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West
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Regional
Partnership






POPULATION NEEDS ASSESSMENT
2022 - 2027

LEARNING
DISABILITY



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This chapter includes the population needs of adults with learning disabilities. Information about children and young people with learning disabilities, adults with autism who do not also have learning disabilities, and carers of people with learning disabilities/autism can be found in the following chapters:

-  Children and young people
-  Carers who need support
-  Autism.

1. WHAT DO WE MEAN BY ‘LEARNING DISABILITY’?

Learning Disability Definitions

- a) The term ‘learning disability’ is used to describe an individual who has:
 -  A significantly reduced ability to understand new or complex information, or to learn new skills (impaired intelligence); and / or
 -  A reduced ability to cope independently (impaired adaptive functioning); which started before adulthood and has a lasting effect on development. ¹

- b) *“Some people with learning disabilities also have physical and/or sensory impairments, mental health problems or other ‘neurodevelopmental disorders’ such as autism. People who have learning disabilities and other conditions are included in the group of people with learning disabilities as long as they also have learning disabilities. As such, people with Asperger’s Syndrome are not included in this term as by definition they have average or above average intelligence. Further, people with brain injury or trauma sustained in adulthood would not fall within the definition of having learning disabilities.”* ²

- c) **NICE**, in their guidelines on learning disabilities and challenging behaviour describe a learning disability as follows:
“Learning disabilities are heterogeneous conditions, but are defined by three core criteria: lower intellectual ability (usually defined as an

¹ Department of Health, 2001

² https://www.researchgate.net/profile/Eric-Emerson/publication/265306674_A_working_definition_of_Learning_Disabilities/links/5428856f0cf26120b7b5692b/A-working-definition-of-Learning-Disabilities.pdf Accessed 12 November 2021

IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood.”

People with Learning Disabilities in Black, Asian and Minority Ethnic Communities (BAME)

People from minority ethnic communities face particular difficulties when they have a learning disability. A recent report³ highlighted that there is little information about people with learning disabilities from different communities and that the needs of BAME communities are not seen as ‘core business’. The report goes on to suggest that the available data does not give a definitive answer as to how many people with learning disabilities are from BAME communities.

According to Lancaster University’s Centre for Disability Research, between 2011 and 2020, 25% of new entrants to adult social care with learning disabilities were from Black, Asian and Minority Ethnic communities. However, higher rates of identification of more severe forms of intellectual disability are recorded among children of Pakistani and Bangladeshi heritage. The report also identifies the issues of intersectional needs, discrimination, institutional racism and institutional disablism. The briefing paper also looks at how the COVID-19 pandemic has highlighted further evidence of health inequalities for people with learning disabilities from ethnic minorities:

“The pandemic has shone a light on inequalities experienced in general, people from Black, Asian and Minority ethnic communities whatever their social status were disproportionately dying from COVID-19. This was also true for people with a learning disability, who were six times more likely to die from COVID-19 and 40% of which were from Black and Pakistani communities.

Unavoidable deaths are twice as likely in this population, being as high as 44% of all deaths for people with learning disability. Prior to Covid-19, health inequalities and preventable deaths in the learning disability population were recognised to be extremely problematic. This situation appears to have worsened exponentially.

³ Race Equality Foundation, ‘Learning Disability Briefing Paper’, 2021, <https://raceequalityfoundation.org.uk/wp-content/uploads/2021/06/Collaborative-briefing-learning-disability-FINAL-1.pdf> Accessed 12 November, 2021

It is hard to disagree with the conclusion that there is a disproportionate burden of poor health on people with learning disabilities and particularly those with a learning disability from BAME communities.”

Race Equality Foundation

Population figures

There are approximately 1.5 million people with learning disabilities in the UK. There are 2.2 % of adults who are estimated to have a learning disability and 2.5% of children. Mencap estimate that there are approximately 40,000 adults with a learning disability in Wales, and 16,000 children. ⁴

According to population data from the Office for National Statistics (2019)⁵ there are:

- 🧩 Approximately 54,000 adults with a learning disability in Wales.
- 🧩 Approximately 40,000 adults of working age with a learning disability in Wales.
- 🧩 Approximately 16,000 children with a learning disability (0-17) in Wales.
- 🧩 Approximately 5,000 children with a learning disability (0-5) in Wales.

However, Mencap⁶ state that only 1 in 4 people with a learning disability in Wales are known to social services.

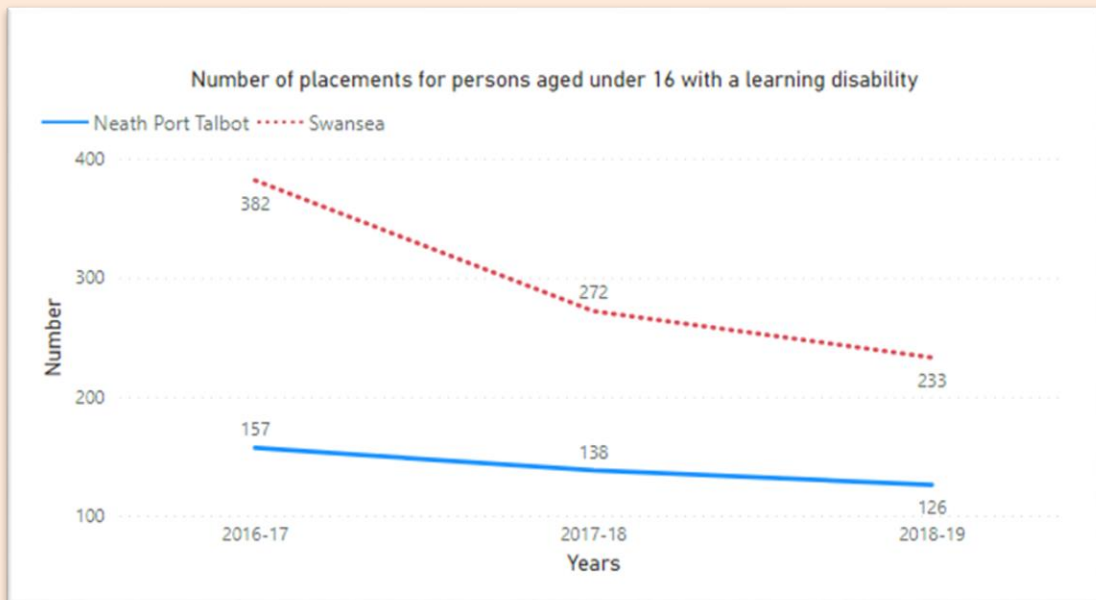
Local authorities submit numbers of all persons identified as having a learning disability currently known to the authority and included in a register of records for the purpose of planning or providing services. These are published on the [StatsWales](#) website. The register of people with learning disabilities data may be an underestimate of the total number of people with learning disabilities as registration is voluntary.

The following graphs break down the number of placements for children and adults, including people over the age of 65 in the region:

⁴ <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability> Accessed 8 November.

⁵ Office for National Statistics [Accessed 12 November 2021]

⁶ Mencap [Accessed 12 November 2021] <https://www.mencap.org.uk/>

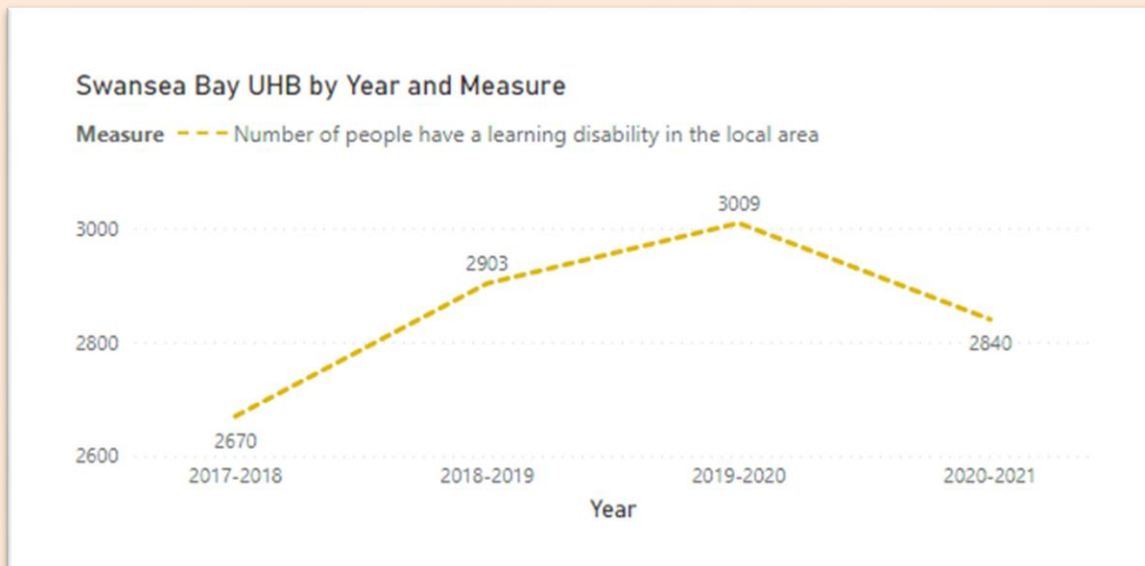


Source: Social Care Wales



Source: Social Care Wales

Swansea Bay University Health Board provide data on the number of people with a learning disability up until 2020/2021 in the region:



Source: Swansea Bay University Health Board Intelligence Unit

There were 1691 placements for people with a learning disability in Swansea and Neath Port Talbot in 2018/19, however Swansea Bay University Health Board recorded 2903 people with a learning disability in the local area for the same year.

Swansea Bay University Health Board's data on people with a learning disability increase to 3009 in 2019/20 but drop to 2840 in 2020/21, however there is no further information to support the decline.

In the West Glamorgan region, future projections for people with a Learning Disability for the 0-17 age group, suggest there will be 1936 children in Swansea and 1136 in Neath Port Talbot by 2040, which is an increase of 1.4%.











In the West Glamorgan region, data on future projections for people with a learning disability for the over 18 age group isn't currently available, and generally there is limited data on the population of people with a learning disability. Data is also not currently available to identify people with a learning disability in cohorts of the population including people who are BAME, those who identify as LGBTQ+, and other protected characteristic groups.

From the data that is available, gaps have been identified in how data is recorded and presented. The West Glamorgan Regional Partnership acknowledges the gaps in data as a concern that will need to be addressed going forward. The development of recording future data will be discussed in section 5 of this chapter.

2. LIFESTYLE FACTORS AFFECTING PEOPLE WITH A LEARNING DISABILITY

West Glamorgan's Regional Partnership's Learning Disability Board are currently in the process of developing a 5 year Regional Learning Disability Strategy.

To determine the vision and main themes of the strategy, the board have confirmed the strategy should link to the [Welsh Government National Outcomes Framework's](#) well-being definitions in relation to a person in eight aspects of their lives:

-  Securing rights and entitlements
-  Physical and mental health and emotional well-being
-  Protection from abuse and neglect
-  Education, training and recreation
-  Domestic, family and personal relationships
-  Contribution made to society
-  Social and economic well-being (including participation in work)
-  Suitability of living accommodation.

The national outcomes link into the following research regarding lifestyle factors for people with a learning disability:

Health Inequalities

People with a learning disability have worse health than people without a learning disability and are more likely to experience a number of health conditions (co-morbidities).

Source: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities> [accessed 9 December 2021]

In a paper written for the University of Hertfordshire, Blair⁷ identified that The Confidential Inquiry into the Premature Deaths of People with a Learning Disability (CIPOLD) found that people with a learning disability have far worse health outcomes than those in the general population. These include:

- 🌸 Reduced access to and less likely to receive interventions for their obesity, including screening for thyroid disease and diabetes
- 🌸 Greater risk of death from amenable causes (avoidable due to medical intervention)
- 🌸 Variance (approximately 48%) in amenable death rates in the non-learning disability population
- 🌸 Low take up for national cancer screening programmes (for example, breast, bowel and cervical)
- 🌸 Low uptake of immunisations such as 'flu vaccinations
- 🌸 Increased risk of death due to respiratory infection – one of the highest causes of amenable death.

Research carried out by NHS England⁸ for 2018-19 showed that males with a learning disability have a life expectancy at birth of 66 years. This is 14 years lower than for males in the general population.

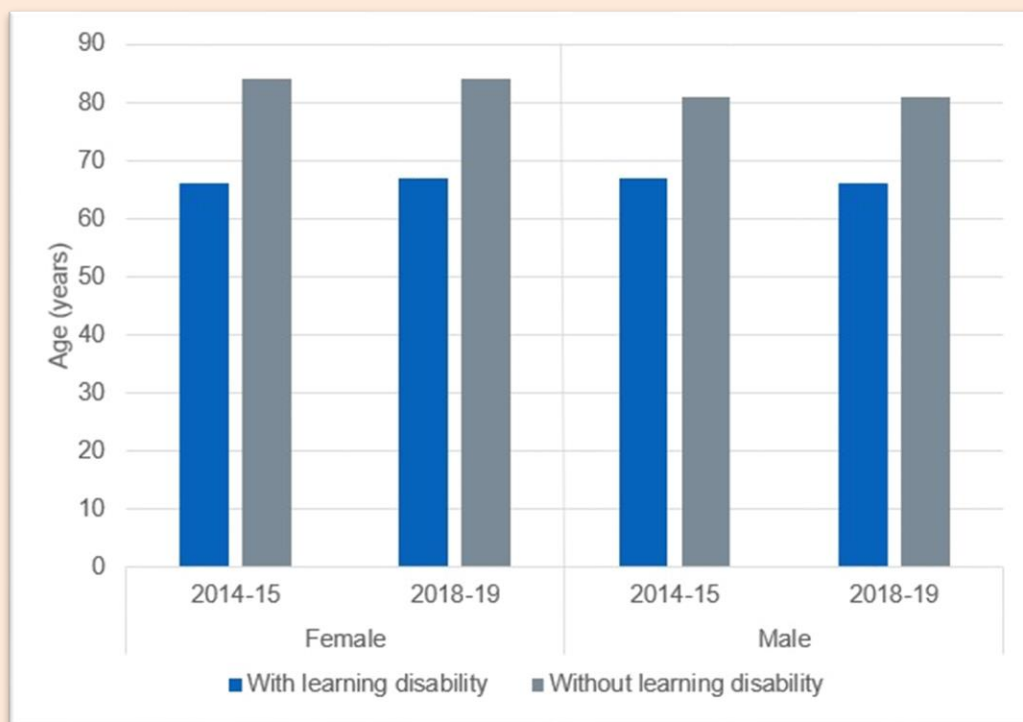
Based on 2018-19 data, females with a learning disability have a life expectancy of 67 years. This is 17 years lower than for females in the general population.

⁷ Blair, J 'The health needs of people with learning disabilities: issues and solutions' Intellectual Disability and Health, University of Hertfordshire, <http://www.intellectualdisability.info/how-to-guides/articles/thehealth-needs-of-people-with-learning-disabilities-issues-and-solutions> Accessed 8 November 2021.

⁸ NHS Digital 'Health and Care of People with Learning Disabilities, Experimental Statistics: 2018 to 2019' <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2018-to-2019/condition-prevalence> Accessed 8 November 2021

There has been no statistically significant change in life expectancy for patients with a learning disability between 2014-15 and 2018-19, despite pressures for improved services and care.

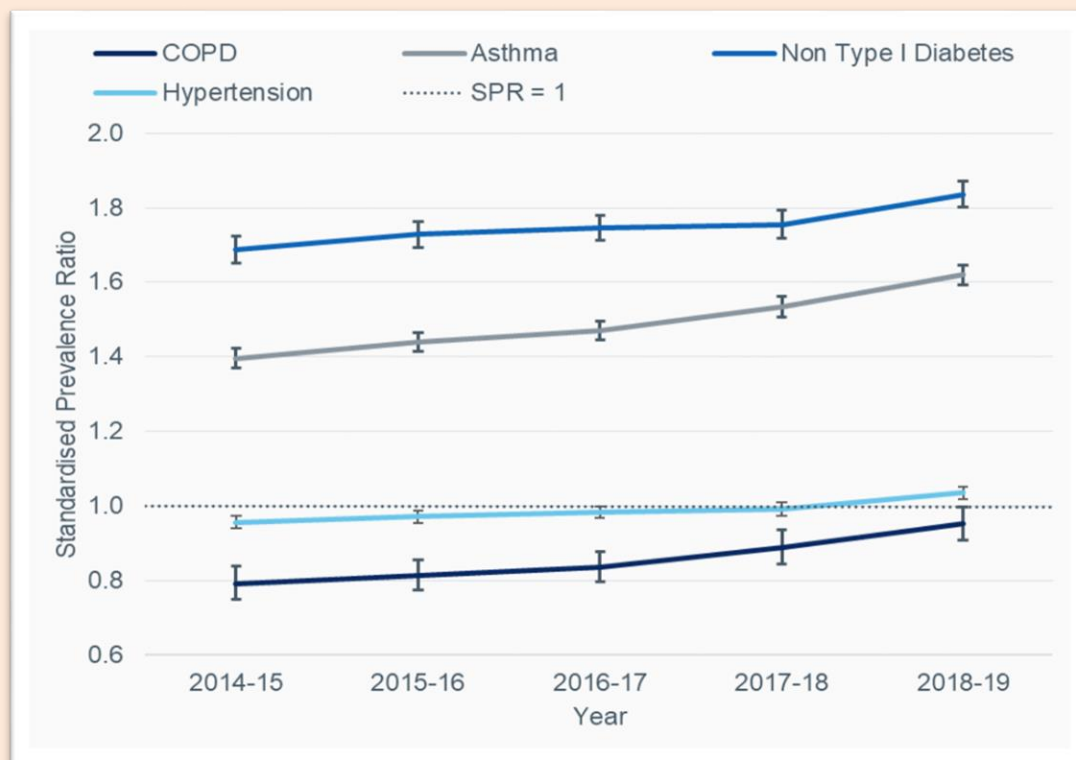
Figure 1: Life expectancy for males and females with and without a learning disability, for 2014-15 and 2018-19.



People with learning disabilities also have much higher mortality rates than other people in the same age group.

Moreover, the NHS study found that epilepsy was 26 times more common in people with learning disabilities than would be expected for an equivalent cohort of the general population. Also, the standardised prevalence ratios for asthma, hypertension and type 1 diabetes had all seen a statistically significant increase compared to 2017-18 data. So, even where people with a learning disability were less likely to have a condition, their chances of having it have increased, as shown below:

Figure 2 Comparative rates of prevalence – Key long-term conditions



Also, the NHS has produced summaries covering the various areas in which people with learning disabilities experience health inequalities. These include:

Breast cancer	Cancer	Cardiovascular disease
Cervical cancer	Constipation	Contraception
Dementia	Diabetes Type 1	Diabetes Type 2
Dysphagia	Epilepsy	Falls, fractures, accidents and injuries
Hypertension	Menopause	Menstrual issues
Mental health problems	Mortality	Oral health
Osteoporosis	Overweight, obesity and underweight	Physical activity
Physical impairments	Pregnancy and birth	Respiratory disease
Sensory impairments	Sexual health	Sleep problems
Substance misuse	Thyroid disorder	

There is research evidence (albeit now quite old) that shows that people with learning disabilities can suffer from poor health care because of ⁹:

- 🧩 patients not being identified as having a learning disability
- 🧩 a lack of accessible transport links
- 🧩 staff having little understanding about learning disability
- 🧩 failure to recognise that a person with a learning disability is unwell
- 🧩 failure to make a correct diagnosis
- 🧩 anxiety or a lack of confidence for people with a learning disability
- 🧩 lack of joint working from different care providers
- 🧩 not enough involvement allowed from carers
- 🧩 inadequate aftercare or follow-up care.

Finally, people with learning disabilities are encouraged to have annual health checks. There is a range of resources for supporting this and other aspects of health care for people with learning disabilities (e.g. the Turning Point Health Checklist¹⁰).

[A review in 2015](#) found wide-ranging evidence to suggest that disabled people in Wales experience considerable general and more specific healthcare access issues.

Background evidence suggests there is a strong correlation between poverty and disability, and that such poverty is compounding already existing inequalities in access to better health. For example, many disabled people have considerably shorter life-expectancies and there is evidence to suggest that this is caused by inequitable levels of healthcare provision.

The main findings of the review include:

- 🧩 The inequality gap in 'disability free life expectancy' in Wales is 14.8 years for males and 12.5 years for females, between the most and the least deprived groups.
- 🧩 There is evidence from international sources to show that people with certain impairments have considerably shorter life-expectancies in

⁹ Emerson, et al, 'Health inequalities and people with learning disabilities in the UK', 2012

¹⁰ Turning Point 'Learning Disability Health Toolkit', [https://www.turning-point.co.uk/cache_1ebe/content/TP-Health-Toolkit-2016%20\(web\)-509091000025941.pdf](https://www.turning-point.co.uk/cache_1ebe/content/TP-Health-Toolkit-2016%20(web)-509091000025941.pdf)
Accessed 9 November 2021

comparison to the general population and that some of these differences are due to inequitable levels of care.

- 🌐 There is an association between poor health literacy and adverse health outcomes and the evidence shows that people who report long-term limiting illnesses or disability perform lower than average in literacy and numeracy assessments – often a background determinant of levels of health literacy.
- 🌐 Carers have disproportionately poorer health in comparison to the general population, and there is also specific evidence which suggests that caring, considered independently, can have adverse health outcomes.
- 🌐 Evidence suggests that reforms contained under the Welfare Reform Act will disproportionately and negatively affect Wales, will disproportionately and negatively affect disabled people, and will have adverse health outcomes among people in Wales.
- 🌐 There is a lack of research concerning the efficacy of both telehealth services and personalisation approaches for disabled people in Wales.¹¹

Housing

Housing needs can change, especially if coming out of residential education establishments. People felt there is no clear pathway for young people to transition to adulthood. It was also found that whilst some Local Authorities were good at identifying children from 14 years old and planning for their future housing and support needs, involving housing associations and support providers at an early stage, this was not consistent across Wales. The lack of clear data on people with a learning disability and what their future needs might be, for example, was an identified issue which hindered long term planning.¹²

Stuart Ropke, chief executive of Community Housing Cymru said: ‘The COVID-19 pandemic has laid bare the importance of home. There is strong evidence that poor housing is associated with poor physical and mental health; it costs the NHS in Wales more than £95m per year in treatment costs. By investing in new and existing homes that are adaptable, warm, and safe we can make a huge contribution to

¹¹ Review of Evidence of Inequalities in Access to Healthcare Services for Disabled People in Wales

¹² [learning-disability-improving-lives-programme-june-2018.pdf \(gov.wales\)](#)

preventing ill health in the first place, and support people to remain independent in their own homes for as long as possible. Overcoming the scale of health inequalities in Wales needs a cross-government strategy that brings Wales' collective resources to the table and tackles the root causes of poor health.'¹³

Poverty and Employment

Disabled people in Wales are more likely than non-disabled people to live in poverty. A report in 2015 found that the poverty rate for families with at least one disabled adult was 33%, if disability benefits are excluded from the household income, in comparison to 23% for the general population in Wales.

Source: Disability Rights Equality and Human Rights Commission Supplementary submission to inform the Committee on the Rights of Persons with Disabilities (CRPD) List of Issues on the UK (Equality and Human Rights Commission, 2017).

A 2011 report into disability poverty in Wales found that:

- 🌐 disabled people in Wales were twice as likely as non-disabled people to live in a low-income household
- 🌐 33% of disabled people of working age were found to live in poverty, higher than anywhere else in the UK. When the additional costs of disability are taken into account, 50% of working age disabled people in Wales were considered to be living in poverty
- 🌐 31% of households with a disabled adult were living in fuel poverty, double the 2004 figure.

In addition, the report found that 55% of disabled people in Wales were not in employment and, though Wales has seen greater reductions in these rates since 2009 than elsewhere in the UK, the rate of worklessness in Wales remains higher than the rest of UK¹⁴.

A recent BBC news article¹⁵ notes that 54,000 people in Wales have a learning disability but, UK-wide, just 6% are in employment. Learning Disability Wales (LDW) calls for the Welsh Government to create a national job coaching service to support people into paid jobs.

¹³ [Wales needs a clear strategy for tackling wider health inequalities - Learning Disability Wales \(ldw.org.uk\)](#)

¹⁴ Allen, Joe (March 2011), Disability Poverty in Wales, Leonard Cheshire Disability

¹⁵ <https://www.bbc.co.uk/news/uk-wales-59391210> [accessed 9 December 2021]

The Engage to Change¹⁶ partnership¹⁷ has made proposals to Welsh Government for a national offer that would assist in levelling the playing field for people with a learning disability or autism and anticipates the need to support people's access to any employability initiatives that are available. Their recommendations include:

- 🌐 The National Job Coaching Service to help people with a learning disability or autism to find, get, learn and keep a job through the supported employment model and to assist their access to other Welsh Government and UK employability schemes (e.g. Kickstart, Communities in Work Plus).
- 🌐 A national Supported Internship offer that would provide up to 12 months on the-job training with a large employer, or local networks of SMEs, and the prospect of a paid job at the end.
- 🌐 A flexible Employer Development Grant that could support employees by subsidising wages or other employer costs over a 6–12-month period.
- 🌐 An emphasis on indigenous provision in Wales, securing knowledge of local employer networks to match our expectation of a shift to local recruitment practices among employers.

In response, the Welsh Government has published their new Plan for Employability and Skills¹⁸ strategy in the March 2022 which set out their plans to drive up employment rates even further. This includes setting and monitoring challenging diversity targets on all Employability programmes and services, maintaining employment subsidies to incentivise underrepresented groups including those with a learning disability and to drive forward solutions to tackle socio-economic disadvantage to disabled people in Wales. This will include acting on these recommendations and will include working with key employers, such as the NHS, to improve the number of job opportunities available.

A study into the finances of families of disabled children conducted in 2018 found that only 18% of respondents said that their disability

¹⁶ <http://www.engagetochange.org.uk/> [accessed 9 December 2021]

¹⁷ <https://business.senedd.wales/documents/s112831/34.%20Engage%20to%20Change.pdf> [accessed 9 December 2021]

¹⁸ Stronger, Fairer, Greener Wales, 2022 https://gov.wales/sites/default/files/publications/2022-03/stronger-fairer-greener-wales-plan-employability-and-skill_0.pdf

benefits could cover the extra costs linked to their child's disability or health condition.

These extra costs are significant, with 33% paying over £300 a month and 10% paying £500-£1000 a month in disability related costs. 36% reported that changes to the benefits system in the past two years had left them worse off. These disadvantages will have been made worse by the effects of the pandemic and the extra pressures experienced by families. The Children and Young People Committee should pay special attention to how policy decisions will affect economically disadvantaged families with disabled children and young people.¹⁹

Loneliness, Social Isolation and COVID-19

Many people with a learning disability were socially isolated before the pandemic, and while lockdown has given some people new opportunities to connect with people online, for others the pandemic has left them even more isolated than ever before. There have been issues with some supported living and residential settings not allowing people to see their families, despite Welsh Government guidance to the contrary, as the interpretation of the guidance by individual providers or local authorities seemed to vary greatly. Welsh Government have called on all committees to closely monitor how people with a learning disability in supported living and residential settings are treated in the coming months, and how their rights can be maintained²⁰.

Recent data show that people with learning disabilities are more likely to contract COVID-19, have a more severe case of COVID-19, and are at least three times more likely than people without learning disabilities to die from COVID19. Inequalities in health, wellbeing, social isolation, employment and poverty that existed before COVID-19, along with separation from family and friends and changes to routines, may have been exacerbated during the COVID-19 pandemic.

The Disability Equality Forum has published a report about the impact of the COVID-19 pandemic on disabled people²¹.


¹⁹ [Priorities of the 6th Senedd – What we think is important - Learning Disability Wales \(ldw.org.uk\)](https://www.idw.org.uk/priorities-of-the-6th-senedd-what-we-think-is-important)

²⁰ [Priorities of the 6th Senedd – What we think is important - Learning Disability Wales \(ldw.org.uk\)](https://www.idw.org.uk/priorities-of-the-6th-senedd-what-we-think-is-important)


²¹ Welsh Government (2021) Locked out: liberating disabled people's lives and rights in Wales beyond COVID-19 [Accessed 6 December 2021] <https://gov.wales/locked-out-liberating-disabled-peoples-lives-and-rights-wales-beyondcovid-19.html>

A wide range of available evidence, both statistical and anecdotal, was examined with a view to understanding and learning from disabled people's experiences. The report found that the pandemic has highlighted inequalities in society and further eroded the rights of disabled people in Wales. The Disability Equality Forum urge the Welsh Government to take urgent action in response. In their response to the report, the Welsh Government outline their commitment to set up a Ministerial Task Force to address the issues raised and implement the recommendations.

The findings highlight five areas of concern:

 The social versus the medical model of disability:

The social model of disability had largely been discarded during the pandemic, with policy makers, politicians and professionals reverting to the medical model. The report states that some measures introduced to prevent the spread of Covid-19 thoughtlessly added to barriers disabled people encounter in their day to day lives, resulting in exclusion from public spaces, social and healthcare services, and access to basic medicines and food.


 Human rights:

The enquiry revealed that there was wide-spread concern about the suspension of key provisions in the Social Services and Well-being (Wales) Act 2014 (unless services were needed to “protect an adult from abuse, neglect, or at risk of abuse or neglect”) as a result of the Coronavirus Act (Commencement No 1) (Wales) Regulations 2020. The report is clear that urgent measures need to be taken to ensure that the human rights of disabled people cannot be eroded in this way again by “enshrining fundamental rights and safeguards (contained in the United Nations Convention of the Rights of Disabled People) into future Welsh law.”


 Health and well-being:

Data shows that in the period March-July 2020, 68% (almost 7 in 10) of COVID-related deaths in Wales were disabled people. There has also been significant data to suggest that people with a learning disability were disproportionately more likely to die from COVID-19. However, evidence suggests that this death rate was not simply the inevitable consequence of pre-existing health

conditions or impairments, as socio-economic factors and existing inequalities within society also contributed to many deaths.

 Socio economic disadvantage (including housing and employment):

Evidence produced for the report on the impact of COVID-19 on disabled people in Wales demonstrated a clear link between outcomes and poverty, social deprivation, state benefits, housing and experiences of work and employment. All have contributed to the disadvantages disabled people have experienced during the pandemic. Disabled people in Wales are more likely to experience relative income poverty and live in more economically deprived areas than non-disabled people. Nationally, disabled people have disproportionately fallen behind with household bills during the pandemic due to their position in the labour market and the increased costs associated with being disabled.

 Exclusion, accessibility and citizenship:

As a group, disabled people have experienced significant additional social exclusion during the pandemic including inaccessible public spaces, services, practices, public ignorance, poor communication and policy decisions. The result has been a loss of independence and a loss of citizenship. On the other hand, some groups of disabled people have found new opportunities for working, socialising, connectivity and learning through the increased use of digital technology during the pandemic, overcoming previous negative assumptions that this would be beyond their capabilities.

Digital Inclusion

The priorities of the Climate Change, Environment and Infrastructure Committee state the need to establish high speed internet throughout Wales to help people stay connected and improve digital infrastructure. We would like the committee to take into account that for many people with a learning disability it will take more than just high-speed internet to stay connected.



While the pandemic has led to many people with learning disabilities gaining important new digital skills, the pandemic has also highlighted the harsh realities of digital exclusion. Many people with a learning disability simply did not have the technology and/or skills to engage with

others online during lockdown and were therefore left in total isolation. Not only were they not able to keep in touch with friends and family but with so many services switching to online they found everyday living extremely difficult. For example, online shopping, virtual appointments with support staff, ordering prescriptions, etc.

More work needs to be done to ensure people with a learning disability have the technology and skills to navigate their daily lives and stay connected while at the same time making sure that those who do not have digital skills can still access life²².

Transport

Public transport should be accessible and inclusive to all. It should support people to participate fully in all aspects of life, such as work, volunteering, socialising and access to services. Travel by public transport should be a safe and pleasant experience, which facilitates the right to independent living and other human rights. However, The Equality and Human Rights Commission found that public transport in Wales often does not meet the needs of older and disabled people. Half of rail stations in Wales, for example, are not fully accessible to disabled people, with 34% having no access for wheelchair users. These barriers to independent travel can restrict older and disabled people's right to participate in aspects of everyday life. The study found major problems for disabled people and older people in Wales and that equality considerations for disabled and older people were not given enough importance in public transport in Wales:

-  Older and disabled people said that they found the public transport system in Wales largely inaccessible. They faced a broad range of barriers to travel within a system that did not conform to the social model of disability, or support their independence. Consequently, they felt their opportunities had been limited, and that they had been left behind.
-  For public transport to become accessible and inclusive, public bodies must develop and deliver actions that respond to the needs of older and disabled people. The research shows that better consideration and integration of equality into transport strategies and policies, using the Wales specific duties as a guide, will ensure that

²² [Priorities of the 6th Senedd – What we think is important - Learning Disability Wales \(ldw.org.uk\)](https://www.lidw.org.uk/priorities-of-the-6th-senedd-what-we-think-is-important/)

public bodies meet the aims of the Public Sector Equalities Duty, and build an accessible and inclusive public transport system in Wales.²³

The Welsh Government have recently launched a new Transport Strategy for Wales which outlines their commitment to making transport services and infrastructure accessible and inclusive by aiming to remove barriers that prevent people from using sustainable transport.²⁴

Education

The Additional Learning Needs and Education Tribunal (Wales) Act 2018 (“ALNWA 2018”) will change the way that children and young people aged 0-25 with additional learning needs (“ALN”) are supported in Education in Wales. The Code came into force on 1 September 2021.

The legislation will have a phased implementation. From 1 September 2021 onwards, new learners with Additional Learning Needs will be supported by the new system, and learners using the old system (SEN) will transition over a three-year period. The Welsh Government is determined that the new ALNWA 2018 regime will deliver a fully inclusive education system for learners in Wales, where needs are identified early and addressed quickly. It is intended that the planning under the new regime will be flexible and responsive, with the learner at the centre of everything.²⁵

²³ The Equality and Human Rights Commission (2020) Accessible public transport for older and disabled people in Wales [accessed: 09 December 2021]

²⁴ Welsh Government (2021) Llwybr Newydd: the Wales Transport Strategy

²⁵ Gov.Wales; <https://gov.wales/additional-learning-needs-special-educational-needs>, [accessed 12 November 2021)

Local data recorded in the Pupil Level Annual School Census (PLASC) is shown in the table below

Pupil Level Annual School Census summary data by local authority (pupils aged 5 to 15 in primary, middle or secondary schools)

Area	Year	All pupils (1)	Black, Asian and minority ethnic (3)	Eligible for free school meals (3 year average)	English as an additional language (A, B or C) (2)	Special educational needs - School Action	Special educational needs - School Action Plus	Special educational needs - Statemented
Neath Port Talbot	2020-21	17,249	1,090	4,209	216	2,184	1,329	687
Swansea	2020-21	28,515	4,512	6,301	1,902	3,987	2,290	1,269
West Glamorgan	2020-21	45,764	5,602	10,510	2,118	6,171	3,619	1,956

Source: [Additional learning needs \(special educational needs\) | Sub-topic | GOV.WALES](#)

Advocacy

The Foundation for People with Learning Disabilities identify the term 'advocacy' to describe what a member of the community (an 'advocate') is doing when they provide support to a person who may feel vulnerable, isolated or disempowered. They also identify that in many cases during childhood, it will be the individual's parents who take on the role of advocate for their children. However, as a child moves into adulthood, they may choose to take on the role of advocate for themselves. They suggest it is useful to differentiate between advocacy and self-advocacy. The latter involves people speaking out for themselves to express their own needs and represent their own interests.²⁶

Whilst it has not been possible to source up to date information from a Welsh perspective, People First in England (an advocacy group for people with learning disabilities) asked its members what they thought should be the priorities for improvement, noting that this was undertaken some time ago. They identified:

- 🌈 Campaigning for more use of Easy Read documents – because it gives people with learning difficulties choice, control and independence. This means that people can make better decisions.
- 🌈 Better funding for local self-advocacy groups - because they support people with learning difficulties to get rid of barriers that stop people being a part of society. They also support local people with learning difficulties to have a voice and speak up.
- 🌈 More local advocacy and support for people with learning difficulties – because you cannot take part in the life opportunities that are open to everybody else.²⁷

The Scottish Independent Advocacy Alliance conducted research into the impact of independent advocacy on the lives of people experiencing Learning Disabilities. They found that independent advocacy filled a need for people with learning disabilities which other services did not

²⁶ The Foundation for People with Learning Disabilities, 'Advocacy', <https://www.learningdisabilities.org.uk/learning-disabilities/a-to-z/a/advocacy> Accessed 9 November, 2021

²⁷ People First, 'Important Campaign Areas chosen by our members', <https://peoplefirstltd.com/policy-and-campaigns/important-campaign-areas-chosen-by-our-members/> Accessed 9 November, 2021

address. It can contribute to both hard outcomes (such as finding a job, winning a court case or receiving the correct benefits) and soft outcomes (such as empowerment and self-esteem) which have a great impact on a person's wellbeing. They also found the relationship with an advocate can help create a network of support.²⁸

The Challenging Behaviour Foundation identified that for some people, (e.g. those vulnerable people with profound and multiple disabilities), who may not be able to communicate their own wishes, it may be necessary to have a non-instructed Independent Advocate²⁹.

Transition into Adulthood

All young people need support as they move towards adulthood. Young people with learning disabilities have the same hopes for a good adult life but most will need additional help. The services that their families may have worked so hard to get for them will usually change when they reach the age of 18 (although the age differs in different services). The Children's Commissioner Wales³⁰ found that there is almost universally a huge task for young people and their families to navigate and negotiate the move to adult health and social services, college courses and the prospects of employment or other worthwhile activity after college. During their research, they heard from a few families that have been well supported through this period, with dedicated transitions support, including life skills development from local authority or voluntary sector projects. However, the majority had found this process confusing, difficult and anxiety provoking. Young people had not had the opportunities to be involved in this planning that they have the right to, with planning too often done 'about them' rather than 'with' them. Key messages from young people and their families included:

- 🧩 Young people's participation in planning and decision-making appeared to be very low – this meant that their different priorities and specific interests could get missed.

²⁸ Scottish Independent Advocacy Alliance 'Without advocacy I'd probably be dead', 2014, <https://www.siaa.org.uk/wp-content/uploads/2021/02/Karin-Report-V1.pdf> Accessed 9 November 2021

²⁹ The Challenging Behaviour Foundation 'Commissioning advocacy services for individuals with severe learning disabilities - A Pamphlet for Commissioners', <https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/Advocacy-guide-for-commissioners.pdf> Accessed 9 November 2021.

³⁰ Children's Commissioner Wales (2018) 'Don't Hold Back' Transitions to adulthood for young people with learning disabilities

- 🌸 Parents play a crucial role and are relied upon to do so, but often feel overwhelmed and anxious about the future – they need support and recognition.
- 🌸 Some young people face a considerable change in how much support they receive after the age of 18 due to different thresholds rather than a sudden change in need – contrary to the Social Services and Well-being (Wales) Act 2014.
- 🌸 Every service has different ways of transferring to over-18s services. Having a key worker or transition service is very valuable.
- 🌸 Social isolation is a problem for many – even though friendships are rated as young people’s top priority
- 🌸 There are very limited opportunities for work and apprenticeships, with no supported employment opportunities – despite evidence suggesting this is particularly effective.
- 🌸 Young people, parents and professionals all agree that young people with learning disabilities are still expected to slot into services that already exist, with limited options if that doesn’t fit their needs.
- 🌸 Almost all of the above points run contrary to the aspirations of the Social Services and Well-being (Wales) Act 2014 and the Wellbeing of Future Generations (Wales) Act 2015, and to rights under the UNCRC and UNCRPD.
- 🌸 Where young people and their families reported good experiences, they had been involved, they were clear about the process, they felt well supported by a keyworker, lead professional or dedicated transitions service and they often had access to a youth-centred provision that helped young people prepare for adulthood and expand their social and community networks.

A recent review by Care Inspectorate Wales³¹ looked at early help, care and support and transition for disabled children. They highlight areas where improvements are needed and some positive practice.

Acknowledging that the landscape of social care and health care services has changed as a result of the pandemic, they urge Regional Partnership Boards to take account of the findings. They recommend that they reflect on the pandemic and plan future integrated service delivery, which places the best interests of disabled children at the

³¹ Care Inspectorate Wales (2021) National review of early help, care and support and transition for disabled children in Wales

centre of decision making. It stresses the importance of promoting the rights of disabled children and their parents/carers, ensuring their voices are central to decisions made. Also emphasised is the need for transition planning to be undertaken in a timely manner and to include disabled children, their families and relevant professionals/agencies.

3. WHAT SERVICES ARE USED BY PEOPLE NEEDING LEARNING DISABILITY SUPPORT?

People with learning disabilities are a very diverse group. Whilst some people need 24-hour support, others have limited or no social care support. The process of accessing social care and health care services can be complex.

A review of inequalities in access to health services for disabled people in Wales³² published in 2015 found that:

- 🌈 only 24% of people with depression and anxiety disorders had received any form of treatment
- 🌈 many deaf and hard of hearing people were forced to make contact with their GP in a method that was not optimal and 90% of GP surgeries in Wales did not offer suitable alternatives for making appointments. There were also barriers to arranging interpretation or communication support
- 🌈 there are significant geographic variations in access to healthcare services for disabled people across Wales, particularly in terms of mental health and rehabilitation services
- 🌈 there are seen to be negative and disproportional impacts on the health outcomes of disabled people as a direct result of the Welfare Reform Act.
- 🌈 The review also highlighted a ‘a severe lack of published evidence in terms of access to healthcare services for disabled people in Wales’.

Health

Swansea Bay University Health Board provides specialist adult learning disability services across the geographical area covered by Swansea Bay, Cwm Taf Morgannwg and Cardiff and Vale University Health Boards, a combined population of around 1.2 million people. As such we plan and provide services commissioned by Cardiff and Vale and Cwm Taf Morgannwg UHBs for their populations and work in partnership with seven local authorities.








³² Review of Evidence of Inequalities in Access to Healthcare Services for Disabled People in Wales: Executive Summary (Welsh Government, 2015). Accessed: 12 November 2021.

Services are operationally managed within the Mental Health and Learning Disability Service Group of the Health Board with a specific Division focussed on Learning Disability Services.

The following information describes the services delivered across Swansea Bay, Cardiff and Vale, and Cwm Taf Morgannwg University Health Boards.

Community Teams

There are 7 Community Learning Disability Teams:-

-  Swansea
-  Neath
-  Bridgend
-  Rhondda Cynon Taf North
-  Rhondda Cynon Taf South
-  Cardiff
-  Vale of Glamorgan.

The community teams are multi-disciplinary including Psychology, Community Learning Disability Nursing, Occupational Therapy, Physiotherapy, Speech and Language Therapy and Psychiatry. Access to specialist dietetics and Arts Therapies is available in some areas.

The Community teams provide a single point of access to local Health support from team members and act as conduit for referral to the Specialist Behavioural Services, Specialist Residential Units and the Acute Admissions Units (AAUs). The community teams deliver services across a range of settings including service user homes, local authority care provision, day services, educational settings and third sector social care provision.

The teams work in an integrated way, coordinated within a multi-disciplinary framework, operate Monday to Friday 9am-5pm and aim provide high quality, evidence-based services.

In addition to the CLDTs, there are three specialist community teams, additional specialist nurse roles, Acute Admission Units and Specialist Residential Services as set out below.

Facing the Challenge (FTC) – Neath and Swansea.

A specialist service for children and young people with learning disabilities whose behaviour could be described as challenging, Facing the Challenge deliver positive behaviour support (PBS) person centred functional behavioural assessment and intervention.

The team work intensively with children and young people as well as with their parents and carers, offering group interventions for families and siblings. Facing the challenge works to understand the communicative intent of behaviours that challenge and develop evidence based, person centred interventions that seek to increase quality of life and teach skills to support the young person's ability to engage in meaningful ways and develop to their full potential.

Specialist Behaviour Team (SBT) Across Swansea Bay footprint

The specialist behaviour team deliver person centred, evidence based positive behaviour support (PBS) to adults. The team works intensively to seek to understand communicative function of challenging behaviour

through individualised functional assessment and PBS intervention in partnership with the community learning disability teams.

PBS plans are developed to increase the person's quality of life, teach skills and reduce restrictive practice. The team support MDT behavioural assessment in specialist residential settings and work closely with the AAUs to reduce length of stay and increase positive outcomes for the person. They also support social care partners and families to maintain community placements reducing unnecessary admissions to in-patient facilities.

The team are also responsible for delivery of psychology into the specialist residential services.

Learning Disability Intensive Support Team (LDIST) Swansea, Neath Port Talbot and Bridgend.

A team of nurses and support workers who provide prompt, short-term, intensive support to adults with learning disabilities who are experiencing episodes of mental and/or physical ill health that require extra support in addition to the community learning disabilities teams (CLDT) or acute learning disabilities liaison nurses. Working in conjunction with CLDTs, LDIST takes the service to the service user e.g. in their home, day service, as well as acute hospitals and are able to work with the service users across a variety of settings. LDIST enhances continuity of care and increases access to service support for the most in need by providing a 7-day service inclusive of weekends and bank holidays 9am-5pm and out of hours on week days 8am- 9pm.

LDIST prevent crisis by using PBS and other support models to support service users experiencing an acute change in mental and/or physical health needs in community settings reducing the occurrence of; diagnostic overshadowing, risk of placement breakdown and unnecessary admissions to AAUs. LDIST can also provide input into acute hospitals facilitating reasonable adjustments thus reducing health inequalities. LDIST enable the reduction of bed days for those admitted to AAUs or acute hospitals by supporting & expediting safe discharge with ongoing support post discharge.

Acute Liaison Nurses

The service aims to improve the experiences of people with a learning disability in secondary care settings. This is done in a variety of ways including training of hospital staff, role modelling positive approaches, advising on reasonable adjustments, helping individuals and hospitals to plan for complex admissions and discharges providing a crucial link between secondary care and community teams.

Specialist Epilepsy Nurses

Two specialist epilepsy nurses work across all areas. They play an important role in passing on skills and knowledge to others and providing direct clinical intervention to those with the most complex needs. They work alongside Consultant Psychiatrists and also provide nurse led care.

Specialist Residential Services

Specialist residential services (SRS) were established in the early 90s to facilitate the closure of Learning Disability institutions such as Ely and Hensol Hospitals.

The Tier Three Specialist Residential services comprise of seven, five bedded bungalows located in different communities across the Health areas of SBUHB, Cwm Taf, and Cardiff and the Vale. These were set up with the intention of accommodating service users with continuing health care needs. Since the establishment of the units, there have been very few discharges to social care placements. There was a perception that these settings were established as homes for life after the closure of the institutions and there has not been a clear plan for supporting people to move on. We know that there are people who could be safely supported within social care placements. This is being reviewed within the modernising learning disability services work.

The Units are registered as hospitals, and are nurse led, with dedicated support from Psychiatry (one Registered Clinician per unit) and Psychology input from the Specialist Behavioural Service. The range of clinical presentations for the resident population include severe challenging behaviours with co-morbidities such as Autism/Autistic Spectrum Condition, Adult ADHD, a range of Mental Health problems and a small cohort who present with a history of high risk behaviours

thus requiring high levels of supervision and support from trained and experienced staff.

Referral to these units can be made by NHS professionals. All individuals referred will have been fully assessed as meeting the criteria for NHS Continuing Health Care under the All Wales Framework.

The residential units for individuals with behaviours that challenge are:

Residential units for people with behaviours that challenge in SBUHB (Neath & Swansea)

Unit name	Based	Number of beds
Dan Y Deri	Swansea	5
Swan Yr Afon	Seven Sisters	5

Acute Admission Units (AAUs)

Three acute admission units provide in-patient assessment and treatment for adults with learning disabilities who require specialist, hospital based assessment and intervention and operate within the PBS framework. All individuals admitted to the units can expect a standardised approach to their assessment and treatment.

Bed numbers by Acute Admissions Unit (Swansea)

Unit name	Based	Number of beds
Llwyneryr	Swansea (Morrison)	7

Social Care

The tables below evidence the number of community placements for individuals over the age of 16 broken down by Local Authority in the region, since April 2017. The numbers are increasing steadily, which is expected as people are living longer. This suggest that the demand for placements will continue to grow over the next 5 years.

Number with parents/family

Number of community placements with their parents / family for persons aged 16+ with a learning disability

Years	Neath Port Talbot	Swansea	West Glamorgan
2016-17	163	425	588
2017-18	185	441	626
2018-19	168	466	634

Source: SocialCareWales

Supported living

Number of community placements in lodgings / supported living for persons aged 16+ with a learning disability

Years	Neath Port Talbot	Swansea	West Glamorgan
2016-17	69	243	312
2017-18	83	251	334
2018-19	83	260	343

Source: SocialCareWales

Own home

Number of community placements in their own home for persons aged 16+ with a learning disability

Years	Neath Port Talbot	Swansea	West Glamorgan
2016-17	6	164	170
2017-18	7	150	157
2018-19	7	135	142

Source: SocialCareWales

Residential

Number of local authority residential accommodation (staffed or unstaffed) placements for persons aged 16+ with learning disabilities

Years	Neath Port Talbot	Swansea	West Glamorgan
2016-17	1	12	13
2017-18	1	12	13
2018-19	1	18	19

Source: SocialCareWales

Other

Number of community placements for persons aged 16+ with learning disabilities

Years	Neath Port Talbot	Swansea	West Glamorgan
2016-17	246	836	1082
2017-18	288	842	1130
2018-19	270	861	1131

Source: SocialCareWales

Number of private or voluntary residential accommodation (staffed or unstaffed) placements for persons aged 16+ with learning disabilities

Years	Neath Port Talbot	Swansea	West Glamorgan
2016-17	49	76	125
2017-18	50	61	111
2018-19	49	80	129

Source: SocialCareWales

Swansea

The City and County of Swansea's current Commissioning Strategy Adult Learning Disability Services (published in 2017)³³ outlines the services available for adults with a Learning Disability at the time of publication. The Commissioning Strategy is due to be reviewed, which has been delayed due to the impact of the Covid-19 pandemic. Below are the services available to adults with a Learning Disability from the Commissioning Strategy:

Accommodation options and related support

Having secure and appropriate accommodation is fundamental to the delivery of people's wellbeing outcomes.

Fully Independent Living


Living independently in ordinary housing as a tenant through a housing association, local authority or private landlord

Living at home with family carers


We will support people to remain at home with family carers if this is what they want and a range of day, respite and support services will be available to support this.


Independent living with low level support


Living in ordinary housing as a tenant through a housing association, local authority or private landlord with minimal (1-3 hours a week) tenancy/domiciliary support. This support could be provided through any of these agencies:


-  **Tenancy Support Unit** is available to all residents of the county, including residents of housing associations, local authority or private landlords and owner occupiers. Services are free and they can help with for example, accessing benefits and looking at benefit maximisation, advice on budgeting and debt management and setting up and maintaining gas and electricity accounts.

³³ City and County of Swansea Commissioning Strategy Adult Learning Disability Services

-  **Coastal Housing** provides an assessment and tenancy support service which aims to support people to prepare them to take on and manage their own tenancy. This service is short term.

-  **Pobl Doorways** support people to develop skills they need to be more independent in their own tenancy or living at home with family carers.

-  **Domiciliary care providers** who support people with their personal care needs.

-  **Support Options** specialise in domiciliary support in meeting the personal care needs of people with complex health needs living at home with family carers.


Support for people with medium to high levels of need


Supported Living

Living in ordinary housing as a tenant, usually shared living with 2-3 other people with a learning disability with an appropriate level of tenancy and domiciliary support. This could mean 24-hour support through to much lower levels depending upon the person's needs. Additional support can be accessed on a 24-hour basis. It is always the intention to increase independence and reduce levels of support over time if possible.

Shared Lives

Living with a paid, trained family, long term, under a license arrangement. Carers include couples, single people, male and female carers and carers of different ages who we match to service users whose needs they can best meet. Some of these carers have specialist training to meet more complex needs. This service is provided by Ategi, which is a regional service.





-  **Residential and nursing care** means living in private registered residential care or nursing homes, which are either specialist learning disability provision, or homes which support older people.

 **Emergency short term accommodation and support:**
Maesglas Community Support Unit is local authority emergency, temporary residential care accommodation for when current arrangements fall through for whatever reason. The aim is to get people home again as soon as possible and if people cannot go back home, to support the move into alternative living arrangements.

Shared Lives provides emergency support provided by paid, trained carers in their own home. This is also provided by Ategi.

Work/Education/Occupation/Relationships


Through the range of support and services available, the aim is to promote:


-  contribution to society through work, work related activity and constructive occupation
-  growing independence and involvement in community activities
-  the development of social support networks
-  personal and skills development.

Work Development Service





The service supports individuals to gain educational and vocational qualifications and provides work opportunities via a number of projects, with a view to supporting people into either paid or voluntary work.

The service is based at Fforestfach Day Service and links in with a number of projects that work across the Swansea area in partnership with other departments, local organisations and businesses.

 Neighbourhood Environment Action Team (NEAT) works in partnership with the Council's Environment Department, to clean up the streets, wasteland, canals, etc.

 Swansea Action Team (SWAT) works in partnership with the Council's Environment Department to recycle old furniture. The


Baling Plant recycles household items in partnership with a local employer.

-  Victoria Park Kiosk and Catering Services works in partnership with Mental Health services. This project has a kiosk in Brynmill providing snacks and takeaway meals to members of the public. It also provides a buffet service to the Council or other organisations on request.
-  Ground Force and Ground Maintenance provides a service to the public as well Social Services doing maintenance work and makeovers. The service also has a nursery in Fforestfach that provides bedding plants, hanging baskets, garden furniture and is open to the public.
-  The Bike Scheme works in partnership with the Environment Department and it renovates old bikes, which are then sold or donated.
-  Work placements with a Job Coach in a variety of businesses including offices, catering, cleaning, retail/food, animal centres, nurseries, schools and cafes. These are seen as a stepping-stone to employment or voluntary work.


Education, Skills development and Constructive Occupation

If people are not ready for the world of work or work experience, then it may be that skills development, adult education or constructive occupation are required.

Local Day Services

-  West Cross and Glandwr Day Service and the Social Development Service can help people access education, develop skills and explore opportunities for constructive occupation. The support provided can take place in a range of settings across Swansea, as well as in the service itself. Support includes:

- Further education courses or development of daily living skills
- Leisure, fitness and cultural opportunities within Swansea
- Workshops, groups, clubs and activities
- Skills training to increase independence, such as travel training, shopping, cooking meals, and housekeeping
- Community work such as litter picking and gardening projects.

 **Connect** is based in Swansea Marina and runs workshops and social activities with the aim of tackling social exclusion. The service is provided on a sessional basis and is aimed at people who are already relatively independent.

Special Needs' Day Services


These are for young people who have a very severe learning disability and the world of work and adult education seems impossible. They provide day services to people who have profound and multiple learning disabilities and who could not safely receive a service in a mainstream day service. Opportunities to develop and maintain life skills in a positive and stimulating environment are offered. Parkway Special Needs' Day Service is for people who require the support of health professionals in order to manage the complexity of their health needs.


Whitethorn's Intensive Day Service

For people who may temporarily need a more structured day service than our mainstream services can provide, Whitethorns Day Service offers a short to medium term intensive service.


Woodlands Day Service


Community Lives Consortium provides an intensive day service for people whose behaviour challenges and who need a much quieter and protected environment.


 **New Horizons at Swansea Vale Resource Centre** aims to enable people with a learning disability who also have a physical disability or sensory impairments to gain greater independence and develop a range of skills


 **Flexible Support Service** - The Flexible Support Service provides a range of support on an individual and group basis aimed at encouraging greater independence and social skills usually this means a move away from day services towards the young person taking more responsibility of their day-to-day lives and decisions and greater involvement in their local communities.

The support available includes:

 **Support towards greater independence** for individuals who are planning to move to independent living by providing training, advice and guidance on household bills, living skills, budgeting and welfare benefits. The service is available to support at any time of the day or night where emergencies arise for people living on their own.

 **Emergency short-term support** where there is no appropriate alternative service available.

 **Social Clubs** during the day and evening offering people a chance to meet others and join in social and community activities. There are currently social clubs on each day of the week.

 The **Signpost Service** provides a drop in service at St Phillips Community Centre on a Monday and Wednesday for individuals seeking information on social, educational and leisure groups and activities in Swansea.

'Having a Break'

A short break (respite) offers time out from the normal routine offering an opportunity to support and sustain the caring relationship.

Day services and services to support people to remain at home are part of this support to carers, as are the social clubs both of which are detailed above.

From time to time, carers and those they care for may need a longer time apart and there is a range of services to give a break from this usual routine to allow everyone to recharge.

Using a Direct Payment

Some people use a direct payment to pay for breaks, which can be decided and organised by themselves. Direct payments can be given in lieu of a service that someone has been assessed as needing and where the direct payment will achieve the outcomes that have been identified.

Shared Lives

A flexible and responsive service provided in a homely environment for overnight stays or sessional periods during the day.

Residential Respite Services

For people whose needs are best met in a residential care setting, we have the following provision based in the local community:

- Ty Cila, Killay, - provides breaks for people who have more complex needs and who need an adapted environment and more specialist support
- Cadle Respite Service, Swansea – Community Lives Consortium provide this residential service for adults whose behaviour challenges and where a more protected environment is needed.

‘Voice, choice and control’

Independent Professional Advocacy Service

Mental Health Matters (Wales) is commissioned to provide independent advocacy for adults who access social services, including people with a learning disability, to support their voice within the assessment and care management process and other social services functions.

West Glamorgan People First

West Glamorgan People First are commissioned to support co-productive commissioning arrangements.

Neath Port Talbot

Neath Port Talbot County Borough Council's (NPT CBC) Strategic Delivery Plan for Learning Disability Services (2018)³⁴ outlines the number of people with a learning disability in receipt of services at the time of publication to support the proposed their commissioning intentions, outcomes and action plan to change services.

Current Service Model

There are currently 403 'placements', i.e. people (aged 18+) with learning disabilities in receipt of one or more service.

	People
Residential	33
Standard Res	4
Domiciliary	29
Day Care	39
Adult Family Placement	24
Respite	3
Supported Living	136
Direct Payment	135
	403

The current service model is not as progressive as it could be, being heavily reliant on care provided in a residential home or an historical model of supported living. This has resulted in an under-developed market for more enabling services which promote greater levels of independence.

Residential care and supported living is provided by around a dozen different service providers across 60 locations, including 15 people currently living outside of Neath Port Talbot.

NPT CBC's Strategic Delivery Plan for Learning Disability Services is due to be reviewed, but has been delayed due to the impact of the Covid-19 pandemic. The services are divided into four main categories:

³⁴ Neath Port Talbot County Borough Council, Social Services, Health and Housing Directorate – Strategic Delivery Plan for Learning Disability Services

- 1) Housing Options and Related Support
- 2) Direct Services
- 3) Independence
- 4) Forums.

1) Housing Options and Related Support

NPT CBC have a range of options for individuals with a learning disability, depending on their support and accommodation needs. For those individuals who are identified for requiring accommodation and support an appropriate package of care will be commissioned which will be able to meet their own going needs.

Fully independent living

No support provision is required, and accommodation can be sourced via Housing Associations, Voluntary Organisations or the Private Rented Sector.

Living at home with family carers

If it is their choice we will support individuals to remain at home with their families and carers. If their needs have been assessed as requiring support they are able to access respite, day services, and domiciliary care and support either within the home or in the community, in line with their support plan.

Move on accommodation

Accommodation which is a PAN Disability model which offers accommodation on a time limited basis to help develop a person's independence and daily living skills. Support is not attached but there are mechanisms in place to source appropriate care. This is managed by the local authority.

Move On Panel

This is facilitated by the Local Authority, and brings all Local Housing Associations and professionals together to meet on a regular structured basis. The purpose of this panel is to identify individuals whose support needs have reduced to expedite them into independent Housing Association living accommodation.

Family Tenure

The accommodation is managed and facilitated by family members who have sole responsibility for the maintenance and upkeep of the property. Support may be commissioned by the Local Authority or sourced via a Direct Payment.

Inherited Tenure

The accommodation is willed or gifted by the owner of the property. The family member remains residing at the accommodation and the management and maintenance of the property is undertaken by a third party i.e. solicitor or trust. Support may be commissioned by the Local Authority or sourced via a Direct Payment.

Assisted Home Buy

This accommodation model allows for the individual to purchase a property via a mortgage and benefit from the ability to co-own with the Local Housing Association. Support may be commissioned by the Local Authority or sourced via a Direct Payment.

Independent Living with low level support

Individuals have a tenancy agreement with a housing association, local authority or private landlord and have accessibility to tenancy. Support may be commissioned by the Local Authority or sourced via a Direct Payment.

Neath Port Talbot Community Independence Service

This service provides housing-related support that enables vulnerable individuals to improve their independent living skills, while promoting their independence. It provides one to one support to help people manage and maintain their homes, tenancies and personal circumstances. Support available includes budgeting, planning and preparing meals, assistance with weekly shopping, assistance at medical appointments, ensuring homes are kept safe and clean and in line with tenancy agreements and encouragement to take part in social activities in the local community.

The Wallich's PAWS Project

This service provides low level housing related support to anyone living within Neath Port Talbot, who is either homeless or, struggling to manage their accommodation which could lead to them becoming homeless. Support can be provided to address tenancy management issues, including Anti-social behaviour or neighbour disputes; managing money including benefit maximisation, budgeting and addressing rent arrears or other debts; and support to develop independent living skills such as setting up utilities and accessing other services. The service is also able to provide mediation, and access to a volunteer befriending service.

Coastal Housing/Tai Tarian

Provide a time limited assessment and tenancy support service with the objective of supporting individuals to take on and manage their own tenancy.

Domiciliary Care Providers

Provide individuals with personalised packages of care to include a variety of support such as personal care, independent living skills, accessing the community, maintaining and developing friendships and supporting with day to day living.

Pobl Doorways

Promote and support individuals with their independent living skills, this can be done within their own accommodation where they hold a tenancy or living at home with families or carers.

Supporting Living

Supported living services enable people with a learning disability to live independently in their own home, with appropriate support to help them manage their own tenancy and achieve greater freedom and control of their lives. Support can be provided in a person's own house, their flat or in a shared living environment. There are a number of properties within the County Borough which have been in place for a number of years. This supporting living model has demonstrated capacity for providing effective care and support to people with a very broad range of needs.

Closer to Home Scheme

The accommodation is offered on a supported living basis, however, the staffing ratios are greater in part due to the individual needs. The intention of these schemes is to move people that have been previously moved into out of county care homes back into their local communities through the provision of specialist supported living services.

Extra Care Scheme

The accommodation is offered on an independent supported living basis. Floating support is provided on an individual need basis which includes a dedicated communal area at the location and 24 hour call-on support.

Moving Forward – New Schemes

Within in Neath Port Talbot County Borough Council we are constantly striving to meet the needs of learning disability and looking for new housing opportunities for individuals where outcomes can be achieved. Currently we have 2 projects underway to include:

- **ASD Scheme- Supported Living**

We have secured capital from the Welsh Government's Integrated Care Fund, in partnership with First Choice Housing Association and Swansea Bay University Health Board. The scheme involves placements for three residents who have ASD and a mental health diagnosis. The anticipated commencement of the scheme is 2022/23.

- **Core & Cluster – New Innovative Model**

The core-cluster model represents a dynamic service delivery system which, in a sense, artistically fits services to client needs. It brings together core supported living model alongside cluster independent accommodation with floating support. We are currently working in partnership with First Choice Housing and have secured a property and land which will accommodate this scheme. It includes a bungalow for two individuals – core supported living and land which will house 4 flats for cluster independent living. The scheme is in two phases and completion of Phase 1 is anticipated September 2022 and Phase 2 2023/24.

Shared Lives

Approved Shared Lives Carers support people to live in ordinary households and share their home and family life with them. Carers offer short term breaks including emergency placements and long term arrangements. In some situations individuals are supported through the day with their approved shared lives carer.

Shared Lives Carers are assessed, checked, trained and approved then guided and monitored to support people who they have been carefully match with. Shared Lives support people over the age of 18 and can support people who had a learning disability or mental health issue to live or stay as independently as possible within a family setting. They can also provide support to people with Autistic Spectrum Disorder, people who have extra needs because of their age, their behaviour, physical disabilities or dementia. Individualised training will be provided according to the needs of each person.

The care they provide is monitored by Shared Lives schemes that are regulated and inspected by the Care Inspectorate Wales to ensure high standards. Ategi provide this service for NPT CBC.

Residential and Nursing Care

NPT CBC currently commission with 22 residential care homes who provide these services for individuals with a learning disability.

A residential care home or a nursing care home is registered under relevant statutory regulations where the provider delivers 24 hour personal care and or nursing care and accommodation.

The service being commissioned is aimed at individuals 18 years of age and over who have been assessed as having a learning disability, with or without a requirement for nursing care, and have a support plan in place which may be best met either in the short term or in the longer term by being in a residential or nursing care placement.

When required, the Council and, if appropriate, the Health Board will require the provider to deliver a progression or recovery model that has

a proven ability to work and can enable or re-able the individual to move to more appropriate models of support that can ensure the individual achieves greater independence.

There will be occasions when individuals may be appropriate for residential and nursing care in the longer term. When this is the case, the provider will be required to, if appropriate, maximise the person's independence as far as would be reasonably possible.

When appropriate, assistive technology will also be used to ensure people are kept safe and to promote independence.

2) Direct Services

NPT CBC provides a range of services for people with learning disabilities which enable individuals to take part in activities where they can maintain and develop new skills and meet their personal outcomes. The services promote independence alongside providing opportunities for individuals to access work and community based activities. The services provide care and support for individuals and respite for carers.

B'spoked/Fresh Start

B'spoked is a training and employment centre based at B'spoked Enterprises - Neath Abbey and Croeserw Community Enterprise Centre (Fresh Start). This service provides work, training and employment opportunities for adults with low to moderate learning disabilities. The purpose is to create a live environment which prepares and provides service users with the tools and skills to develop their potential and to support their progression to paid or voluntary employment or community based activities.

Plans for the future: It is proposed to enhance the training and employment model and develop it to become an independent living hub with the inclusion of two new training flats where people can develop daily living and independence skills and where assessments can be carried out by practitioners.

Community Connecting Team

The Community Connecting Team (CCT) deliver community based opportunities to vulnerable people from the age of 16 years old living in Neath Port Talbot. The service enables people who have significant support needs to access meaningful social, leisure, education, learning and volunteering activities. Activities take place Monday to Friday and include morning, afternoon and evening sessions. All activities take place within community settings.

Complex Needs Day Service

Day services for people with complex needs are delivered across 3 sites in Neath Port Talbot, (Trem Y Mor, Brynamlwg and Rhodes House). Each of the facilities is designed to meet the individual needs of the people who use these services and focus on either challenging behaviour or ASD, complex needs or generic needs.

The services provide individuals with support to improve and maintain health with input from health professionals, and wellbeing and social inclusion by providing activities and opportunities within the service bases and the local community.

Emergency Respite and Short Stay Accommodation – Trem Y Mor

Trem Y Mor is a respite and interim emergency care service situated on the beach front of Aberavon. It is regulated by Care Inspectorate Wales (CIW). The service provides respite for the carers of people living in Neath Port Talbot with the primary support need being learning disability. This care is delivered in a sixteen bedded purpose built facility. Trem Y Mor provides a safe and supportive care environment enabling individuals to achieve personal outcomes. The service will encourage individuals to participate in a variety of activities both in-house and the local community in order to promote positive health and wellbeing throughout their stay.

New Developments

Since 2020, The Remodelling of Day Service Opportunities Programme (RDSO) has been in place. The purpose of the programme is to deliver

an individual directed model of adult social care that minimises dependency and enables people to live as independently as possible within their own homes and communities.

Services will be provided using community assets in a coproduction method, becoming a more enabling service and working more closely with the community.

Services will traditionally move from some building bases and be provided in an array of different venues/scenarios. A number of work streams have been established to identify, change, implement and develop services as part of the programme and this work is ongoing.

3) Independence

NPT CBC encourages individuals with a learning disability and carers to have a voice, choice and control of their lives and that they have the right support, at the right time to make informed decisions. This is being developed and enhanced in the following ways:

Self- Advocacy

Self -Advocacy promotes equality, social justice, social inclusion and human rights. It aims to make things happen in the most direct and empowering ways possible. It recognises that self-advocacy – whereby people, perhaps with encouragement and support, speak out and act on their own behalf – is the ultimate aim. NPT CBC have a commissioned service with Mental Health Matters who provide this service. There are currently two dedicated Independent Professional Advocacy Officers (IPAs), additional support is provided by an Advocacy Team working across the county borough with individuals who have a learning disability.

Direct Payments Support Service

Direct Payments are offered, following an assessment, to people as an alternative to either in house services or commissioned care, allowing them to employ Personal Assistants (PAs) of their choice. Direct Payments enable people to meet their outcomes and exercise choice and control over the care they receive.

The in house Direct Payments Support Service (DPSS) sets up new packages, provides employment guidance and supports with the recruitment of PAs as well as providing a range of other services. The DPSS provides a comprehensive service supporting employers and Personal Assistants to work as safely as possible and in line with employment law.

Digital Inclusion

This is to ensure the benefits of the internet and digital technologies are available to everyone. People with learning disabilities are supported in Direct Services, NPT CBC to develop the skills to use Information Technology and assistive technology to promote independence, manage daily living activities and develop and maintain connections.

4) Forums



NPT CBC support a number of forums for learning disability, which enhances the link between the local authority and the individual. An example includes:

Neath Port Talbot Learning Disability Providers Forum

This forum has been established to enable regular dialogue and liaison between commissioners of learning disability services in the borough and providers who are commissioned by NPT CBC and others to deliver learning disability services in the borough.

The Forum is a means of sharing information, promoting best practice and making key decisions on issues relating to the delivery of learning disability services in the borough.

The Forum:

-  discusses key changes to learning disability services in the borough as a result of statutory, regulatory or other market wide changes in the sector
-  shares and discusses innovative ideas, ways in which services can be better improved in the borough and the sharing and implementing of best practice

- 🌸 informs and updates providers on commissioning intentions from the Council and Swansea Bay University Health Board around learning disability services;
- 🌸 continues to maintain excellent working relationships by those attending
- 🌸 supports providers in areas such as workforce development, registration requirements especially in relation to ongoing changes in regulations from Welsh Government as they would apply to learning disability services;
- 🌸 encourages better joint working between commissioners and providers and encourages increased joint working in the market
- 🌸 acts as a means by which key decisions can be made between commissioners and providers in the market.

Day Services - Situation across the region at the time of writing

As part of the winter emergency response programme, the regional partnership mapped the internal and external day services currently open in the region for people with a learning disability. A mapping exercise evidenced that in November 2021:

Swansea

- 🌸 13 internal day centres were partially open.

Neath

- 🌸 5 internal day centres were partially open
- 🌸 2 external day centres were fully open
- 🌸 1 external day centres were partially open.


Please note that the above represents a snapshot in time during the COVID-19 crisis.


Current Third Sector Projects for People with a Learning Disability

The following projects are currently ongoing in the region, funded via the Regional Partnership:

- 🌸 **Leonard Cheshire** - This project aims to reduce the needs of individuals to access higher tier services and support them to remain independent. It supports disabled people in the community

and living in specialist social care services across the region to learn crucial skills and stay connected to their community, families, and friends throughout the pandemic.

 **Discovery Student Volunteering Swansea** - The project provides fortnightly sessions for adults with a learning disability with the aim of improving emotional literacy, awareness of self-care and self-help techniques and overall wellbeing, in order to prevent the need for mental health support and intervene early if low-level mental health problems are present, preventing them needing to access higher level support.

 **Dimensions Cymru** - This project seeks to support early intervention wellbeing initiatives across four Supported Living sites in Swansea. It focuses on the people who live at the sites during the pandemic, many of whom have been shielding with little social contact due to complex health conditions. They aim to rebuild, strong, resilient, healthy and happy communities of people who are able to take on new challenges and grow in their independence by developing resilience through well-being activities.

4. WHAT IS BEING DONE TO SUPPORT PEOPLE WITH A LEARNING DISABILITY?

Legislation, Policy and Guidance

Social Services and Well-being (Wales) Act 2014

The Social Services and Well-being (Wales) Act 2014³⁵ introduced a major change to social care in Wales, putting prevention and promotion of well-being for everyone who has care or support needs on a statutory footing for the first time. The Act changed the way people's needs are assessed and the way services are delivered so that people have more of a say in the care and support they receive. The act also promotes a range of help available within the community to reduce the need for formal, planned support.

³⁵ Welsh Government (July 2016), Social Services and Well-being (Wales) Act 2014: The Essentials, [accessed: 12 November 2021].

The Act replaced parts of the Children Act 1989, giving a new definition of a 'child at risk' and a duty to report a child at risk for all relevant partners of a local authority.

Disabled children were classified as 'children in need' under the Children Act 1989. The concept of a 'child in need' is not replicated in the new act which refers to children and young people who have a need for care and support defined around ability to achieve the well-being outcomes outlined in the act around education, health and so on.

Well-being of Future Generations (Wales) Act 2015

The Well-being of Future Generations (Wales) Act 2015³⁶ requires listed bodies to work together to improve the economic, social, environmental, and cultural well-being of Wales. One well-being goal is a more equal Wales where everyone can reach their potential. The Act offers the potential to improve services and support for disabled people in Wales. The Act brings a requirement to think about the long-term impact of decisions, work better with people, communities, and professionals and to prevent persistent problems such as poverty, health inequalities and climate change.

The Equality Act³⁷ came into force in October 2010, bringing together different laws that cover discrimination. It introduced a Public Sector Equality Duty which requires all public bodies to tackle discrimination, advance equality of opportunity and promote good relations. Under the Act, disability is one of the protected characteristics, meaning that disabled people should be treated equally. Protection from discrimination applies in situations such as education, employment, exercise of public functions, provision of goods and services, facilities and transport.








³⁶ Welsh Government (8 August 2016), Well-being of Future Generations (Wales) Act 2015, [accessed: 12 November 2021]

³⁷ Legislation.gov.uk <https://www.legislation.gov.uk/wsi/2011/1064/contents/made> [accessed: 12 November 2021]

The Additional Learning Needs and Education Tribunal (Wales) Act 2018³⁸ (ALNWA 2018) will change the way that children and young people aged 0-25 with additional learning needs (ALN) are supported in Education in Wales. The code came into force on 1 September 2021.





The legislation will have a phased implementation. From 1 September 2021 onwards, new learners with Additional Learning Needs will be supported by the new system, and learners using the old system (SEN) will transition over a three-year period. The Welsh Government is determined that the ALNWA 2018 regime will deliver a fully inclusive education system for learners in Wales, where needs are identified early and addressed quickly. It is intended that the planning under the new regime will be flexible and responsive, with the learner at the centre of everything.

The following changes have been introduced:

-  Introduction of the term Additional Learning Needs (ALN) to replace the terms 'special educational needs' (SEN) and 'learning difficulties and/or disabilities' (LDD).
-  Legislation that covers the age range 0 to 25. This will replace the two separate SEN systems covering children and young people of compulsory school age and young people in post-16 education.
-  A single individual development plan (IDP) to replace the existing variety of plans for learners in schools and further education.
-  Increased participation of children and young people in the planning process, so planning is something done with them rather than to them.
-  High aspirations and improved outcomes. This will be the focus of the IDPs.
-  A simpler and less adversarial system. The process of producing and revising an IDP should be much simpler than is currently the case with statements of SEN and should avoid the adversarial nature of the existing approach.
-  Increased collaboration and information sharing between agencies. New roles are created to support this – Additional Learning Needs

³⁸ Gov.Wales; <https://gov.wales/additional-learning-needs-special-educational-needs>, [accessed 12 November 2021)

Coordinators in education settings; Designated Educational Clinical Lead Officers in health boards; and Early Years ALN Lead officers in local authorities.

-  Avoiding disagreements and earlier disagreement resolution about the IDP or the provision it contains.
-  Clear and consistent rights of appeal including a right of appeal to a tribunal where disagreements about the contents of an IDP cannot be resolved at the local level.
-  A statutory ALN code to set out the duties of local authorities and other organisations responsible for the delivery of services to children and young people with ALN.
-  A bilingual system where services must consider whether provision is needed in Welsh and take all reasonable steps to secure it.

A Healthier Wales

Both social care and health care are dealt with under different legislation, and it is not uncommon for local authorities and health boards to disagree about which organisation is responsible for providing services. The Welsh Government acknowledges these challenges in their plan for health and social services - A Healthier Wales (updated October 2021)³⁹. They outline their ambition to improve how health and social services work together, so that they are designed and delivered around the needs and preferences of individuals, with a much greater emphasis on keeping people healthy and well. The plan sets out a long-term vision of a 'whole system approach to health and social care', which is focussed on health and well-being. It is based around four aims:

1. Improved population health and well-being.
2. Better quality and more accessible health and social care services.
3. Higher value health and social care
4. A motivated and sustainable health and social care workforce.

There are ten national design principles to drive this change and transformation which are: prevention and early intervention, safety, independence, voice, personalised, seamless, higher value, evidence driven, scalable and transformative services.






³⁹ A Healthier Wales: our plan for health and social care (Welsh Government 2021)

Learning Disability – Improving Lives Programme

The Learning Disability - Improving Lives Programme⁴⁰ forms part of Welsh Government's Prosperity for All⁴¹ strategy, a single cross-cutting strategy to inform all decision-making, providing a framework for improved cross-government working and to improve the quality of people's lives. The review took a lifespan approach from pregnancy to end of life. The three key priorities are:

1. To reduce health inequalities – through reasonable adjustments to mainstream services and access to specialist services when needed
2. To improve community integration, including increasing housing options closer to home; integrated social care, health and education; and, increased employment and skills opportunities.
3. To enable improved strategic and operational planning and access to services through streamlined funding, better data collection, partnership working and more training and awareness.

The programme focuses on improving services in five key areas:

-  Early years – reducing adverse childhood experiences and improving the ability of parents with a learning disability to bring up their children
-  Housing – new models of supported housing will be developed, helping people to live closer to their friends and families
-  Social care – making sure everyone who needs it has a access to good quality care and support which is focused on their needs
-  Health – through reasonable adjustments to mainstream services and access to specialist services when needed. To address health inequalities, making sure people with a learning disability receive the annual health checks they are entitled to and health boards ensure they meet the needs of people with a learning disability when in hospital
-  Education, skills and employment – supporting young people to make the most of their potential, and when they become adults ensuring they have the right support to allow them to live successful lives,

⁴⁰ The Learning Disability - Improving Lives Programme (Welsh Government 2018). Accessed 12 November 2021

⁴¹ Prosperity For All – Economic Action Plan (Welsh Government, 2017)










through providing targeted careers advice and making sure more people with a learning disability have paid jobs. (Welsh Government (2018) Learning Disability – Improving Lives Programme).

A review was undertaken by the National Collaborative Commissioning Unit (NCCU Feb 2020) which identified 70 recommendations, 68 of which are for providers and commissioners of care. Welsh Government will be working with stakeholders to support action planning at a national level and where it makes sense to take an all-Wales approach to resolving some of the issues identified in the report.

Welsh Government Learning Disability Action Plan 2021-2026

Although the Learning Disability Improving Lives programme ended in March 2021, at the time of writing a new Welsh Government Learning Disability Action Plan 2021–2026 is out for consultation. It identifies key areas, actions and outcomes that will be pursued over the years ahead. It aligns fully with the Welsh Government Programme for Government commitments, incorporating Improving Lives legacy actions.

The key areas covered within the plan are:

-  Overarching/cross-cutting; including cross-government activity that may not sit in one specific area
-  COVID-19 recovery
-  Health - including reducing health inequalities and avoidable deaths
-  Social Services and Social Care
-  Facilitating independent living and access to services through increased access to advocacy and self-advocacy skills, engagement and collaboration
-  Education including Children and Young People's services
-  Employment and skills
-  Housing – Appropriate housing, close to home, with access to joined-up services.
-  Transport.

The plan provides a high level, strategic overview of areas of priority activity over the coming years. It will be supported by a more detailed

implementation plan that sets out the specific actions within each area that will help deliver on the main themes contained within the action plan. It is anticipated that both documents will be published in the spring of 2022.

UK Strategies

In July 2021, the UK Government published a national disability strategy⁴² that covers the whole UK and all types of disabilities, but with each legislative body also adding its own statements and expected to implement its own actions.

The vision set out in the strategy is to transform the everyday lives of disabled people, and it is informed by the UK Disability Survey that questioned some 16,000 disabled people in the early part of 2021.

The strategy focuses upon improving the lived experience of disabled people and identifies how many:






- 🌐 wake up in a home that is not adapted to their needs
- 🌐 rely on an unpredictable transport network to get out and about
- 🌐 navigate inaccessible and inflexible workplaces or education settings
- 🌐 face limited choice and additional expense when shopping around for goods and services
- 🌐 use unresponsive and fragmented public services that do not meet their needs
- 🌐 feel excluded from leisure opportunities and socialising
- 🌐 find themselves barred from exercising rights such as voting and serving on a jury.

The strategy sets out practical steps to improve disabled people's everyday lives with immediate commitments to improve every part of a disabled person's day, from the moment someone gets up to the moment they go to bed.

⁴² UK Government, 2021, '*National Disability Strategy*', Accessed 12 November, 2021

There is then the longer-term ambition of putting disabled people at the heart of the design and delivery of services, with ambitious changes to how the government works with and for disabled people into the future.

There is a commitment to work across government departments to embed the following elements, which underpin the government's future approach to disability:

-  Ensure fairness and equality – empowering disabled people by promoting fairness and equality of opportunities, outcomes and experiences, including work and access to products and services.
-  Consider disability from the start – embedding inclusive and accessible approaches and services to avoid creating disabling experiences from the outset.
-  Support independent living – actively encouraging initiatives that support all disabled people to have choice and control in life.
-  Increase participation – enabling greater inclusion of a diverse disabled population in the development and delivery of services, products and policies.
-  Deliver joined up responses – working across organisational boundaries and improve data and evidence to better understand and respond to complex issues that affect disabled people.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The purpose of the convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and was ratified by the UK Government in 2009.

Welsh Government contributes to the UK state report which is reported on every five years, and have made a commitment in the Framework for Action on Independent Living⁴³ to fulfil their obligations under the Convention including meeting the appropriate recommendations from the UN Committee.

⁴³ Action on Disability: The Right to Independent Living Framework and Action Plan (Welsh Government 2019) accessed February 2022

Impact of COVID-19

Recent data show that people with learning disabilities are more likely to contract COVID-19, have a more severe case of COVID-19, and are at least three times more likely than people without learning disabilities to die from COVID-19. Inequalities in health, well-being, social isolation, employment and poverty that existed before COVID-19, along with separation from family and friends and changes to routines, may have been exacerbated during the COVID-19 pandemic.

A recent House of Commons report⁴⁴ stated that the death rate from COVID-19 for people with learning disabilities was up to 6.3 times higher than for the general population. It was also reported (quoting a Public Health England report) that:

“...there were far greater mortality rates in younger adults with learning disabilities, compared to the general population. The death rate for people aged 18 to 34 with learning disabilities was 30 times higher than the rate in the same age group without disabilities. As noted in the report, people with learning disabilities are more likely to have other physical health conditions such as obesity and diabetes, and certain kinds of learning disability, such as Down’s syndrome, can make people more vulnerable to respiratory infections, which can increase their risk of dying from COVID-19.”

House of Commons Report, - Support for People with a Learning Disability, Page 8.

The report also said that The Joint Committee on Vaccination and Immunisation (JCVI) advised that adults with Down’s syndrome are in priority group 4 for vaccination, as they are considered ‘clinically extremely vulnerable’.

⁴⁴ House of Commons Library, 2021, ‘Support for People with a Learning Disability’, Social and Cultural <https://researchbriefings.files.parliament.uk/documents/SN07058/SN07058.pdf> Accessed 12 November 2021








As identified above, the impact of COVID-19 on people with a learning disability for Black, Asian and Ethnic Minority communities has been particularly more significant than on the general population⁴⁵. This was reinforced in terms of people with a learning disability by a British Medical Journal editorial⁴⁶, that called for them to be a priority and protected. An extensive and detailed study of the impact of COVID-19 on people with learning disabilities⁴⁷ concluded that people with learning disability have markedly increased risks of hospital admission and death from Covid-19, over and above the risks observed for non-COVID causes of death.

They also concluded that prompt access to COVID-19 testing and healthcare is warranted for this vulnerable group, and prioritisation for vaccination and other targeted preventive measures should be considered.

The 'Locked Out: liberating disabled people's lives and rights in Wales beyond COVID -19' report concluded that:

*"The coronavirus pandemic has amplified pre-existing socio-economic inequalities in society and their influence on health outcomes."*⁴⁸

The report provided evidence on multiple issues where people with learning disabilities were negatively impacted including:



-  Accessibility of public services
-  Access to justice
-  Safe, accessible and affordable travel
-  Health services in Wales
-  Mental health and wellbeing
-  Economic poverty
-  Accessible housing

⁴⁵ Race Equality Foundation, *ibid*

⁴⁶ BMJ Editorial, 'Covid 19: People with learning disabilities are highly vulnerable', BMJ, 2021, <https://www.bmj.com/content/374/bmj.n1701> Accessed 17 November, 2021.

⁴⁷ BMJ, 'Risks of covid-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform' 2021, <https://www.bmj.com/content/374/bmj.n1592> Accessed 17 November, 2021.

⁴⁸ [Locked out: liberating disabled people's lives and rights in Wales beyond COVID-19 \[HTML\] | GOV.WALES](#) (February 2022)

-  Work and employment
-  Access to public space and public life.

The report also calls on Welsh Government to re-affirm its commitment to the [social model of disability](#).


5. CONCLUSION AND GAPS IDENTIFIED

In the West Glamorgan region, data on future projections for people with a learning disability for the over 18 age group isn't currently available, and generally there is limited data on the population of people with a learning disability. Data is also not currently available to identify people with a learning disability in cohorts of the population belonging to other protected characteristic groups.

From the data that is available, gaps have been identified in how data is recorded and presented. The West Glamorgan Regional Partnership acknowledges the gaps in data as a concern that will be addressed going forward.

As part of the development of the Regional Learning Disability Strategy, the required data to underpin the planning on which services are needed for the region is being collated. This will provide a direction of travel that has been developed by people with a learning disability, their parents/carers and staff working in these services, and will begin the process for a programme of change across the partnership, as well as management of dependencies across other programmes to embed the importance of our vision for learning disabilities in all of our transformation activities.

This chapter has highlighted issues faced by people with a learning disability that, if through the engagement events comes through the regional population, our commitment for future working must include:

-  A strategic approach to support people with learning disabilities driven by the needs of the population, including a person-centred approach to working with people;

- 🌸 Embedding the right principles across our organisations and services including how we address common issues like language, stigma and discrimination;
- 🌸 More engagement with and representation of service users, carers and other key stakeholders including co-production activities;
- 🌸 Better quality data including real life experiences and case studies from across our population groups;
- 🌸 Better use of resources, assets and skilled workers to deliver better outcomes more efficiently;
- 🌸 Transforming how services are delivered through trialling new models of care and integration of service provision

The data development agenda is a key consideration in addressing the points above. There is a need to:

- 🌸 ensure there is common understanding and consistency across the partners in the way the data is recorded and analysed
- 🌸 carry out further analysis to plan for the needs of the region's population.

The modernisation of services is another key area of work which requires a specific focus to effectively address inequalities and inequities, driving forward improved services.

To fully address this for the learning disability population across the region, a Learning Disability Programme has been introduced within the governance of the West Glamorgan Regional Partnership. The first aim of the group is to develop a Regional Learning Disability Strategy that will outline in more detail how the needs of people with learning disabilities will be met over the next five years.




As at spring 2022, planning of the strategy is in progress. The project began in 2021 with the creation of a regional Strategy Development Group. At the time of writing this chapter, a commissioned organisation is in the process of facilitating co-produced engagement events for people with learning disabilities. The aim of these events is to ensure people with lived experience have the opportunity to highlight what changes are needed in line with the current vision statement, to identify

key priorities, and to allow them to have meaningful conversations about what matters to them. Engagement with professionals working with people with learning disabilities is also planned.

The vision for people with a Learning Disability is as follows




“Children, Young People and Adults with a Learning Disability in West Glamorgan have a sense of belonging and can participate fully within inclusive communities; they have access to additional support to imagine and reach their full potential and current barriers and inequalities experienced by people with a learning disability in West Glamorgan are replaced by an active assertion of their Human Rights.”

The Learning Disability Strategy Development Group provides a shared mechanism to develop and oversee strategic planning between statutory partners, members of the community and carers that seeks to achieve the vision. This will be realised by:

-  Co-producing a five year regional, all age, Learning Disability Strategy and associated Action Plan with a particular focus on prevention and early intervention. This will be a living document which will be monitored and reviewed annually by the Learning Disability Strategy Group
-  Bringing coherence to the approach in the Regional Partnership Board, specifically for learning disabilities.
-  Reducing health inequalities for people with learning disabilities.

It will provide a complementary function to the purposes of other programmes within West Glamorgan, including Transforming Complex Care, and Children and Young People.

The overarching objectives of the programme are:

-  To provide the right support at the right time to people with learning disabilities
-  To understand the demand for services and the capacity across the region to be able to meet demand
-  To develop ways of working to engage with wider partners and stakeholders to improve the lives of the people of West Glamorgan

- 🌸 To map and align regional programmes, work streams and services delivering improvements for people with learning disabilities
- 🌸 Enhance focused outcomes and experiences for people with a learning disability.

Initial draft priorities that have been agreed by the board include:

- 🌸 Reducing health inequalities
- 🌸 Response to recovery of COVID-19
- 🌸 Visibility in society/being an equal part of the community
- 🌸 Securing rights and entitlements
- 🌸 Physical and mental health and emotional well-being
- 🌸 Protection from abuse and neglect
- 🌸 Education, training and recreation
- 🌸 Domestic, family and personal relationships
- 🌸 Contribution made to society
- 🌸 Social and economic well-being (including participation in work)
- 🌸 Suitability of living accommodation.

These priorities will be further developed through the engagement events being held in the spring of 2022. Initial work has however started with the following projects:

Project Name	Summary
Accommodation solutions	Development of a range of accommodation options in the region for young people with complex needs going through transition; younger adults with complex needs
Whole systems approach	Development of a whole systems approach of learning disability processes across the region
Learning Disability Liaison Forum	Enabling coproduction to be embedded as per the Regional Coproduction Framework and supporting involvement in co-designing services that meet their needs
Further education, work, volunteering and day opportunities	Increasing the opportunities for people with a learning disability to be involved in their local community

Reducing health inequalities	Increasing the general health and wellbeing of people with a learning disability across the region
Recovery from COVID-19 for people with a learning disability	Supporting the population with practical pieces of work which will be further developed after discussions on what type of support would be helpful and required.

Future work will inform the direction of the group and will develop the recommendations for the chapter. The content will be refreshed, and outcomes of the engagement undertaken will be incorporated into the new regional strategy going forward.