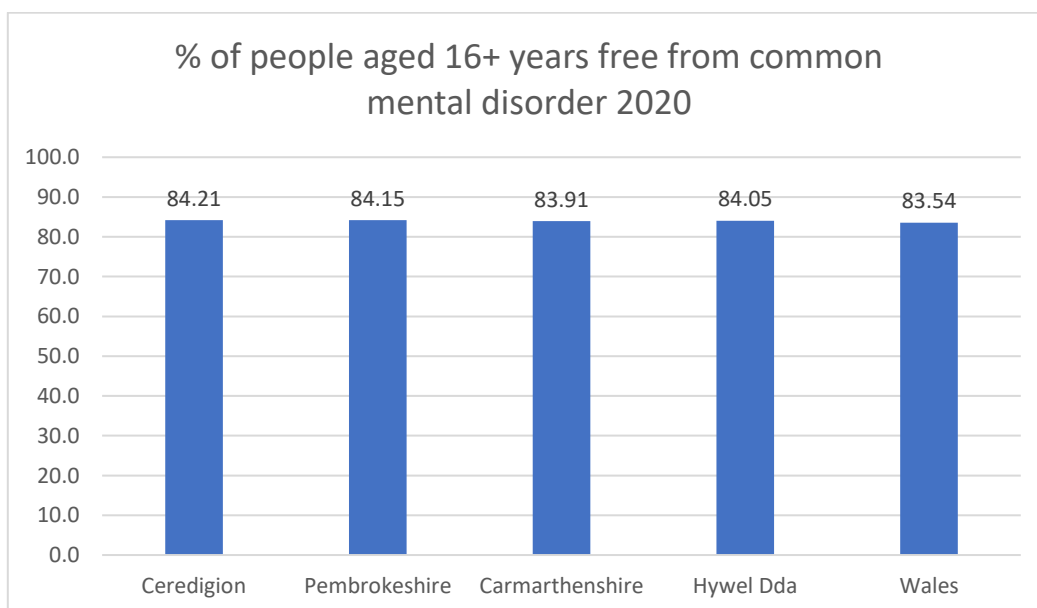
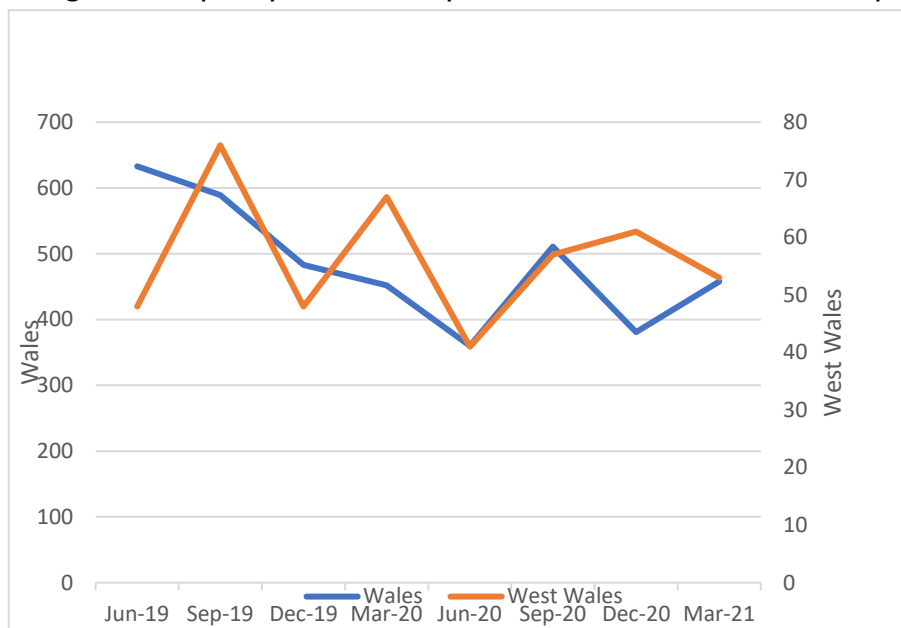


Figure 38: Percentage of people aged 16+ years free from common mental disorders in West Wales local authorities compared to Wales and West Wales as a whole, 2020

The total number of section 135 and 136 detentions in Wales have fluctuated from 2019 to 2021 (figure 42), ranging from a high of 633 per quarter in June 2019 to a low of 360 per quarter in June 2020. Detentions in West Wales have ranged from a high of 76 per quarter in September 2019 to a low of 41 per quarter in June 2020.



Overall, the total detentions in Wales seems to have decreased slightly over the past two years, whereas rates in West Wales have remained around the same.

Figure 39: Section 135 and 136 detentions in Wales and West Wales by quarter

The total patients in mental health hospitals and units with a mental illness have decreased in both Wales and West Wales from 2009 to 2019, although since 2013, this figure has remained relatively stable in West Wales, at around 110 to 125 patients (Figure 43). [7]

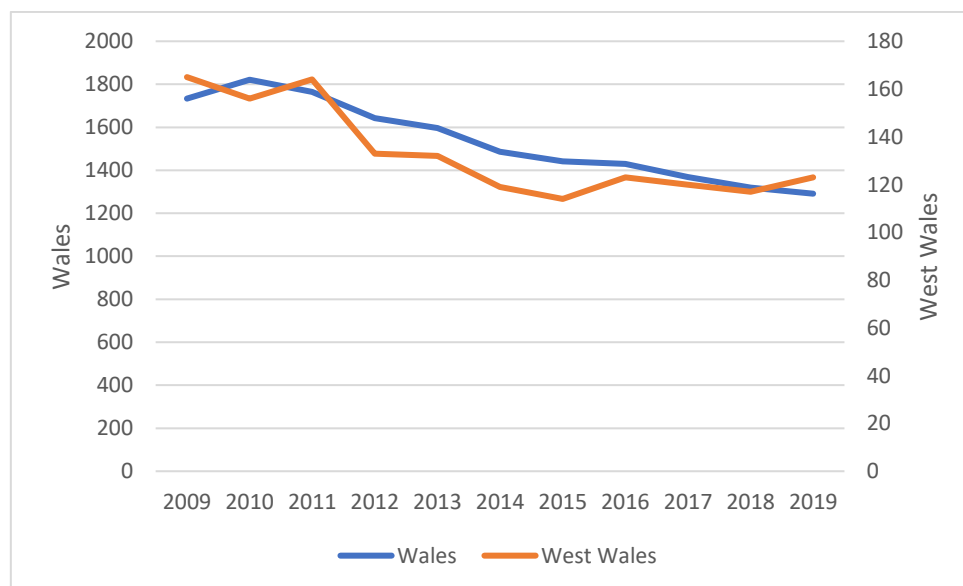


Figure 40: Patients in mental health hospitals and units in Wales with a mental illness

Deprivation of Liberty Safeguard (DoLS) Requests

The total number DoLS requests from 2017 to 2020 is shown in figure 44 below, for each local authority. The total number of requests has increased in both Carmarthenshire and Pembrokeshire since 2017, while remaining at around the same

level in Ceredigion (Figure 1.2) [8]. The main group of individuals with DoLS applications were older people, with 87% of applications made against someone over the age of 65 in 2019-20. Overall, the total number of DoLS requests has been increasing in West Wales, from 598 in 2017-18 to 832 in 2019-20.

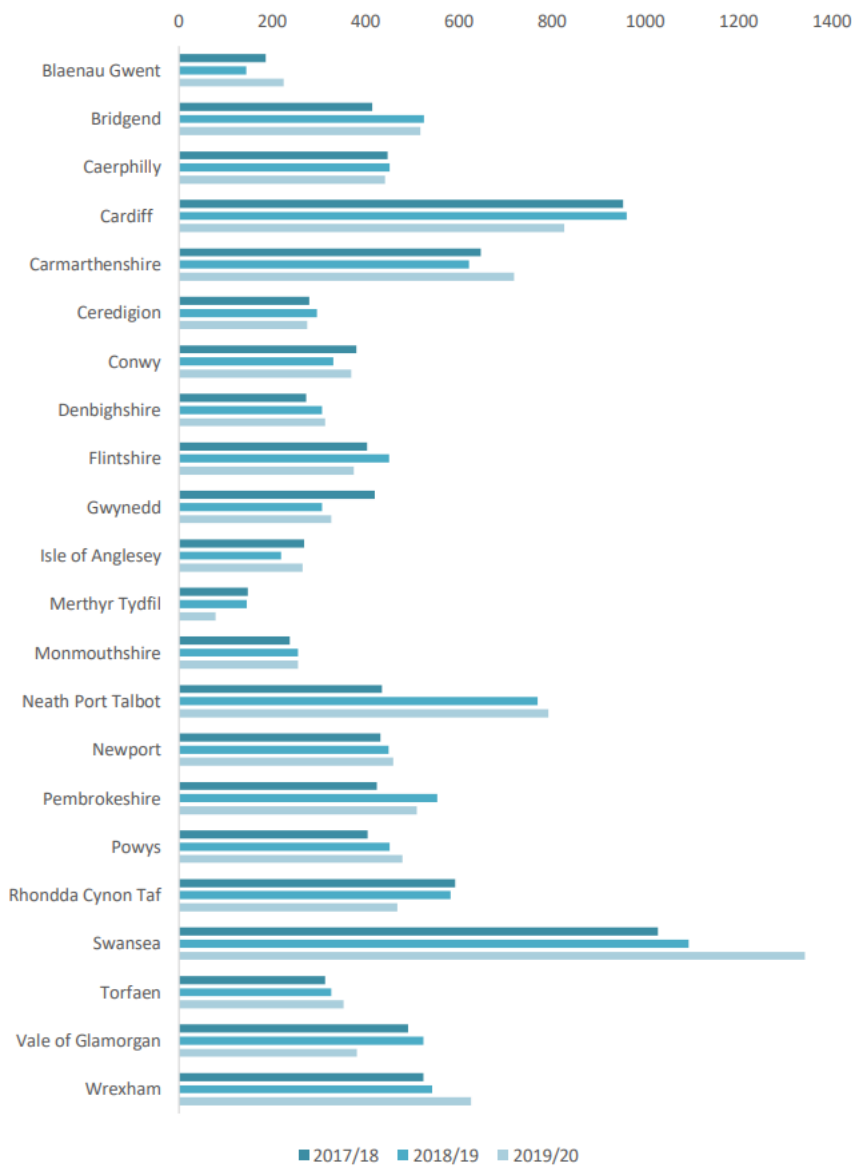


Figure 41: Deprivation of liberty safeguard requests received by each local authority from 2017 to 2020 [8]

Total Suicides in West Wales

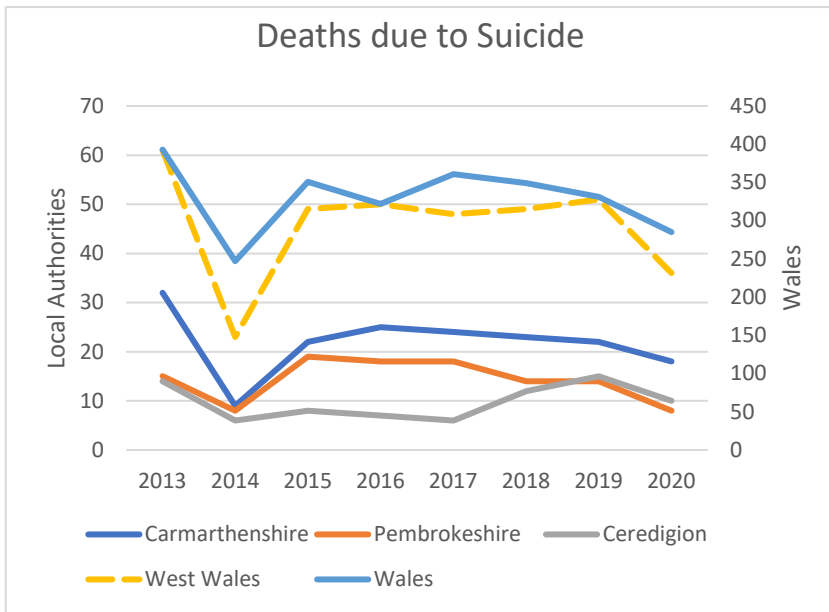


Figure 45 shows the total number of suicides in Wales and the three local authorities from 2013 to 2020. Roughly 250 to 400 people in Wales commit suicide each year. In West Wales this has fluctuated from around 25 to 60 people each year. [9]

Figure 42: Yearly deaths due to suicide in local authorities and Wales, 2013 - 2020

HEALTH and PHYSICAL DISABILITIES: Current Legislation and Regulations

The following Acts contain provisions which support independent living:

The 'Social Services and Well-being (Wales) Act 2014' provides the statutory framework to deliver the Welsh Government's commitment to transform social services in Wales to improve the well-being of people who need care and support and carers who need support. The Act sets out a definition of well-being for people who need care and support. Everyone, adult or child, has the right to be heard; to shape the decisions that affect them' and to have control over their day-to-day lives. The code of practice in relation to Part 2 of the Act provides guidance to local authorities on their duties in this regard. This code of practice requires local authorities, when exercising social services functions in relation to disabled people who need care and support and disabled carers who need support, to have due regard to the UN Convention on the Rights of Disabled Persons.

The Act also extends the eligibility and accessibility of Direct Payments, which provide an important mechanism by which people can exercise choice, voice and control to decide how to meet their needs for care and support and achieve their personal wellbeing outcomes. The 'Well-being of Future Generations (Wales) Act 2015' sets out seven well-being goals - for national government, local government, local health boards and other specified public bodies. It also specifies the ways in which these bodies must work, and work together, to improve the well-being of Wales. This includes the five 'ways of working' to guide the Welsh public services in delivering for people.

The 'Housing (Wales) Act 2014' includes provisions aimed at modernising and improving conditions in the private rented housing sector and for improving the practices of landlords and letting agents. Private landlords are now required to register and where they are carrying out lettings or property management work to become licensed, or to appoint licensed agents to carry out such work. As well as being required to be licensed, agents are required to be registered. It is intended this will improve standards of letting and management practice in the private rented sector.

The 'Renting Homes (Wales) Act 2016' provides a simplified legal framework for renting based on two types of occupation contract, which will replace most existing tenancy arrangements. This will apply to social housing provided by local authorities and housing associations and to rentals from private landlords. Model written statements of contract will be provided. This will make it is easier for disabled and non-disabled people to understand their rights and responsibilities. In addition, the Act provides a new form of occupation contract for any person who occupies premises in conjunction with the provision of particular support services, including supporting people who require additional assistance to achieve independent living for example because of cognitive or intellectual impairments. Additionally, the Act will extend succession rights to carers, for which current housing legislation makes no provision.

[action-on-disability-the-right-to-independent-living-framework-and-action-plan.pdf \(gov.wales\)](#)

[Strategic Equality Plan 2016 \(gov.wales\)](#)

The Renting Homes (Wales) Act 2016

<http://senedd.assembly.wales/mgIssueHistoryHome.aspx?IIId=12055>

<http://www.legislation.gov.uk/anaw/2016/1/contents/enacted>

[well-being-of-future-generations-wales-act-2015-the-essentials.pdf \(gov.wales\)](#)

[social-services-and-well-being-wales-act-2014-the-essentials.pdf \(gov.wales\)](#)

The Housing (Wales) Act 2014

<http://senedd.assembly.wales/mgIssueHistoryHome.aspx?IIId=8220>

<http://www.legislation.gov.uk/anaw/2014/7/contents/enacted>

HEALTH and PHYSICAL DISABILITIES: Current Care and Support Provision

People with health conditions and/or physical disabilities 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 support, preventative services, such as dietetic support and advice.
- Multiple and complex needs requiring coordinated multi-agency support to address and manage specific issues.

[The Welsh Government's Framework for Action on Independent Living](#), published in 2013, set out actions to promote an inclusive and enabling society, to ensure people of all ages and from all communities can maintain independent living, enjoy well-being and access appropriate support when and how they need it.

Wherever possible we will seek to "co-produce" services in West Wales. That is, we will work with stakeholders including disabled people to design, deliver and evaluate new initiatives.

HEALTH and PHYSICAL DISABILITIES: Additional Data

Claiming Support

The main types of benefit available for people between the ages of 18-64 living with a serious illness or disability are disability living allowance and personal independent payment. There are over 22,000 people who are entitled to Personal Independence Payment (PIP) in the Hywel Dda University Health Board. Over 10,000 people are entitled to Disability Living Allowance (DLA) in the West Wales area and over 13,500 people entitled to Attendance Allowance (AA).

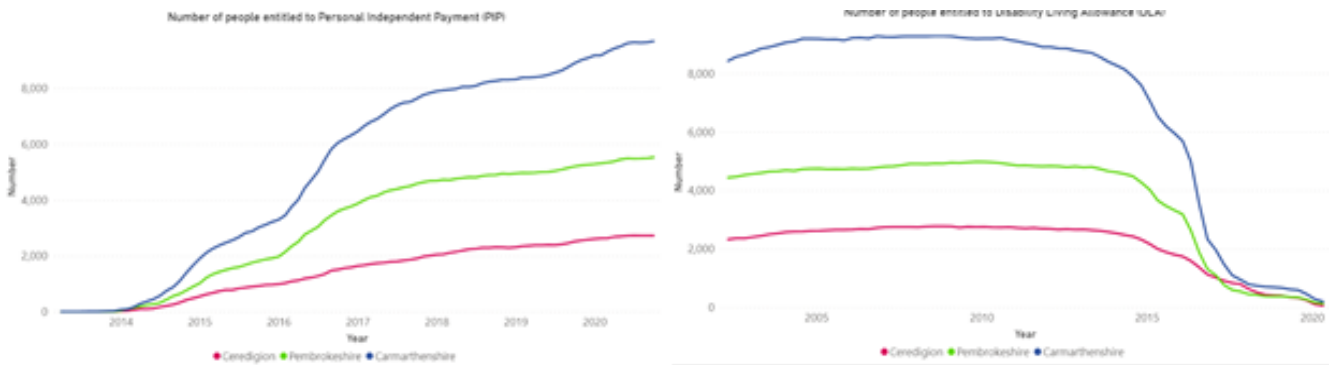


Figure 43: Number of people entitled to Personal Independence Payments and Disability Living Allowance in the West Wales area

Limiting Long-term Illness

A long-term health problem or disability that limits a person's day-to-day activities, and has lasted, or is expected to last, at least 12 months also includes problems that are related to old age. Data from the 2011 census highlighted that Carmarthenshire had the highest percentage of people whose day to day activities were limited (25.4%) or limited a lot (13.6%), followed by Pembrokeshire (22.5% and 11.1% respectively) and then Ceredigion (21.1% and 10% respectively).

As can be seen in the figure below the percentage of those who are EA core or work limited disabled are mainly higher in females than males, except in Pembrokeshire where males (23.4%) are higher than females (22.4%). Percentages are higher overall in Carmarthenshire (28.4%) for both males and females.

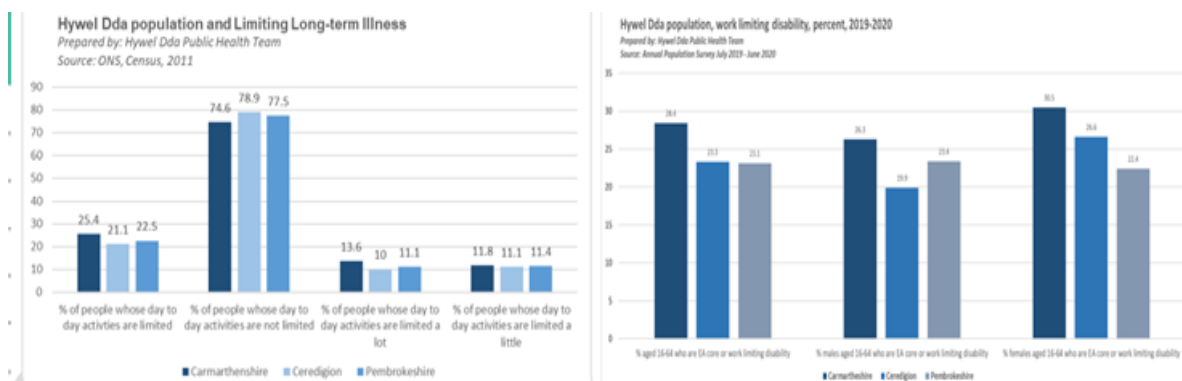


Figure 44: HDdUHB population and Limiting Long-term Illness and limiting disability

SENSORY IMPAIRMENT: Current Legislation and Regulations

There are many policies, acts and programmes in Wales supporting how people with sensory impairment live their lives including:

1: The All-Wales Standards for Accessible Communication and Information for People with Sensory Loss [8]

The All-Wales Standards for Accessible Communication and Information for People with Sensory Loss were published in 2013 by NHS Wales. The purpose of the standards is to ensure that the communication and information needs of people with sensory impairment are met when accessing healthcare services.

Welsh Government. Available at
<https://gov.wales/sites/default/files/publications/2019-04/all-wales-standards-for-accessible-communication-and-information-for-people-with-sensory-loss-large-print-0.pdf>.

2: Support for Children and Young People with Multi-Sensory Impairment in Educational Settings [9]

The Support for Children and Young People with Multi-Sensory Impairment in Educational Settings guide was produced by the Welsh Government in 2019 to provide a summary of evidence about the effectiveness of different educational approaches for supporting young people and children with multi-sensory impairment/deafblindness from a commissioned rapid evidence assessment (REA).

Welsh Government. Available at
<https://gov.wales/sites/default/files/publications/2019-12/191209-support-for-children-and-young-people-with-multi-sensory-impairment-in-educational-settings.pdf>

SENSORY IMPAIRMENT: Current Care and Support Provision

The following support services are available in West Wales:

- Eye Clinic Liaison Officers (ECLOs) are in hospitals and provide support to help link visually impaired patients to the correct services and help navigate the complexity of possible treatments and services.
- Specialist Rehabilitation Officers are located within social care and help to support people who have lost or are losing their sight. Rehabilitation officers can help patients experiencing visual impairment to maintain independence, regain lost skills or build confidence. They can also assist with mobility training, which can help an individual to regain their confidence in going outdoors safely and independently.
- Specialist Services such as mobility and communication equipment and services including braille and lip-reading services where appropriate

The following third sector organisations also offer support:

- Royal National Institute for Deaf People (RNID) is a charity that operates across the UK and works to make life fully inclusive for deaf people and those with hearing loss or tinnitus.
- The Royal National Institute of Blind People (RNIB) is a charity that operates across the UK and works on behalf of more than 111,000 people in Wales living with sight loss.
- Wales Council of the Blind (WCB) is an umbrella agency that represents vision impairment within Wales, and works to campaign, lobby and support the improvement of services for people with sight loss.
- Wales Council for Deaf People (WCDP) are an umbrella association of both voluntary and statutory organisations providing support for people who deaf, deafened, hard of hearing or deafblind in Wales.
- Deafblind UK currently supports people with dual sensory impairment in England, Wales and Northern Ireland.

SENSORY IMPAIRMENT: Additional Data

Sight Loss

Sight loss affects people of all ages, but especially the elder population, with one in five people over the age of 75, and one in two people over the age of 90, living with sight loss. Nearly two thirds of people with sight loss are women. Adults with learning disabilities are ten times as likely to be blind or partially sighted than the general population. [2]

The following table provides the figures on the number of people registered as partially sighted or blind in each county.

	Carmarthenshire	Ceredigion	Pembrokeshire
Number of people registered as partially sighted or blind (2018/19)	987	308	644

Table 7: Number of people registered as partially sighted or blind in local authorities [3]

As can be seen in figure 1.1 below the number of people with visual impairment in the three local authorities is predicted to rise towards 2043. This mirrors the national projections [4].

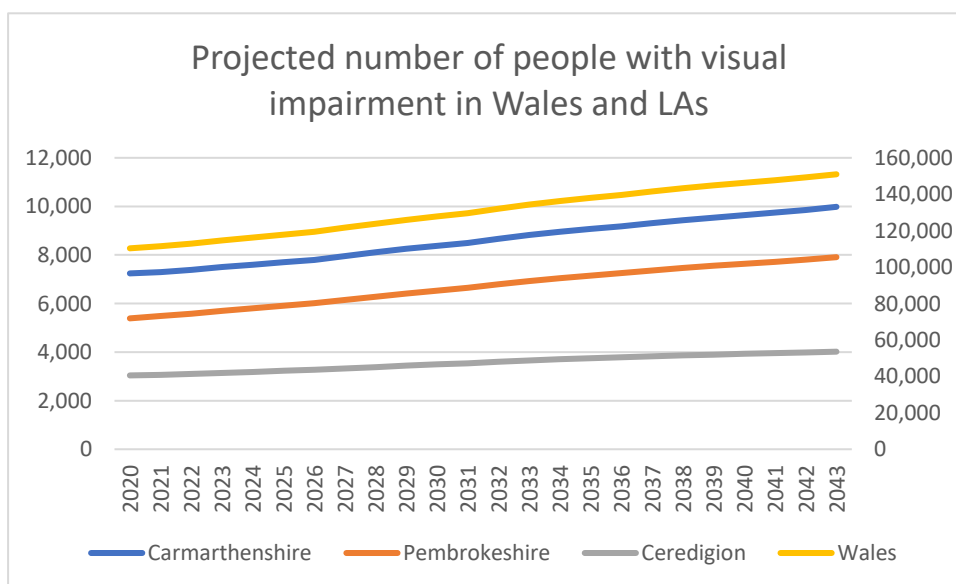


Figure 45: Projected number of people with visual impairment in Wales and Local Authorities, 2020 – 2043

Carmarthenshire

	2020	2043
0-19	73	71
20-64	1238	1201
65-74	1581	1704
75+	4349	7007
Total	7241	9982

Table 8: Predicted number of people with visual impairment in Carmarthenshire in 2020 and 2043 by age group

Pembrokeshire

	2020	2043
0-19	47	42
20-64	820	767
65-74	1143	1211
75+	3380	5889
Total	5390	7909

Table 9: Predicted number of people with visual impairment in Pembrokeshire in 2020 and 2043 by age group

Ceredigion

	2020	2043
0-19	28	25
20-64	453	382
65-74	642	626
75+	1919	2986
Total	3040	4019

Table 10: Predicted number of people with visual impairment in Ceredigion in 2020 and 2043 by age group

As can be seen in the tables above, it is projected that the increase in overall numbers of visually impaired in the population is solely seen in older people, with little or no projected change in people under 75. This can be explained by the growing population of this age group. Sight loss is also closely linked with certain medical factors, such as diabetes and obesity – both of which are increasing in the UK.

Hearing Loss

As seen in figure 1.2 below, the total number of adults with hearing impairment is projected to increase in all local authorities, and Wales in general from 2020 to 2043. These projected increases are most likely related to the general ageing population, and the fact that hearing impairment is far more common in the older population.

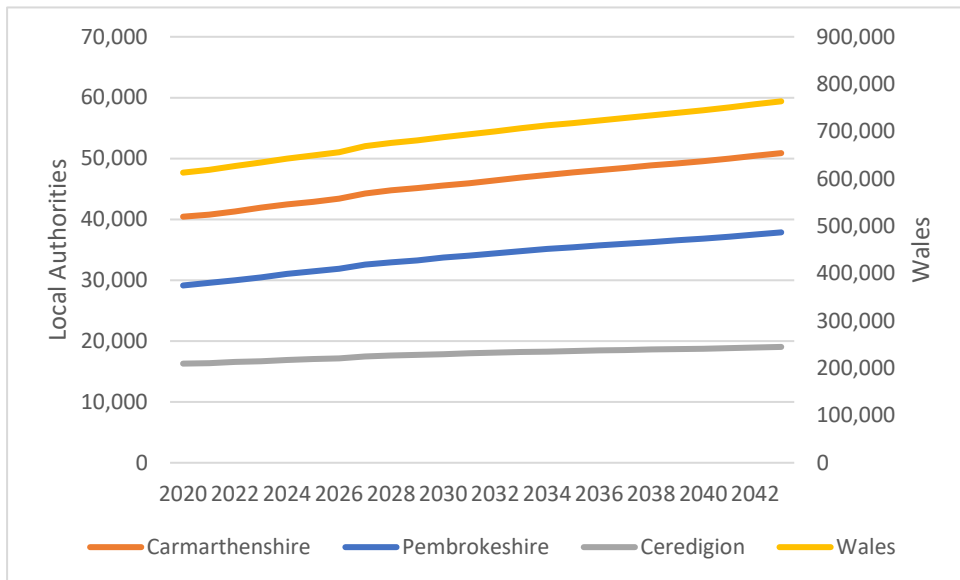


Figure 46: Projected change in adults 18+ with hearing impairment, in Wales and West Wales Local Authorities 2020 – 2043

Carmarthenshire

	2020	2043
18-60	8106	7660
61-80	21666	25598
81+	10666	17623
Total	40438	50882

Table 11: Current and predicted number of adults with hearing impairment in Carmarthenshire by age group

Pembrokeshire

	2020	2043
18-60	5320	4845
61-80	15544	18356
81+	8268	14659
Total	29133	37861

Table 12: Current and predicted number of adults in Pembrokeshire with hearing impairment by age group

Ceredigion

	2020	2043
18-60	2879	2329
61-80	8730	9338
81+	4684	7371
Total	16293	19039

Table 13: Current and predicted number of adults in Ceredigion with hearing impairment by age group

From the data it is predicted that there will be a marked increase in those with sensory impairment towards 2043. This increase is only observed in the elderly population, with a projected decrease in those with hearing impairment in the 16-60 age bracket across all three local authorities.

Dual Sensory Loss

In the UK today, there are an estimated 394,000 people with some degree of sight and hearing loss, approximately 60% of which are over 70 [5]. As people live longer, it is estimated that incidence of acquired deafblindness will increase, leading to the total number of people living with deafblindness reaching 600,000 by 2030 [5]. In a study carried out by Centre for Disability Research (CeDR) it was estimated that 0.031% of children and young people up to the age of 19 in the UK have co-occurring vision and hearing impairments.

SUBSTANCE MISUSE: Current Legislation and Regulations

Wales is fortunate to have a strong legislative framework in the **Wellbeing of Future Generations (Wales) Act**, the **Social Services and Wellbeing Act** and the **Public Health (Wales) Act** that ensures organisations across health, social care and communities work together to improve the health and wellbeing of the population.

The strong strategic links between the Future Generations Act, the Substance Misuse Strategy for Wales and the Wales Reducing Reoffending framework, Integrated Offender Management and Prolific and Priority Offender strategies has seen criminal justice services in Wales aligned to become increasingly more involved in deliverables for the whole country.

Service providers must demonstrate they will be able to work within the principles of an Integrated Offender Management (IOM) approach, including the proactive sharing of non – clinical information and intelligence with Police, Probation, YOPs, Prisons and other locally identified criminal justice and generic service partners in order to reduce criminal activity by individuals dependent on drugs and/or alcohol.

In April 2018, Welsh Government and Her Majesty's Prison and Probation Service in Wales were commissioned with Youth Justice Board Cymru to develop two new Blueprints for the delivery of justice services in a way that reflects the delivery landscape, in Wales; one to address offending by women and the other for youth justice.

There has been considerable work undertaken since then to develop Blueprints that include several ambitious and innovative recommendations for women and youth justice services.

- Youth Justice

<https://gov.wales/supporting-young-offenders>

<https://llyw.cymru/cefnogi-troseddwy-rianc>

- Female Offending

<https://gov.wales/supporting-female-offenders>

<https://llyw.cymru/cefnogi-troseddwy-benywaidd>

The Police and Crime Commissioner, within his Police and Crime Plan 2017-2021, indicated his commitment to tackling substance misuse within his key priorities:

Keeping our communities safe

- Reduce the impact and harm caused to communities through substance misuse by commissioning services to support individuals to become less dependent on substances

Protecting our communities from serious threats

- Educate young people on the dangers of using substances, including the potential links to organised crime activity that might lead them to a lifestyle of exploitation
- Identify and dismantle the threat posed by OCGs and work with others to disrupt OG activity in particular the trafficking and supply of Class A drugs

A recently commissioned needs assessment for victims and vulnerable people delivered for the Police and Crime Commissioner (PCC), included the following recommendation:

The PCC is recommended to work with Area Planning Boards (APBs) and health boards to develop a single Dyfed-Powys approach.

Key considerations include:

- a. Ensuring greater equity and consistency in delivery across the region.
- b. Maintaining best practice approaches such as the prison link workers and integration wherever possible into generic substance and alcohol misuse services.
- c. Gaining the benefits of scale to achieve greater value for money.

This recommendation aligns with the PCC's intentions that the direction of travel for provision of substance misuse services be considered as a holistic provision not just for residents of Dyfed Powys but across the whole of Wales, ensuring equity of access and consistency of quality support services. To this end, the current contract proposes short-term break clauses to allow strategic developments at a Dyfed Powys and All Wales level in the immediate future.

Providers are expected to implement and develop a service model that takes account of the above and a range of other local strategies and guidance and any successor policies and guidance.

SUBSTANCE MISUSE: Current Care and Support Provision

Prevention: Whole Population and Targeted Interventions

Whole Population Prevention:

There is no locally co-ordinated campaign that addresses whole population prevention. Key messages need to be developed to respond to trends of use emerging for different age groups and showing evidence of harm.

Screening and Brief Interventions in primary care:

The evidence base clearly states that this should be in place across primary care settings for all patients or as a minimum those at risk. There is currently no co-ordinated programme of screening in place within primary care

Treatment and Recovery

Access, treatment models, age appropriateness of treatment:

There is evidence that older (40/50 plus) substance users are reluctant to seek support from traditional services, because of the model of service provision and concerns over stigma at accessing a drug and alcohol service. We need to think differently about what services are offered (not just for this age group), across the health system and in different settings, to avoid this stigma.

Psychology and psychological support for older adults with alcohol dependence issues.

Dual Diagnosis psychology/psychological support:

Gap in provision for those who don't have Serious Mental Illness but suffering from significant other mental health issues as well as issues with drugs, alcohol, and other lifestyle behaviours

Prescribing Capacity:

Rapid access to prescribing is a protective factor against drug related deaths. Same day prescribing models are in place in other parts of the country, longer waits are in place locally with Carmarthenshire having the third highest drug related deaths in Wales. Local model reliant on GP capacity for prescribing

Service User Involvement:

Good local service involvement but little involvement of service users within planning process

Harm Reduction Learning and Implementation:

Review of alcohol deaths as well as drug deaths needed, and we need to establish non-fatal reviews

Housing:

Fundamental to an individual's ability to recover. Limited options available locally and housing reallocation policies often detrimental to recovery

The West Wales Region's current response to the Welsh Government Delivery Plan 2019-2022 is outlined below:

Welsh Government Delivery Plan 2019-22 Key Aim and Outcome	Local Action
<p>Key Aim 1 Preventing Harm Outcome 1 People are able to make informed choices in order to prevent and reduce the harm associated with substance misuse</p>	<p>Development of specific campaigns targeted at older populations</p> <p>Cross partnership Prevention Summit to be held in 2019, to explore the approach across the board to Prevention</p> <p>Prevention and Community asset-based development role established to lead on resilience-based model development, community co-production work and model implementation</p>
<p>Key Aim 1 Preventing Harm Outcome 2 Drug and Alcohol Issues are identified and tackled early</p>	<p>Screening and brief intervention primary care pilot to be implemented, one in each county. The health coach model is an umbrella term used to describe may different interventions that "coach" or actively support people to self-care. It uses behavioural change techniques and has good evidence of impact</p>
<p>Key Aim 2 Support for substance misusers to improve their health and maintain recovery Outcome 3 The physical health and wellbeing of people with substance misuse issues are improved and related inequalities are minimised</p>	<p>Service Development Manager to be appointed to lead on service user involvement model, co-occurring service developments, case review co-ordination and further develop models of service provision.</p> <p>Housing – Contribution to Supported Housing Dry House project to ensure continuation of service and increase bed capacity.</p> <p>Alcohol Psychologist to be appointed to sit within the hospital Alcohol Liaison Service.</p> <p>Advance Nurse Prescribing model to be developed</p>
<p>Key Aim 2 Support for substance misusers to improve their health and maintain recovery Outcome 4 People with substance misuse issues have the skills, resilience and opportunities to gain and maintain economic independence and the negative impact of substance misuse on the Welsh economy is minimised</p>	<p>Local work to be scoped out in 2020/21</p>

<p>Key Aim 2 Support for substance misusers to improve their health and maintain recovery</p> <p>Outcome 5 People with substance misuse issues participate in culturally diverse activities including the arts, sports and recreation</p>	Local work to be scoped out in 2020/21
<p>Key Aim 2 Support for substance misusers to improve their health and maintain recovery</p> <p>Outcome 6 Everyone affected by drug or alcohol issues are treated with dignity, fairness and respect</p>	<p>Media Strategy to be developed</p> <p>Community Resilience building models to be explored</p>
<p>Key Aim 2 Support for substance misusers to improve their health and maintain recovery</p> <p>Outcome 7 Everyone affected by drug and alcohol misuse can access timely, evidence based. Safe and effective quality services</p>	New service contracts to include requirement to work out of hours
<p>Key Aim 3 Supporting and protecting families</p> <p>Outcome 8 Social exclusion as a result of drug and alcohol misuse is minimised</p>	Local work to be scoped out in 2020/21
<p>Key Aim 3 Supporting and protecting families</p> <p>Outcome 9 The harms of drug and alcohol misuse are reduced for children and families</p>	A cross partnership "prevention summit" to be held in 2019 to explore the approach across the board to "prevention" including community, family and individual resilience building, ACES, County Lines and Safeguarding.
<p>Key Aim 3 Supporting and protecting families</p> <p>Outcome 10 Outcomes for children and families on the edge of care are improved</p>	<p>Specialist CAMHS Early Intervention Psychologist for Drug and Alcohol Use to be appointed</p> <p>Expansion to Specialist CAMHS Substance Misuse Co-occurring service to ensure targeted and earlier intervention</p>
<p>Key Aim 4 Tackling availability and protecting individuals via enforcement activity</p> <p>Outcome 11 People are/ feel safer in relation to crime</p>	Work collaboratively with Dyfed Powys Police and Police and Crime Commissioner via the APB to address alcohol and drug related crime, including County Lines
<p>Key Aim 4 Tackling availability and protecting individuals via enforcement activity</p> <p>Outcome 12 Welsh speakers and their families to receive support through their own language</p>	Local work to be scoped out in 2020/21
<p>Key Aim 5 Partnerships, workforce and Service User Involvement</p> <p>Outcome 13 Area Planning Boards are fit for the future</p>	Development of more formal cross partnership interfaces between partnership lead officers and Partnership Boards
<p>Key Aim 5 Partnerships, workforce and Service User Involvement</p> <p>Outcome 14 The drug and alcohol workforce is skilled and informed</p>	Continue to ensure training needs of service staff are considered

<p>Key Aim 5 Partnerships, workforce and Service User Involvement</p> <p>Outcome 15 Service user involvement to be embedded into delivery and planning of services</p>	<p>Establish and implement a local Service User involvement framework</p>
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Table 14: West Wales' response to the Welsh Government Delivery Plan 2019-2022

SUBSTANCE MISUSE: Additional Data

According to Public Health Wales, (2019) 2018 saw the highest recorded drugs related deaths for Wales but 2019 saw significant decreases in both drug poisoning deaths (down 26% on 2018) and drug misuse deaths (down 21% on 2018). Drug related deaths have increased in Hywel Dda over the last few years. There were 17 deaths in 2018, 18 deaths in 2019 and a significant rise in 2020 with 29 drug related deaths.

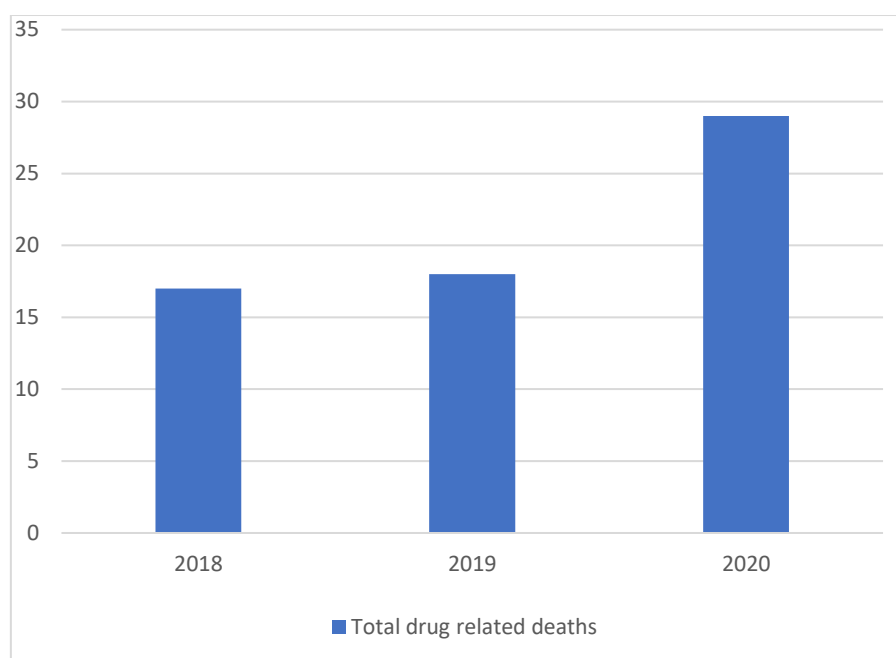


Figure 47: Number of drug related deaths in Hywel Dda by year (2018-2020)

The proportion of female deaths has increased since 2018. In 2018, there were a total of 17 drug related deaths, 3 of which were female. This accounts for 17.6% of all deaths. In 2019, there was a slight rise to 4 female deaths of the total 18 deaths, resulting in an increase in proportion to 22.2%. The trend not only continued in 2020 but appears to accelerate as of the total 29 drug related deaths, 10 were female. This accounts for 34.4% of all drug related deaths in 2020, almost double the proportion from 2018.

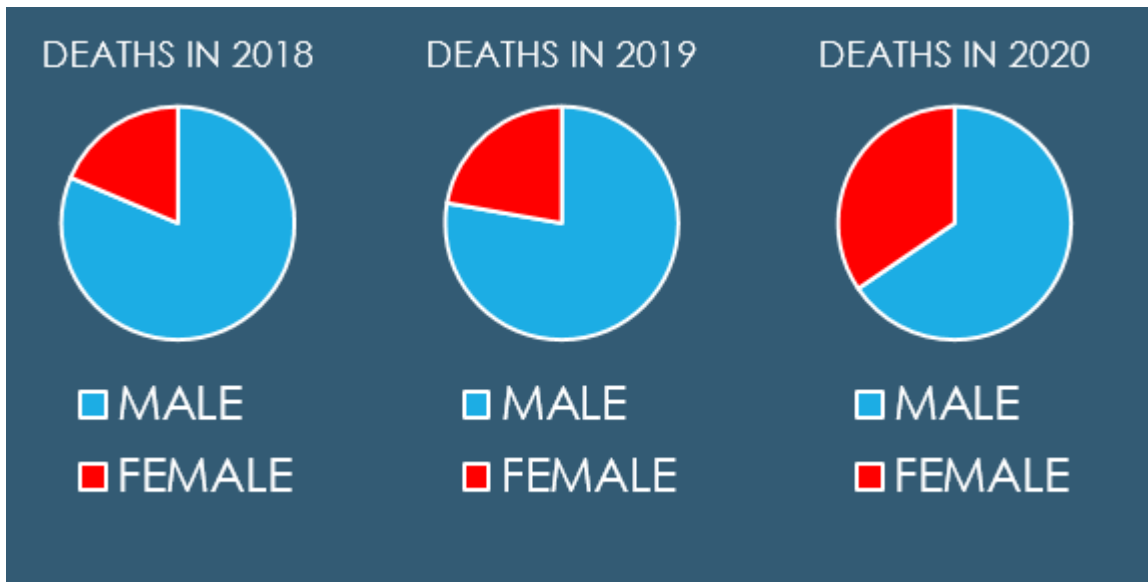


Figure 48: Comparison charts to show the changes over time in the gender of drug related deaths in Hywel Dda (2018-2020)

There is a trend developing with a noticeable increase over the three years of deaths in the 40-49-year-old and over 50-year-old age brackets. Although it is too early to determine if this is a sustained trend, it is clear that this is an issue that requires attention. In 2018 there were 6 deaths in people age 40 to 49 years of age but this has increased to 10 (2019) and 12 (2020), double the proportion from 2018. Although deaths in over 50s are small in number, the proportional jump is dramatic, rising from 1 death in 2018 and 2 in 2019 to 5 in 2020. It is unclear whether these deaths are related to conditions resultant to long term drug misuse or specific acute incidents. The impact of COVID is also unknown. DPP evidence around drugs being accessed via the dark web.

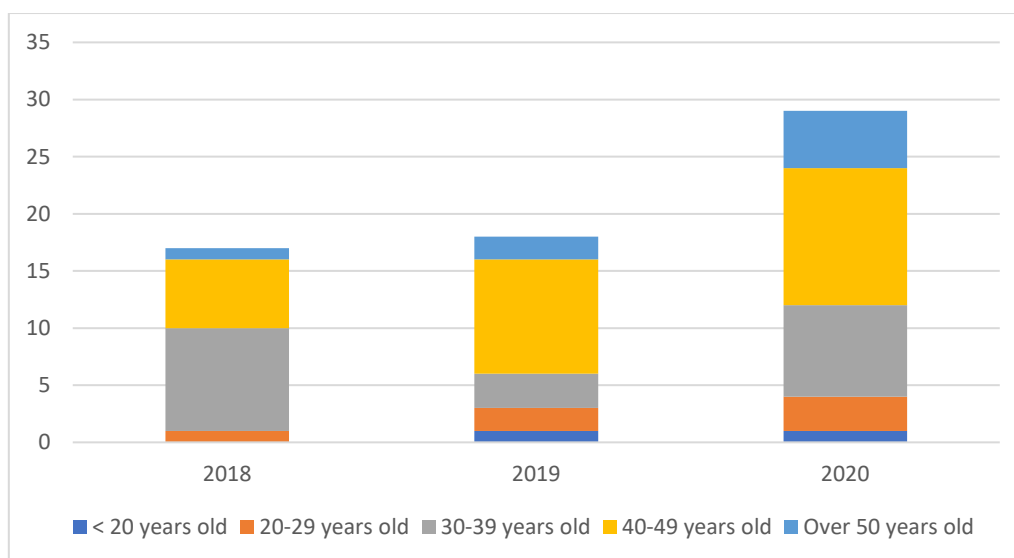


Figure 49: Age distribution of drug related deaths in Hywel Dda 2018-2020

In 2018 there were 9 deaths in Carmarthenshire, 3 in Ceredigion and 5 in Pembrokeshire. In 2019, the number of deaths in Carmarthenshire reduced to 6 whilst

Ceredigion experienced an increase to 7. Pembrokeshire remained static at 5 deaths. However, in 2020 the trend of increasing drug related deaths is evident with 8 in Ceredigion, 10 in Carmarthen and 11 in Pembrokeshire. DPP evidence around drugs being accessed via the dark web.

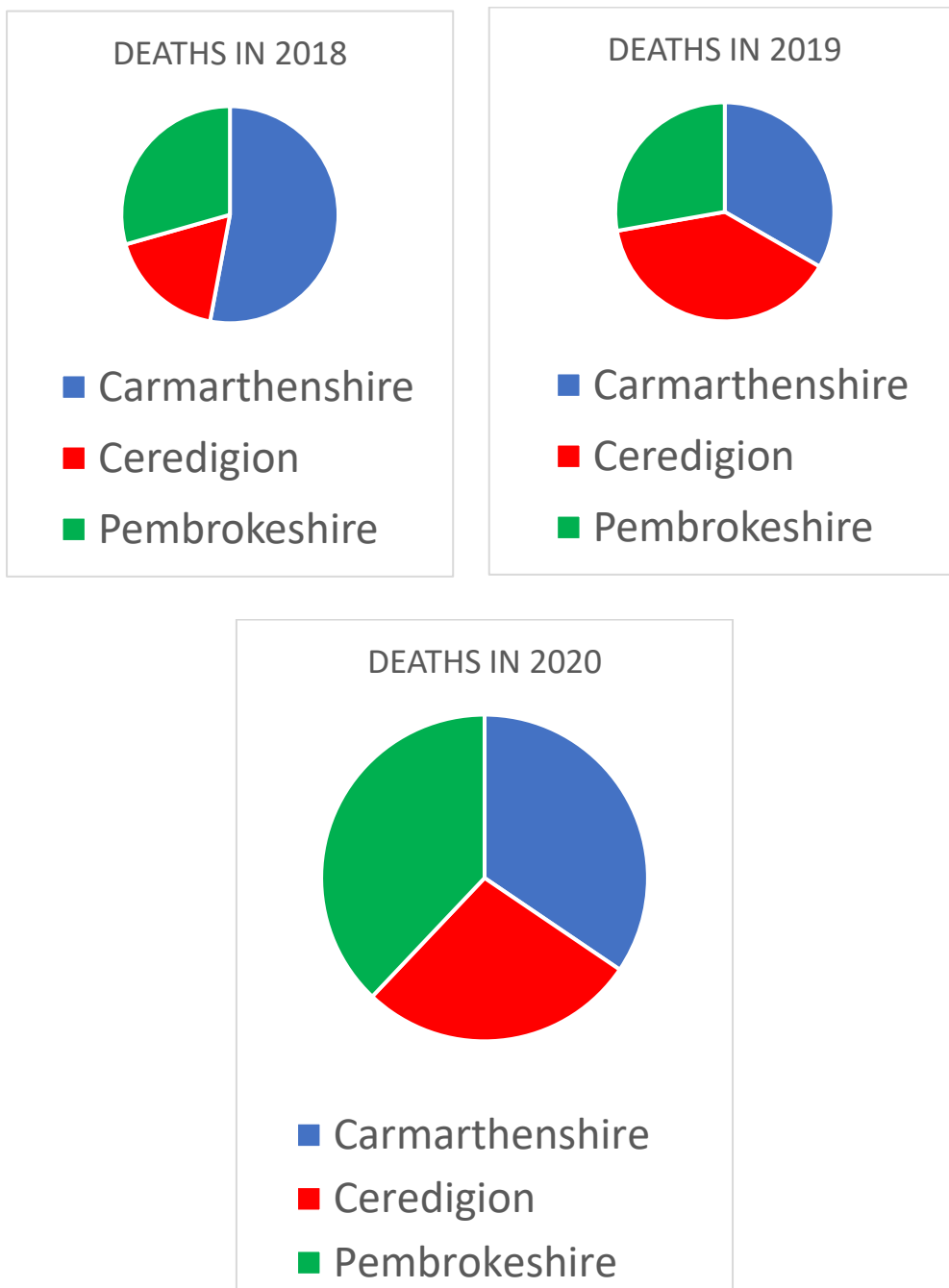


Figure 50: Geographical spread of drug related deaths in Hywel Dda 2018-2020

VAWDASV: Current Legislation and Regulations

As required by the VAWDASV Act, the Welsh Government published its five-year national strategy in 2016. This was followed by publication of its national delivery framework and in 2019, the Welsh Government published national indicators for measuring progress against the Act.[10] The Welsh Government has published a number of guidance documents and national standards to help deliver commitments within its five-year strategy including:

- Whole Education Approach to Violence Against Women, Domestic Abuse and Sexual Violence in Wales Good Practice Guide
- Violence Against Women Domestic Abuse and Sexual Violence – Guidance for Governors
- National Advisers Annual Plan [4]
- Information and guidance on domestic abuse and sexual violence: Safeguarding older people (60+) in Wales
- National Training Framework Statutory Guidance
- Ask and Act Training Guidance
- Local Strategies Statutory Guidance
- Commissioning Violence against Women, Domestic Abuse and Sexual Violence Services Statutory Guidance

National Standards for working with Perpetrators

VAWDASV: Current Care and Support Provision

Development of an integrated outcomes framework agreed by all commissioners to ensure consistent, meaningful, and comparative reporting.

- Adopting commissioning models that allow for flexibility and development to meet changing needs rather than prescriptive funding that limits creativity / innovation and results in services that are restricted in the services they can provide.
- Providing stability to the sector in terms of the duration of the contract(s) and funding for the lifetime of the contract for Domestic Abuse, Sexual Violence and Violence against Women services.
- Development of a service model whereby any eligibility criteria associated with accessing service provision is based solely on a need to access rather than a level of risk, complexity, or the availability of services.

VAWDASV: Additional Data

The availability of data specific to is limited. As and when data is available, it will be added to the chapter.

Domestic abuse victim characteristics, England and Wales: year ending March 2021
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