

**LEARNING DISABILITIES
AND AUTISM**



WHAT DO WE MEAN BY LEARNING DISABILITY

“ A learning disability describes people who take longer to learn and who may need support to develop new skills, understand complicated information and interact with other people ”

As well as having a learning disability, a lot of people have other physical or emotional conditions and may receive more than one diagnosis. This could have an impact on the kind of support they and their family need in their day-to-day life. Conditions closely associated with learning disability include:

- Down's Syndrome – a genetic, lifelong condition, Down's Syndrome is the most common form of learning disability. Down's Syndrome is not inherited but happens by chance. It is estimated that 45% of people with Down's Syndrome will develop dementia.
- Autism and Asperger's Syndrome – autism is not a learning disability but approximately half of people with autism have some form of learning disability. Asperger's Syndrome is a form of autism which causes communication and emotional problems.
- Global Development Delay – this term is used when a child takes longer to reach specific developmental milestones such as learning to walk, talk or interact socially than other children their age. For some the delay can be short term and with additional support can be overcome. However, in some cases the delay may be significant and the child will need continuing support which indicates they may have a learning disability.
- Challenging Behaviour – this can include outbursts, hitting or kicking other people or people hurting themselves. Behaviour is considered challenging if it is damaging to the person and others around them. Manchester's Hester Adrian Research Centre reports that approximately 1 in 7 people with a learning disability will have challenging behaviour. With as many as 1 in 18 will have 'more demanding' challenging behaviour.





WHO IS AFFECTED AND HOW ?

▼ IN WALES:

It is sometimes difficult to identify learning disability at birth and it may not be until the age of 4 or 5 that a diagnosis can be made. However:

- Based on the Welsh Government Daffodil Data Projection model it is estimated that in the general population of Wales, 21 people in every 1,000 have a learning disability.
 - ▶ Congenital hearing loss is present at birth.
 - ▶ Acquired hearing loss happens later in life, either during childhood, the teenage years, or in adulthood, it can be sudden or happen slowly over time.
- In Wales 2.8 per 1,000 people aged 65+ are projected to have a moderate/severe learning disability, compared to 5.5 per 1,000 for those aged 18 – 64. In other words, the proportion of the population with a moderate or severe learning disability aged 65+ is roughly half that of adults under the age of 65.
- In Wales in 2014-2015 known learning disability service users represented approximately 82% of the projected number with a moderate/severe learning disability.



▼ IN WESTERN BAY:

In Western Bay it is estimated that a total of 14,264 people have a learning disability (Daffodil, 2015).

— **BRIDGEND: 3,860 PEOPLE**
(1,210 aged 0-17 and 2, 650 aged 18+)



NEATH PORT TALBOT: 3,805 PEOPLE
(1,172 aged 0-17 and 2, 633 aged 18+)



SWANSEA: 6,599 PEOPLE
 (1,946 aged 0-17 and 4, 653 aged 18+)



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- Many children, young people and adults with a mild/moderate learning disability are able to cope with everyday life without support.
 - There is some evidence to show that there is a higher rate of severe learning disabilities in the British Asian population (Emerson et al, 1990).
 - Studies show that people with a learning disability suffer with poorer health than the general population. Research by the Institute for Health research at Lancaster University shows people with a learning disability have an increased risk of early death. Studies have shown that the risk of dying before 50 is 58 times greater than in the general population.
 - Respiratory diseases are the leading cause of death for those with learning disabilities, followed by coronary heart disease.
 - People with a learning disability are also more likely to develop other conditions such as early onset dementia, epilepsy and mental health problems.
 - Obesity is more common for those with a learning disability than in the general population.
 - People with a learning disability are vulnerable to social exclusion and discrimination.





WHO IS RECEIVING HELP AND WHAT SUPPORT IS AVAILABLE ?

▼ EDUCATION:

	Speech, Language and Communication Difficulty	Autistic Spectrum Disorder	Moderate Learning Difficulty	Physical Medical Difficulty	Behaviour Social and Emotional Difficulty
Bridgend	17	119	27	14	43
Neath Port Talbot	89	158	236	22	51
Swansea	400	282	278	133	95
	Severe Learning Difficulty	Profound and Multiple Learning Difficulty	Hearing Impairment	General Learning Difficulty	Visual Impairment
Bridgend	69	45	4	10	2
Neath Port Talbot	70	23	16	2	10
Swansea	74	48	37	31	28
	Attention Deficit Hyperactivity Disorder	Dyspraxia	Dyslexia	Multi-sensory Impairment	Dyscalculia
Bridgend	9	1	3	0	0
Neath Port Talbot	0	1	21	0	0
Swansea	17	6	5	4	0



▼ **ADDITIONAL LEARNING NEEDS TRANSFORMATION PROGRAMME:**

The Welsh Government has developed an Additional Learning Needs Transformation Programme which is intended to transform the separate systems for special educational needs (SEN) in schools and learning difficulties and/or disabilities (LDD) in further education, to create a unified system for supporting learners aged from 0 to 25 with Additional Learning Needs.

In December 2016 new legislation: the Additional Learning Needs and Tribunal (Wales) Bill and statutory guidance was introduced to support the Transformation Programme.



▼ **TOTAL NUMBER OF LEARNING DISABILITY CLIENTS (AGED 18+) RECEIVING SERVICES DURING THE YEAR**

	2012 - 2013	2013 - 2014	2014 - 2015
Bridgend	444	445	410
Neath Port Talbot	598	614	652
Swansea	743	768	766

Social Services support just over half of the adult learning disability population to live at home with family carers. However, there is a gap in our understanding of the support needs of these family carers.

It is known anecdotally that there are increasing numbers of older people who continue to care for their adult child(ren) with a learning disability. We lack good quality data on this subject and it is an identified data gap. It would be valuable information in terms of planning services for ageing learning disability clients living at home whose parents become unable to care for them.



▼ **NUMBER OF COMMUNITY PLACEMENTS IN THEIR OWN HOME FOR PERSONS (AGED 16+) WITH A LEARNING DISABILITY**

	2012 - 2013	2013 - 2014	2014 - 2015
Bridgend	44	39	48
Neath Port Talbot	96	17	8
Swansea	136	121	111

The rate of community placements in their own homes for persons with a learning disability aged 16 and over is significantly lower in Neath Port Talbot than in the other areas of Western Bay. Residential care is still often seen as the first option rather than exploring other options to ensure people are able to stay in their own homes.

▼ **NUMBER OF LEARNING DISABILITY CLIENTS (AGED 18+) SUPPORTED IN THE COMMUNITY DURING THE YEAR**

	2012 - 2013	2013 - 2014	2014 - 2015
Bridgend	380	388	354
Neath Port Talbot	446	458	490
Swansea	672	686	726

Since the late 1980s it has been public policy to ensure people with a learning disability are supported in the community settings rather than in institutional forms of care such as special hospitals, residential and nursing care.



▼ **NUMBER OF LEARNING DISABILITY CLIENTS (AGED 18+) SUPPORTED IN THE COMMUNITY DURING THE YEAR**

	2012 - 2013	2013 - 2014	2014 - 2015
Bridgend	116	104	86
Neath Port Talbot	98	88	90
Swansea	129	118	147

Respite can be a key provision to support people with a learning disability who continue to live at home with relatives or others. Effective respite can prevent escalation in need for a person with a learning disability to be looked after in a more formal setting such as supported living or residential / nursing care.

Generally across Western Bay by 2014-2015, local authorities are providing slightly more respite care compared to the Wales average.



▼ LIVING ARRANGEMENTS FOR ADULTS WITH A LEARNING DISABILITY

2006 - 2007		2014 - 2015		2006 - 2007		2014 - 2015		2006 - 2007		2014 - 2015													
Bridgend				Neath Port Talbot				Swansea															
31				-				-				8				-							
-				2				5				2				14				3			
7				12				68				76				94				94			
115				148				77				96				182				317			

Number of LD clients aged 18+ in local authority residential care at 31 March (PM2)

Number of LD clients aged 18+ in independent sector nursing care at 31 March (PM2)

Number of LD clients aged 18+ in independent sector residential care at 31 March (PM2)

Number of LD clients aged 18+ in Support accommodation at 31 March (PM2)



▼ FLOATING SUPPORT AND SUPPORT IN FIXED SUPPORTED ACCOMMODATION 2015-2016

	Bridgend	Neath Port Talbot	Swansea
Received a floating support service	Unable to provide	238	-
Received support in fixed supported accommodation	154	85	-
How many male, how many female	Male - 82 Female - 72	Male - 166 Female - 157	-
How many identified learning disability as a lead need	154	122 are receiving a service 'specifically' catering for Learning Disabilities as a lead need	-
How many identified learning disability as a secondary need	Not recorded	Not recorded	-
How many identifies learning disability as a tertiary need	Not recorded	Not recorded	-

An additional 201 Service Users are receiving a Pan-Disability Service, whereby Learning Disability, Mental Health and/or Physical or Sensory Disabilities are supported in equal parts.



Services over the past 20 years have been increasing aimed at supporting the needs of older people with a learning disability as the population has aged. This has seen the development of specialist day services for older people and the development of Shared Lives to offer people a more homely environment as an alternative to residential types of support.

▼ FLOATING SUPPORT AND SUPPORT IN FIXED SUPPORTED ACCOMMODATION 2015-2016

	2006 2007	2007 2008	2008 2009	2009 2010	2010 2011	2011 2012	2012 2013	2013 2014	2014 2015
Bridgend	38	39	38	31	39	45	52	53	40
Neath Port Talbot	26	36	33	42	45	54	58	68	75
Swansea	85	69	62	67	76	81	84	91	86

▼ FLOATING SUPPORT AND SUPPORT IN FIXED SUPPORTED ACCOMMODATION 2015-2016

- Current annual statutory returns for older people allow local authorities to report on the use of 'community support day care' in addition to traditional centre-based day care. Community support day care is envisioned as being day care that promotes greater levels of independence by enhancing the skills of people with a learning disability, such as workplace skills, travel training.
- Across Western Bay, there may be differing approaches to how the forms of day care are recorded and reported. While Neath Port Talbot reports no community support day care, Bridgend has grown this provision while Swansea has reduced it. Conversely, NPT and Bridgend have reduced traditional day care while Swansea has increased it.
- The net change 2006-2015 across Western Bay is to report slightly fewer total adults with a learning disability receiving day care of any kind. It is possible that the day care element of supported living may not be recorded and reported, therefore the number of people receiving day care may be under-reported.



▼ ACUTE ASSESSMENT AND SPECIAL RESIDENTIAL SERVICES - ABMU AREA

Learning Disabilities Acute Assessment and Treatment Unit		
Llwyneryr Acute Assessment and Treatment Unit	<p>Ilwyneryr AATU Clasemont Rd, Morriston Swansea SA6 6AH TEL: 01792 784 012</p>	<p>8 unscheduled care beds for people with learning disabilities and mental health or behavioural problems. To deliver care which cannot reasonably be foreseen or planned in advance or must be delivered overnight or during the weekend.</p>
Learning Disabilities Acute Assessment and Treatment Unit		
Swn-Y-Afon	<p>Brynteg Nant-Y-Cafn Seven Sisters SA10 9ET TEL: 01639 702 906</p>	<p>5 bed longer stay unit for people with learning disabilities and mental health or behavioural problems.</p>
Dan-Y-Den	<p>151 Clasemont Road Morriston, Swansea SA6 6AH TEL: 01792 784024</p>	<p>5 bed longer stay unit for people with learning disabilities and mental health or behavioural problems.</p>
Dan-Y-Bont	<p>Waterhall Road Kenfig Hill Bridgend CF33 6HA TEL: 01792 784 012</p>	<p>5 bed longer stay beds for people with learning disabilities and mental health or behavioural problems.</p>
<p>2014-2015: There were a total of 69 admissions into specialist residential services, 18 (26%) were from the Western Bay area. During, 2015-2016: There were a total of 54 admissions, 12 (22%) were from the Western Bay area</p>		





THINGS PEOPLE TOLD US THAT MATTER TO THEM

— INFORMATION:

- Have more accessible and easy to read information about social activities, health, community and housing
 - Share information better between professionals to keep everyone informed and to avoid confusion
 - Improve access to technology and provide training to use it
 - Provide an information directory which identifies the services available
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— LOCAL COMMUNITY:

- Make local facilities more suitable for supporting disabled people
- Educate people who work in services such as leisure activities and public transport to have a better understanding of the challenges faced by people with learning disabilities



— INDEPENDENCE:

- Support of friends and family and especially provide opportunities for them to 'take a break'
 - Develop community activities to support people with a learning disability
 - Provide opportunities for volunteering or paid work to make a contribution to society
 - Help people to feel safe in communities to support independence
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— TRANSITION:

- Improve arrangements for young people to better support them into adulthood





WHAT CHANGES DO WE HAVE TO PLAN FOR?

POPULATION CHANGES AND PREDICTED CHANGES IN PREVALENCE

PREDICTED CHILDREN AND YOUNG PEOPLE WITH A LEARNING DISABILITY

2015		2035		2015		2035		2015		2035	
Bridgend				Neath Port Talbot				Swansea			
1,042		1,007		1,009		950		1,676		1,735	
135		130		131		123		217		224	
33		32		32		30		53		55	

	Predicted number of people aged 0-17 with a moderate learning difficulty		Predicted number of people aged 0-17 with a severe learning difficulty (Daffodil)		Predicted number of people aged 0-17 with a profound learning difficulty (Daffodil)
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▼ PREDICTED CHILDREN AND YOUNG PEOPLE WITH A LEARNING DISABILITY

	2015	2020	2025	2030	2035
Bridgend	2,650	2,708	2,750	2,796	2,855
Neath Port Talbot	2,633	2,645	2,650	2,667	2,696
Swansea	4,653	4,796	4,918	5,057	5,208

Improved neonatal care means that more premature babies are surviving. These children have a very high likelihood of severe and multiple disabilities, with 97% of those with a disability having a neurological or intellectual disability.

-  Inequities in quality of life and mortality - There has been historical evidence that the medical care of the physical ailments of those with a learning disability (and those with mental health problems) has been less than adequate. This has been addressed by the NHS in more recent years but there continue to be some legacy issues.
-  There is a demand for a 52-week accommodation service for children with disabilities in Western Bay.
-  Transition planning which enables early identification and information sharing regarding young people aged 14+ to jointly plan for their transition from children's to adult's services.
-  Older people with learning disabilities are living for longer, including those with multiple learning disabilities. There is also an ageing population and these factors combined mean that there is a growing and ageing population.



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- Predictions show us that we will see a small increase in the number of older people with a moderate or severe learning disability . This is important because services will need to give consideration to the age related needs of service users such as dementia and physical frailty.
 - The use of Direct Payments – Although the use of direct payments has increased across Western Bay in Learning Disability clients aged 18+, there are very few recorded cases of those aged 65+ using direct payments in this way.
 - Sustainable models of supported living to enable us to continue our approach of supporting people in tenancy based options. This will mean a shift away from the 24/7 model towards a more mixed arrangement. Right sizing will also support us to shift resources in this model.
 - Assistive technology – to explore potential in supported living settings to relieve resources spent on night time support
 - Re-modelling day services to support more people in the community and to support more people into work through the development of social enterprises to lessen reliance on traditional forms of day care
 - Respite – consideration needs to be given to the distribution of resources to better meet need across the region.





AUTISM

— WHAT DO YOU MEAN BY AUTISM

“ Autism is a lifelong condition. Someone may have mild, moderate or severe autism, so it is sometimes referred to as a spectrum or autism spectrum disorder (ASD) ”

Autism is not a learning disability but around half of those with autism may also have a learning disability.

▼ There are three common features of autism, which might affect the way a person:

- interacts with others in a social situation.
|
- is able to communicate with others, thinks about and deals with social situations.
|
- “Asperger’s syndrome is a form of autism which also causes communication and emotional problems. However, people with Asperger’s syndrome often have fewer problems with speaking and are less likely to have a learning disability”.

SOURCE

(Mencap: <https://www.mencap.org.uk/learning-disability/explained/conditions/autism-and-aspergers-syndrome>)



— WHO IS AFFECTED AND HOW ?

Around 700,000* people in the UK are on the autistic spectrum. Together with their families they make up around 2.8 million people whose lives are affected by autism every single day.

▼ IN WESTERN BAY

Projected Number of people aged 0-17 with any autistic spectrum disorder			
% Change in values between initial and comparison year			
Local Authority	2015	2035	Absolute Differnece
Bridgend	338	326	- 12
Neath Port Talbot	327	308	- 19
Swansea	544	563	+ 19
Wales	7,326	7,299	- 27
Western Bay	1,209	1,197	- 12



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- Not all people with a diagnosis on the autistic spectrum will need specialist support to maintain their independence.
 - The increased recognition of Autistic Spectrum Disorder and the improving diagnostic framework means that the number of people diagnosed with ASD is increasing.
 - Families with children and young people with ASD often face particular challenges as their child matures. It will be critical that there are a range of early help and intervention services as well as specialist services for those children with more complex needs to support families from the point of diagnosis through to transition to adulthood.
 - Families with children and young people with ASD are under considerable stress. Dealing with issues of their child's personal hygiene, children eating a limited diet, requiring constant care and attention and spending many hours awake at night makes it difficult for parents/carers to stay in employment. In these instances parental relationship breakdown is extremely high (85%).
 - Managing multiple appointments, education related issues and school holidays are very challenging for parents/carers who often feel guilty about their unavailability to their other children. Parents can limit young people by not allowing them to be socially active and self-reliant and need to be supported to enable their children to develop their independence (Bridgend ASD Mapping exercise – link required).
 - A 2016 Survey of over 2,000 people conducted by the National Autistic Society indicated that just 16% of adults with autism are in full-time paid work.
 - There is no record of the number of people with autism receiving support in Western Bay.



Autism is not a learning disability but around half of those with autism may also have a learning disability.

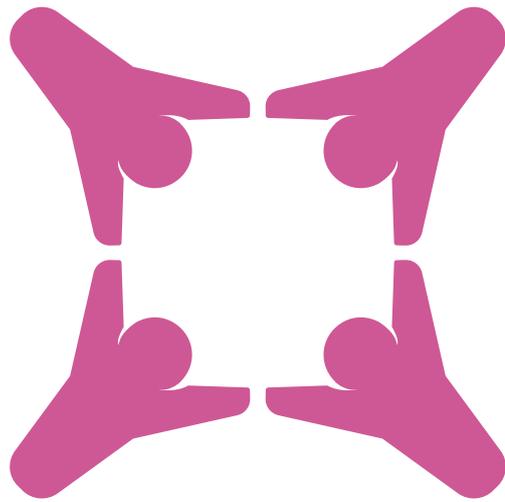
- There are eight residential services in South Wales for people affected by autism. Two in Caerleon and six in the Neath area. The residential services provide people with autism with an environment in which they can learn new skills, become more confident and increase their independence to become full and active members of the local community.
- In addition to this there are six 'daytime hubs' in South Wales where adults with autism can go for support, to socialise and to learn new skills. Two of these hubs are within Western Bay. Glamorgan House in Neath, and Mill court in Swansea.
- The National Autistic Society Cymru also provides short breaks and respite, a University Outreach Service to support students with Asperger's Syndrome, one-to-one outreach support service for children and adults and community based projects.



— WHAT CHANGES DO WE HAVE TO PLAN FOR?

- Whilst the data suggests that the increase in numbers will be small, the levels of need and the services required to meet those needs will have a noticeable impact on the budget.
- Progress the development and implementation of multi-disciplinary assessments to ensure models of care and support are person-centred and holistically respond to an individual's health, social care and support needs.
- Effective, timely and outcome based transition arrangements, particularly between children and young people's services and adult's services but also from working aged to older people's services
- Right sizing of packages of care – refocus practice to focus on developing models of support that encourage independence, embracing prevention, early intervention and less restrictive options.
- Replacement of risk-averse practice with proportionate risk management that will improve outcomes and reduce costs.
- Adoption of a 'progression' model that supports people to maximise their independence.
- Develop the market to develop the whole care pathway, provide alternatives to residential care and to increase choice with health and housing partners.
- Develop personalised services, social co-operatives and skills based opportunities facilitated by increased use of direct payments.
- More effective management of transition between children's and adult's services
- Further development of telecare and tele health to promote and maintain people independence.
- Remodelling of services to move away from traditional establishment based services to promote a, focusing upon reducing dependency and need and using natural support within the community.





WESTERN BAY

POPULATION ASSESSMENT REPORT

www.westernbay.org.uk