

## 5 Learning disabilities

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## 5.1 About this chapter

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

- Children and young people
- Carers
- Autism

### What is meant by the term *learning disability*?

- 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 adult-hood and has a lasting effect on development (Department of Health, 2001).
- b) The term *learning difficulty* is used in education as a broader term which includes people with specific learning difficulties such as dyslexia (Emerson and Heslop, 2010).

### What is meant by the term *autism*?

The term *autism* is used to describe a lifelong developmental condition that affects how a person communicates with, and relates to, other people. Autism also affects how a person makes sense of the world around them. It is a spectrum condition which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. About 50% of people with autism also have a learning disability.

### Policy and legislation

Local councils arrange and provide support for adults with learning disabilities based on the Social Services and Well-being (Wales) Act 2014 - see [appendix 5a](#) for more detail on the new act. Some social services are delivered in partnership with other services including housing, health and education.

Historically, local councils across Wales provided or arranged care and support in line with a range of statutory duties and guidance specifically related to adults with learning disabilities. This has shaped the way in which these services have developed in Wales – see [appendix 5b](#) for more detail.

## 5.2 What we know about the population

In 2014-15 the total number of people with a learning disability known to social services in North Wales was 2,700 as shown in Table 5.1 below. This figure is based on the learning disability registers maintained by local councils, which only include those known to services and who wish to be registered. The actual number of people with a learning disability may be higher.

**Table 5.1** The number of adults on the learning disability register in North Wales

	2012-13	2013-14	2014-15
Anglesey	290	293	303
Gwynedd	535	578	576
Conwy	450	455	463
Denbighshire	389	413	409
Flintshire	463	447	480
Wrexham	500	490	470
North Wales	2627	2676	2701

Source: Local council data

In 2015, around 1,900 adults aged 18-64 were receiving learning disability services arranged by local councils in North Wales (Welsh Government, 2015). The total number of people with a learning disability is estimated to be 2% of the population, which is an estimated 6,100 people aged 18-64 living in communities across North Wales (Institute of Public Care, 2015). Many of these people will have support from family and friends and not receive support from social services.

There has been an overall increase in the number of people receiving services across North Wales in the past five years as shown in Table 5.2. There is some variation in the data year to year due to the small number of individuals, differences in eligibility criteria and changes to the way the numbers are counted and cases closed. A priority for future work is to make sure there is common understanding and consistency across the six North Wales counties in the way data is recorded and analysed.

**Table 5.2** The number of adults aged 18-64 receiving learning disability services in North Wales between 2010-11 and 2014-15.

	2010-11	2011-12	2012-13	2013-14	2014-15
Anglesey	200	150	170	180	180
Gwynedd	230	240	270	200	330
Conwy	340	380	410	420	400
Denbighshire	240	260	280	290	300
Flintshire	430	380	410	410	440
Wrexham	290	280	280	290	280
North Wales	1,700	1,700	1,800	1,800	1,900

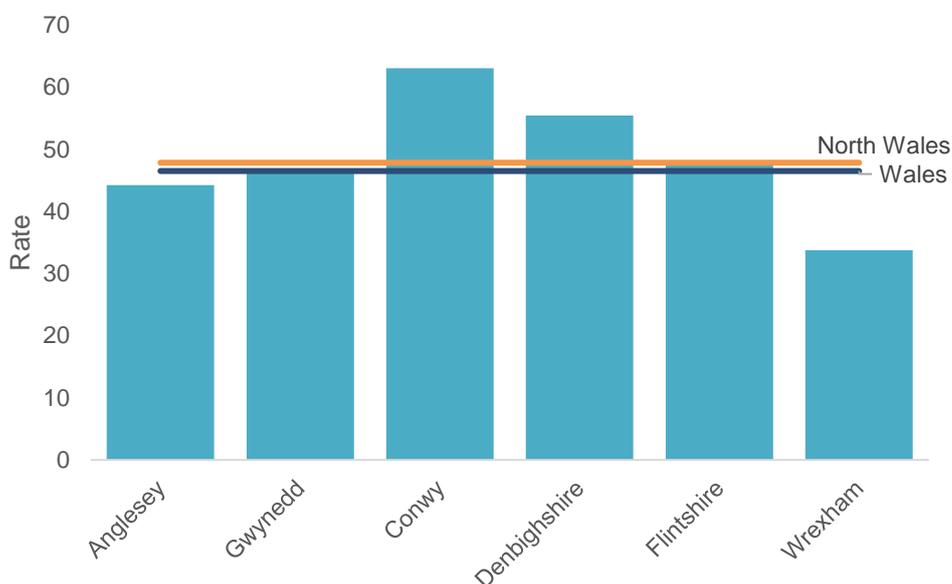
*Numbers have been rounded so may not sum*

Source: Adults receiving services at the 31st March and range of services during the year, Welsh Government

Figure 5.1 shows the differences in rate of adults with learning disabilities who receive services in North Wales. Possible explanations for the differences between counties include differences in eligibility criteria for services or recording methods, for example, some councils include people who attend a social group as receiving a service while others would not unless it was part of a bigger care package. Other reasons may be that there are more people with learning disabilities living in those areas. A small number of these may be people resettled in the area following closures of hospital or care home places or because of specific provision is available such as specialist schools.

The total number of people aged 16-64 in North Wales with a learning disability per 100,000 people is 480. This is similar to the figure for Wales as a whole which is 460 people for each 100,000 people (Welsh Government, 2015).

**Figure 5.1** The rate of adults with learning disabilities aged 18-64 receiving services per 10,000 population



Source: Adults receiving services by local council, client category and age group, Welsh Government

## Future trends

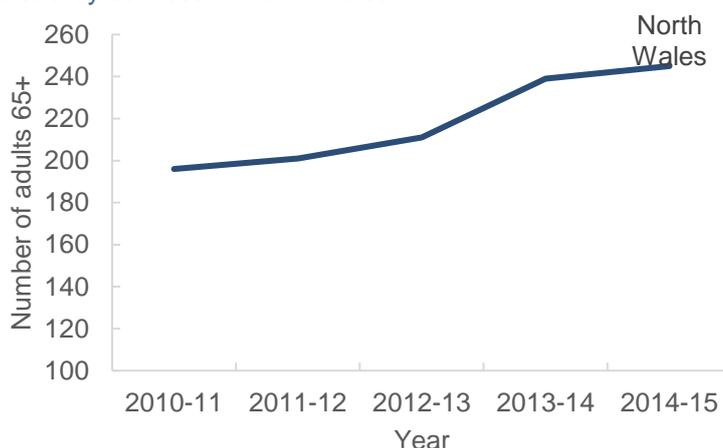
Current projections estimate that the total number of people with a learning disability needing support will increase 2% each year until 2020 and will then stabilise (Local Government Association, 2007)<sup>1</sup>. The Social Services and Well-being (Wales) Act 2014 includes a requirement for local councils to replace existing eligibility criteria for services with a new proportionate assessment focussing on the individual and 'what matters' to them. This may increase the demand upon services. At this stage it is too early to accurately predict the number of individuals with care and support needs who will be eligible for statutory support in the future.

## Older people with learning disabilities

In 2015, there were 250 people aged 65 and over in North Wales who received a learning disability service (Institute of Public Care, 2015; Welsh Government, 2015).

Current trends in North Wales show an increase in the number of people aged 65 and over receiving learning disability services as shown in Figure 5.2. Table 5.3 below shows there is more variation year to year within each county. For example, there has been a small decrease in Conwy over the past five years however, because the numbers involved are so small it is not possible to draw conclusions from this about future trends.

**Figure 5.2** There are an increasing number of people aged 65 and over who receive learning disability services in North Wales



Source: Adults receiving services at the 31st March and range of services during the year, Welsh Government

<sup>1</sup> Another approach estimates that the increase could be between 1% and 8% each year to 2026 depending on whether services are provided to just those with critical or substantial needs or are available more widely Emerson, E. and Hatton, C. CeDR Research report 2008:6 (2008) 'Estimating future need for adult social care services for people with learning disabilities in England'. Lancaster: Centre for Disability Research. Available at: [http://eprints.lancs.ac.uk/21049/1/CeDR\\_2008-6\\_Estimating\\_Future\\_Needs\\_for\\_Adult\\_Social\\_Care\\_Services\\_for\\_People\\_with\\_Learning\\_Disabilities\\_in\\_England.pdf](http://eprints.lancs.ac.uk/21049/1/CeDR_2008-6_Estimating_Future_Needs_for_Adult_Social_Care_Services_for_People_with_Learning_Disabilities_in_England.pdf). This could mean an additional 470 to 2,600 people needing services in North Wales by 2026.

**Table 5.3** The number of adults aged 65+ receiving learning disability services in North Wales between 2010-11 and 2014-15.

	2010-11	2011-12	2012-13	2013-14	2014-15
Anglesey	7	9	13	24	27
Gwynedd	35	34	38	39	49
Conwy CB	53	59	57	56	46
Denbighshire	38	45	46	46	50
Flintshire	33	26	32	46	39
Wrexham	30	28	25	28	34
North Wales	196	201	211	239	245

Source: Adults receiving services at the 31st March and range of services during the year, Welsh Government

People with a learning disability are living longer. This is something to celebrate as a success of improvements in health and social care. For example, the change life expectancy for people with Down’s Syndrome has been dramatic since the 1930s rising from age 10 to around age 50 over the course of 70 years (A.J. Holland, 2000). Evidence suggests that older people are one of the fastest growing groups of the learning disabled population (Emerson and Hatton, 2011).

Older people with learning disabilities have increasingly complex needs and behaviours as they get older which present significant challenges to care services, and staff who work within them, to provide the right type of support. This includes better joint working around payments and resolving disputes quicker (CSSIW, 2016). Creative and innovative design and delivery of services is needed to ensure older people with a learning disability achieve well-being.

There are also increasing numbers of older carers (including parents and family) providing care and support for people with learning disabilities. In future there may be an increase in requests for support from older carers unable to continue in their caring role. The increase in need arising from demographic changes may be more evident in rural areas for example as shown in the pattern of emergency/crisis interventions in Denbighshire. The Social Services and Well-being (Wales) Act 2014 requires local councils to offer carers an assessment for support to those who they care for. It is important to consider the outcomes to be achieved for carers alongside the cared for person and to support carers to plan for the future. See carer’s chapter for more information.

People with learning disabilities are more at risk of developing dementia as they get older (Ward, 2012). The prevalence of dementia among people with a learning disability is estimated at 13% of people over 50 years old and 22% of those over 65 compared with 6% in the general older adult population (Kerr, 2007). The Learning Disability Health Liaison Service in North Wales report that people with learning disabilities are four times more likely to have early onset dementia. People with Down’s Syndrome are particularly at risk and can

develop dementia 30-40 years earlier than the general population with rates of 40% at around age 50 (Holland and others, 1998).

The growing number of people living with a learning disability and dementia presents significant challenges to care services and the staff who work in them, to provide the right type of support.

### **Health needs of people with learning disabilities**

People with learning disabilities tend to experience worse health, have greater need of health care and are more at risk of dying early compared to the general population (Mencap, 2012). For example:

- A person with a learning disability is between 50 and 58 times more likely to die before the age of 50 and four times more likely to die from causes that could have been prevented compared to people in the general population.
- People with learning disabilities tend to be less physically active and are more likely to be overweight and obese than the general population (Liverpool Public Health Observatory, 2013).
- Between 40-60% of people with a learning disability experience poor mental health without a diagnosis.
- People with learning disabilities have increased rates of gastrointestinal and cervical cancers.
- Around 80% of people with Down's syndrome have poor oral health.
- Around a third of people with learning disabilities have epilepsy (at least 20 times higher than the general population) and more have epilepsy that is hard to control.
- People with learning disabilities are less likely to receive palliative care (Michael, 2008).
- People with learning disabilities are more likely to be admitted to hospital as an emergency, compared to those with no learning disability (Liverpool Public Health Observatory, 2013). This may be due to problems in accessing care and lack of advance planning.

People with learning disabilities often have a poorer experience of health services due to communication issues. For example, this may result in diagnostic overshadowing by health professionals attributing symptoms of behaviour to the person's learning disability rather than an illness. This can be a particular issue where needs for support through the Welsh language are not being met (MENCAP, 2007; Welsh Government, 2016). Local councils and health are addressing these issues by developing accessible information for people with learning disabilities to improve communication, including hospital passports and traffic light system.

People with a learning disability often have poorer access to health promotion and early treatment services; for example cancer screening services, diabetes annual reviews, advice on sex and relationships and help with contraception (Liverpool Public Health Observatory, 2013). The Learning Disability Health Liaison Service in Betsi Cadwaladr University Health Board work across North Wales to raise awareness and reduce inequalities. The work includes promoting annual health checks and health action planning to support people to take responsibility for their own health needs and saying how they want these needs to be met.

### **Young people with complex needs**

Medical advances have had a positive impact with more young people with very complex needs surviving into adulthood (Emerson and Hatton, 2008). Services will need to adapt to make sure they can meet the needs of these young people as they make the move into adult services.

Please see children and young people chapter for more information.

### **Other future trends**

There are also changes in expectations of families about the rights of people with learning disabilities to an independent life (Emerson and Hatton, 2008). The new act supports people's independence but puts more emphasis on the role of family, friends and the local community in providing support than on social services. Local councils will need to clearly explain this change or 'there is a risk that the same set of circumstances for a person with a learning disability may be perceived quite differently, with the local authority seeing it as a positive example of co-produced, sustainable social services, and it being experienced as an isolating and confusing predicament by the person themselves' (CSSIW, 2016).

### **Welsh language profile**

There is variation across North Wales in the proportion of people with Welsh as their preferred language. This means that there are varying needs across North Wales for Welsh speaking support staff and to support the language and cultural needs of Welsh speakers with learning disabilities. The need tends to be met better in areas where there are greater numbers of Welsh speakers, such as Gwynedd, than in areas such as Denbighshire and Conwy where recruiting Welsh speaking support staff has proved to be difficult (CSSIW, 2016). Please see the Welsh language profile for more information.

### **Transition between children and adult services**

On the whole, support for young people with learning disabilities into adulthood is working well (CSSIW, 2016). One organisation raised an issue that not every local council provides a transition social worker or a team to coordinate and

manage issues during transition stages of children with Down's Syndrome (Isle of Anglesey County Council *et al.*, 2016).

Local councils in North Wales are reviewing policies and practice to ensure they comply with their duties to improve outcomes, health and wellbeing set out in the Social Services and Well-being (Wales) Act 2014. Councils are expected to work in partnership with health, third and community sector organisations to develop a range of preventative services to support independence. The emphasis is on providing coordinated person centred support which works with the individual to take control of their own needs, rather than making decisions for them, and developing more support provided by the community, in the community.

## **Differences between communities in North Wales**

The need for formal support from social services may vary as a result of differing experiences and expectations of individuals, families and communities in North Wales. There are differences between communities in the extent to which people have approached social services for support, with some areas reporting a reluctance by some families to accept support until a situation reaches crisis point. Some counties report this being more common in rural areas. For example, Denbighshire case records and housing needs spreadsheet show evidence of families not wanting to discuss future housing needs. This can result in an increased likelihood of emergency placements. Other counties report similar findings.

## **Safeguarding**

The Social Services and Well-being Act (Wales) Act 2014 defines that an adult is at risk if: they are experiencing or at risk of abuse or neglect; they have needs for care and support (whether or not the authority is meeting any of those needs), and as a result of those needs are unable to protect themselves against the abuse or neglect or the risk.

In safeguarding adults at risk, local councils should make sure individuals feel they are an equal partner in their relationship with professionals, and remain open to any individual who wishes to invite someone of their choice to support them to participate fully and express their views, wishes and feelings. With this new legislation in place, local councils and partners are provided with an opportunity to review our approach across the region, bring our learning into practice, and to focus on ensuring the adult at risk is always at the centre of our work to support them.

In the year 2015/16, there were 4,000 referrals for adults at risk in Wales. Of these, 15% of referrals were for adults with learning disabilities aged 18-65 and 1% of referrals were for adults with learning disabilities aged 65 and over.

There can be confusion between safeguarding issues and the poor practice of staff that needs to be addressed by care providers. Referrals which do not meet the safeguarding threshold must be screened by the adults at risk teams who make enquiries and determine the next steps. Training for providers is identified as an area for improvement.

Adults with a learning disability are vulnerable to maltreatment and exploitation, which can occur in both community and residential settings (NICE, 2015). In 2014/15 there were 2,500 recorded incidents of disability hate crime which was an increase of 22% on the previous year, although some of this may be due to improvements in police recording rather than an increase in offences (Home Office, 2015). Data from the Crime Survey for England and Wales (CSEW) estimates that there are 70,000 disability motivated hate crimes on average each year (Home Office, 2015). There needs to be increased awareness of disability hate crime and procedures with development of better relationships and understanding across the region. We need to work together to develop a culture where people challenge discrimination and hate crime and where people with learning disabilities feel able to speak up.

An emerging issue identified by staff is an increasing need to provide more support for people with using the internet (including social media and internet dating) due to safeguarding concerns. An additional concern is that decisions to safeguard adults with learning disabilities may make them less safe if they are taken to protect decision makers and stop them having access to things that improve their wellbeing, such as technology (Community Care, 2015).

There are also concerns about domestic abuse and meeting the needs of people from different cultural and religious backgrounds. There is more information in chapter 8 violence against women, domestic abuse and sexual violence.

These issues are discussed in more detail in section 5.3 'What are people telling us'.

Overall, the level of spend on learning disability services has been increasing but we are now faced with supporting more people with less money as a result of reducing local council settlements, Independent Living Fund (ILF) closure & Supporting People funding restrictions.

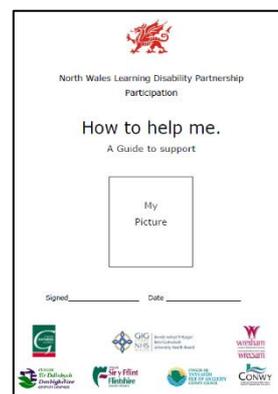
### **5.3 What are people telling us?**

The Regional Learning Disability Partnership focuses on driving forward improved services based on mutual understanding across the six local councils and health. A regional participation strategy and outcome framework has been developed to ensure "the partnership is effective and citizen focused and that it meets the needs of people with learning disabilities and their families" (North Wales Learning Disability Partnership, 2015b).

Learning disability participation is coordinated across the six councils by a Regional Participation Officer. Each county has its own local participation network/forum supported by advocacy. The coordinator supports the local forums to take part, plan events and come together to influence the learning disability services across North Wales. The regional group have chosen to work on the topics below (North Wales Learning Disability Partnership, 2015a)

**1. Leisure.** The event organised highlighted the fact that often people with learning disabilities struggle to attend social events in the evening or have to leave early because of staff handovers or transport issues. Staff attending from the region are working on ideas to enable people to 'stay up late'. This may include local councils re-writing contracts with providers. The participation group chose to promote a 'Friendship group' currently being run in Conwy by a person with learning disabilities to be replicated across the counties

**2. Places people live.** On the whole, people with learning disabilities in North Wales are happy with where they live. The problems they experience tend to be with the way support is provided, particularly when it is inflexible. For example one person said they had to give 24 hours' notice to access money which meant they missed out on buying the dress they wanted at the market. To help with this the group have written a book called 'How to help me' which people with learning disabilities can keep with them, to have their say and to help support staff understand how they would prefer to be supported.



**3. Health.** There are a number of initiatives in North Wales to help improve the health of people with learning disabilities. At their next event, the group will be working on how well people are aware of these and how the take-up can be improved. These include:

- Annual health checks.
- Learning disability nurse based in hospitals who can help people with learning disabilities communication and to complete a traffic light assessment.
- Public health easy read leaflets about health checks.
- Opportunities for physical exercise and healthy eating.

The group are also looking at the quality of mental health services for people with learning disabilities.

Other issues identified by the group include employment and pay for employment; keeping safe when out and about and when using the internet; and hate crime. A group aiming to reduce stigma have produced a poster and

video encouraging people to report incidents of disability hate crime (Conwy Connect, 2014).

Discussion groups held to inform the population assessment highlighted the need for paid work to give a feeling of self-worth and acknowledge people's worthwhile contribution to society. People with learning disabilities also said they would like more opportunities to join in socially with groups from all areas of society, not just those arranged for those with disabilities only. Another theme was the need for good transport to access services (a particular problem in rural areas) and a number of people expressed the desire to learn to drive.

A review of person centred plans in Denbighshire found people with learning disabilities said that the things that work well are their homes (the people they live with and the things they do at home) and leisure (getting out and about and being a part of their community). New things mentioned that work well are having access to technology, such as Wi-Fi and a laptop, and well managed medication. Whereas the things that were not working well were mobility and health (particularly aging, getting around or the increasing effects or chronic health problems) and coping with anxieties and managing behaviours. New things mentioned include problems with the housing environment (often these were little things but they were having a big impact), friendships, relationships and loneliness (people said they wanted more friendships) (Denbighshire County Council, 2016).

### **Feedback from partner organisations**

A questionnaire circulated for the population assessment highlighted that people want to be treated as equal to the rest of the population, they needed help to feel part of the community and to express themselves (Isle of Anglesey County Council *et al.*, 2016). In particular, organisations feel that there is not enough support or opportunities for people with learning difficulties to work and not enough support or opportunities for them to develop new relationships.

They also identified a lack of long term low level support for people who have learning difficulties but do not reach the threshold for a learning disability diagnosis, and who are unlikely to be ever fully able to maintain a housing tenancy independently.

### **Feedback from staff**

Staff consultations were held to inform the population assessment and the issues raised are reflected throughout this chapter. For more information please see appendix 1.

### **National consultation (CSSIW, 2016)**

When asked about their needs most people spoke about their relationship with their care manager and other staff. Concerns were largely about reliability

(turning up on time); dependability (doing what is promised); and availability (having a care manager in the first place).

The findings about providing effective care and support were:

- We need to improve the quality of information about the help that might be available. Concerns about the format of information – for example, too many words, small size of fonts and not enough pictures.
- Concerns about feelings of vulnerability and risk in the community. People said:
  - ‘I get worried in council places – people laugh and I leave’
  - ‘People in the community called me and my family names’
  - ‘Sometimes the kerbs are too high for my wheelchair and the paths not wide enough so I worry I’ll tip into the road or if I go in the road get knocked down’.

They also identified three cross-cutting issues:

1. The quality and reliability of the relationship with staff (including care managers) is crucial to the achievement of positive outcomes for many people with learning disabilities.
2. The ‘helping’ relationship should focus on promoting and supporting the rights of people with learning disabilities including their right to express and exercise choice.
3. The expression of choice should be underpinned by sound risk assessment and risk management so that people feel as safe as possible as they grasp new opportunities.

## 5.4 What support is available at the moment?

People with learning disabilities often need support with many aspects of their lives, including:

- where they live (for example, residential care or supported housing);
- what they do during the day (employment / work experience);
- their social lives;
- having a break (respite).

This support can come from their friends and families or their local community as well as from local councils, health services and/or the third sector.

Local councils across North Wales are continuing to move away from care home provision towards community living and other models of supported housing. The new act has increased the emphasis on support that encourages progression and has a focus on outcomes when procuring support for people.

The National Inspection of Care and Support for people with learning disabilities (CSSIW, 2016) found that:

‘The quality of care and support for many people with learning disabilities in Wales is largely dependent on the effectiveness of the front line social services and health staff who support them. For those who have family carers, it is the tenacity and assertiveness of their relatives that is also often crucial to the outcomes they achieve. Social services and health staff generally work well together at an individual and team level. Much more needs to be done, however, by leaders at all levels to support their staff by working in partnership with people with learning disabilities and family carers to shape care and support for the future.

There are examples where social services and health are thinking and planning together for the longer term and talking and listening to people about their ideas and plans. However, there are too many instances where this is not happening effectively on behalf of people with learning disabilities.’

The report includes 13 recommendations for practitioners, leaders and policy makers. The first three recommendations are around understanding the need, which are being addressed through this population assessment.

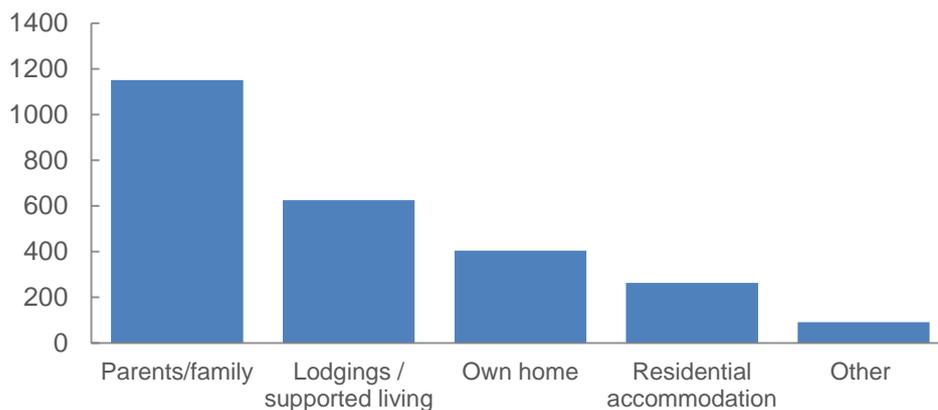
Recommendations four to nine are about providing effective care and support including: reviewing quality assurance arrangements; sharing best practice; clarifying adult safeguarding arrangements; strengthening health liaison work; provision of equipment; and, considering the Continuing Health Care Process to see if improvements can be made.

Recommendations 10 to 13 are about leading in partnership with people.

### **Supported housing: this includes Care Home placements, Community Living and Adult Placements**

As shown in Figure 5.3 the majority of people with learning disabilities in North Wales live with their parents (this pattern is different from the general population). Specialist supported housing is the next most common living arrangement and includes community living and adult placements. The smallest proportion of people with learning disabilities live in residential and institutional care, which reflects the amount of support that goes in to supporting people to stay in their homes. In recent years a number of ‘tailor made’ community living schemes have been developed across the region as a means of helping people to move out of Care Homes.

**Figure 5.3** The majority of people with learning disabilities aged over 16 in North Wales live in community placements with their parents/family (a)



Source: Adults receiving services at the 31st March 2015 and range of services during the year, Welsh Government

(a) The 'Other' category includes health placements and foster placements

There has been a move towards supporting living arrangements from care homes. This can be illustrated by the number of Community Living Schemes that have been developed in each local council area over the past five years.

- Anglesey: Total increase of 7 units: 2 one person units, plus increased multiple person unit from 3 to 4. Adult placements increased by 4.
- Gwynedd: 2 in the last year, including 1 new build project and approximately 1-2 developed each year for the last five years.
- Conwy: 5 new schemes (plus 2 sourced by the families with support provided via Direct payment)
- Denbighshire: 8 new schemes developed
- Flintshire: 5 Community Living Schemes set up in the last 5 years.
- Wrexham: 12 new or remodelled properties developed plus 1 under construction and 1 where land is currently being sourced.

### Future housing needs

Since the 1980s all local councils across North Wales have developed a model of shared supported housing, known as community living. For most people this is seen as more appropriate than long term care home placements, as it means that people are tenants in their own right and have much more control over their daily living patterns. It enables people to live in an ordinary house as a part of their community.

The new act emphasises the need to be part of the community. Although on the whole this model of shared housing has worked well, there is also a need to look at alternative models to community living. In current models people are living together for 10-20 years (longer in some cases), over which time their needs change and it is difficult to find good matches for people over that time scale. New housing models include providing 'own front door' with support.

While a person is living in a supported housing scheme they will receive domiciliary care and/or support in order to promote independence. The care they receive is usually separate from the accommodation. There is a need to work with supported living service providers to develop more outcome based service delivery models, designed to ensure people receive personalised services to meet their assessed needs as identified in their individual support plans.

The aim is to introduce more progressive service delivery models that act as a stepping stone towards greater independence and promote social inclusion and integration into the local community. The support a person receives will change as the person's needs change. It is generally expected that, as people become more connected with their communities and develop their own support networks, their need for formal social care will reduce and support will be adjusted in response to the changing situation.

Ongoing regional work is taking place to review contracting arrangements for domiciliary and supported living framework agreements. The aim is develop a sustainable market in North Wales with a range of providers, delivering care and support to meet the diverse range of needs (including complex needs) across North Wales and continue to reduce the number of out of county placements.

There is also a need to provide or arrange housing support to people who are no longer able to live at home, for example if their family are no longer able to support them. Often individuals and their families find it difficult to think about the future but when a carer passes away, a particularly difficult time will be made more so if there are no plans in place and social services have to find the person a new home in an emergency. Table 5.4 below is an estimate of the number of people with learning disabilities living with older carers in North Wales.

**Table 5.4** The estimated number of people with learning disabilities living with carers aged 60 and over.

	2016 (a)
Anglesey	27
Gwynedd	75
Conwy	50
Denbighshire	50
Flintshire	60
Wrexham	60
North Wales	322

Source: Local council data

Note: Estimated based on date of birth of person with learning disabilities, not the carer.

(a) These figures have been estimated as dates of birth of carers are not recorded as routine.

Housing needs analysis in each county shows some similar needs which include:

- Improved and modernised respite service to provide more opportunities to younger people so that they can have longer breaks which may enable them to remain at home longer. Staying at home is viewed as a positive thing and reflects what is happening within the young population generally. Young learning disabled people are often benefit dependent and being able to afford their own home will increasingly be an issue due to the changes to benefit entitlement and the proposed housing benefit cap. Respite that can equip people with skills training to prepare for a move to a tenancy.
- Respite for people with complex needs and challenging behaviour.
- Long term accommodation for people with complex needs/challenging behaviour which will enable people to return to their home county from out of county placements.
- Accommodation for younger people (transition stage) likely to be bed-sit based and with communal areas, general concierge/warden service with extra support commissioned as required based on assessment. It would meet the needs of: people under 35 where affordability is an issue; care leavers; people with history of minor convictions.
- There is a need to develop alternatives to traditional models of community living, including extra care apartments for people with learning disabilities (own front door, shared support) and a fully accessible intensively supported independent living model of housing.
- Hostel-type accommodation: there are currently limited hostel opportunities that suit people with learning disabilities, this type of accommodation would be short-term.
- Need to plan to meet future accommodation needs of people currently living with older carers.
- There is demand for tenancy based supported housing for individuals of all ages.
- Expand on the Adult Placement / Shared Lives scheme – need to employ more enablers
- Adapted housing for individuals with visual/sensory impairments.

A challenge for all local councils is to find sufficient good quality housing to meet the wide range of needs of people with learning disabilities and enable individuals to have more choice about where they live, who they live with and who supports them. Local councils in North Wales are continuing to explore alternative housing options with key stakeholders, including property developers, registered social landlords, housing departments and housing associations and work together to find innovative housing solutions for people with learning disabilities. This can include better designs and adaptations to existing properties as well as learning from good practice and successful housing projects in other areas, such as ideas for better use of assistive technology to support independence.

Engagement for the population assessment also highlighted an unmet need regionally in relation to high-end jointly funded nursing placements for adults with severe learning disabilities who have health related needs. There are people in Bryn y Neuadd hospital for whom finding placements has proved difficult because there is nowhere they can go that is adequately equipped to meet their needs.

Overall people with learning disabilities told us that housing worked well for them. Please see section 5.3 'what are people telling us' for more information.

## **Day opportunities**

By *day opportunities* we mean formal support for people during the working week which is provided away from their home – this includes work opportunities which tend to have a vocational focus or are based in a business setting. Each county has a mix of direct payments, in-house, independent sector and social enterprises, with a range of services and work based activities in each local council.

A *social enterprise* is a business with profits re-invested back into its services or the community. A *cooperative* is a group acting together voluntarily to meet economic and social need. Local councils have a new duty to promote social enterprises and co-operatives which involve people who needs care and support. Day opportunities are an area we would like to encourage social enterprises and co-operatives to provide.

## **Respite services**

Each county has respite services which give families a break. The arrangements vary from county to county but include respite 'beds' in Care Homes, Adult Placements for respite, short breaks and use of Direct Payments

## **Support services – social and leisure opportunities**

People with learning disabilities often face barriers to accessing socialising or leisure opportunities, for example they may not drive or may need support to use public transport. If local councils did not provide this support then some people would not be able to have a social life. Many of the solutions are low-cost and each county has a different way of funding these services. Some are funded as part of other provision, for example, a provider running disco nights. Others use small grants (either from the council or other funders) or informal arrangements. The provision varies depending on demand and geography. There are opportunities to make sure these services are more user led. For example, the 'Friendship group' currently being run in Conwy by a person with learning disabilities.

## Active support

The social services National Outcomes Framework for people who need care and support and carers who need support is designed to ensure that health and wellbeing is central to the development of service delivery. This includes appropriate support for people who have profound and multiple disabilities. Some individuals may have no speech and sometimes present behaviours that challenge services. Some counties are training internal staff and working with external organisations that practice active support and use functional communication methods.

Active support is an approach for people with very profound needs who are not able to do typical activities independently and has three components:

1. Interacting to Promote Participation. People who support the individual learn how to give him or her the right level of assistance so that he or she can do all the typical daily activities that arise in life.
2. Activity Support Plans. These provide a way to organise household tasks, personal self-care, hobbies, social arrangements and other activities which individuals need or want to do each day, and to work out the availability of support so that activities can be accomplished successfully.
3. Keeping Track. A way of simply recording the opportunities people have each day that enables the quality of what is being arranged to be monitored and improvements to be made on the basis of evidence.

Each component has a system for keeping track of progress, which gives feedback to the staff team and informs regular reviews (Jones *et al.*, 2014).

## Other services and sources of support

### *Grant funding*

The Independent Living Fund (ILF) has been abolished and a reduced amount of funding has been transferred to local councils.

Supporting people funding supports a number of specialised housing projects for people with learning disabilities. This funding has been cut in recent years and cuts are expected to continue putting these projects at risk.

### *Health*

In North Wales we have a liaison nurse service to support communication with people with learning disabilities in hospital.

### *Information*

Dewis Cymru provides information on community based support across the region.

## Advocacy

Please see introduction for more information about advocacy.

## 5.5 Conclusion and recommendations

### Key findings

- **Demography:** The number of people with learning disabilities needing support is increasing and people with learning disabilities are living longer. These demographic trends are likely to continue. The growing number of people living with a learning disability and dementia presents significant challenges to care services, and the staff who work in them, to provide the right type of support.
- **Health needs:** People with learning disabilities tend to experience worse health, have greater need of health care and are more at risk of dying early compared to the general population.
- **Young people with complex needs:** Services will need to adapt to make sure they can meet the needs of young people with complex needs as they make the move to adult services.
- **Attitudes and expectations:** Most individuals and their families want, or expect to have, a greater level of independence and to be a key part of their community. This may include older parents who have never asked for support or carers who find that the support they expected to have is no longer provided or is provided in a different way.
- **Transition between children and adult services:** this works well on the whole and social services will increasingly be focussed on developing an integrated approach which will help with transition.
- **Finance:** The level of spend on learning disability services has been increasing but we are now faced with supporting more people with less money.
- **Legislation:** The Social Services and Well-being (Wales) Act 2014 is changing the way we work, including the way in which we find out what matters to people and the way in which people are supported.
- **Existing provision:** Currently, support is generally provided by immediate family members and/or long term paid care staff.

### Recommendations

1. Support older carers and make sure they have the support and respite services they need. This should include 'planning ahead' services for families which includes work to identify hidden carers and assess their needs for support.

2. Health and social services to work better together make sure there is sufficient support for the health issues of older people with learning disabilities, including people with dementia.
3. Continue to support people with learning disabilities to access health care through the Learning Disability Health Liaison Services, by developing accessible information for people with learning disabilities to improve communication and supporting healthcare providers to better identify people with learning disabilities so they can make 'reasonable adjustments' to their care. Promote access to health promotion and early treatment services.
4. Provide sustainable models of support jointly by health and social care to meet the needs of individuals with complex need. This should include addressing the unmet need for high end jointly funded nursing placements for adults with severe learning disabilities who have health related needs.
5. Support staff to manage changing expectations of support for people with learning disabilities, including changes required by the new act.
6. Recruit more Welsh speaking support staff.
7. Provide more support for people with staying safe when using the internet.
8. Encourage more informal, unpaid support, to reduce reliance on formal paid support. This would help facilitate wider friendships and social lives for people with learning disabilities beyond paid carers.
9. Increase recruitment to the shared lives / adult placements scheme.
10. Develop the provision of assistive technology for people with learning disabilities.
11. Continue to explore and develop housing options to meet the needs of people with learning disabilities in partnership with other organisations.

### **Data development agenda**

- Make sure there is common understanding and consistency across the six North Wales counties in the way data is recorded and analysed.
- Carry out more analysis to support adult services to plan for the needs of young people with complex needs.

### **Equality and human rights**

This chapter includes challenges faced by people with learning disabilities and some of the ways we can work together to meet these needs. People with learning disabilities may also have other protected characteristics and experience additional disadvantage because of these. The chapter looked at particular issues faced by older people with learning disabilities, people with profound and multiple disabilities and the use of the Welsh language. Future work also needs to take into account different issues affecting women and men,

Lesbian, Gay, Bisexual and Transgender (LGBT) people, Black, Asian and Minority Ethnic (BAME) people and a person's religion and beliefs.

There may be other issues affecting groups of people who share protected characteristics which have not been picked up by this assessment. We would welcome any further specific evidence which may help inform the final assessment. This could be addressed in future population assessment reviews, in the development of the area plan which will follow this assessment, or in the services developed or changed in response to the plan.

## **Appendix 5a: Overview of the Social Services and Wellbeing (Wales) Act 2014**

Nationally, the way in which local authorities arrange and provide support for adults with learning disabilities is informed by the new Social Services and Well-being (Wales) Act 2014. This act, which came into effect in April 2016, replaces previous legislation for the delivery of social care and forms the basis for a new statutory framework for social care in Wales. It will transform the way social services are delivered, promoting people's independence to give them a stronger voice and control.

Many of the supporting principles and aims already underpin the changes that have been introduced across Social Services and local councils have been preparing for the implementation of the act with a strong emphasis on training and staff development.

### **How will the Social Services and Well-being (Wales) Act 2014 change things?**

The act will:

- Provide a stronger voice and real control for people over the social care services they use, and will help meet their changing needs. It will drive the development of new models of service that maintain and improve the wellbeing of people in need.
- Promote preventative and early intervention services, based on greater partnership working and integration of services between local authorities and partners.
- Establish Outcome Focused Assessments for individuals and their carers which focus on the outcomes that are important to them, not just about eligibility for a particular service.
- Establish a national eligibility criteria. People will be assessed on what they need, rather than just on what services are available locally.
- Strengthen powers for safeguarding of children and adults, so that vulnerable people at risk in our society can be protected more effectively.
- Promote Direct Payments - extending the range of services available by direct payments, meaning people will have more control over the services they use.
- Provide portable assessments - If people move from one part of Wales to another they will not require their needs to be re-assessed if these haven't changed.
- Establish equivalent rights for carers so that people who care for someone such as an elderly or disabled relative or friend will get similar rights to the people they care for.

The act also places duties on local authorities in relation to providing people with:

- Information and Advice relating to care and support; and
- Assistance in accessing care and support.

Engagement carried out nationally around the impact of the act stresses the importance of helping people with learning disabilities to understand the changes. The report writers said 'Without this, there is a risk that the same set of circumstances for a person with a learning disability may be perceived quite differently, with the local council seeing it as a positive example of co-produced, sustainable social services, and it being experienced as an isolating and confusing predicament by the person themselves. Finally, it should be stressed that the evidence from the national inspection is that many people already rely more on their families for support than they do on services'. (CSSIW, 2016)

More information is available at: <http://www.ccwales.org.uk/the-act/>

## **Appendix 5b: How national guidance has shaped learning disability services**

**National legislation:** There is a statutory duty on the local council to provide information and/or arrange support (and in some cases accommodation) under the National Assistance Act 1948, the Chronically Sick and Disabled persons Act 1970 and the NHS & Community Care Act 1990. Each individual must be assessed using Fair Access to Care.

**1983: The All Wales Strategy (1983) and Revised Guidance (1994):** The All Wales Strategy recognised the rights of people with learning disabilities to normal patterns of life within the community, to be treated as individuals, and to receive additional help and support from the communities in which they live, and from professional services, in developing their potential.

Since the introduction of the All Wales Strategy significant achievements have been made throughout Wales, including the hospital closure and resettlement programme, more localised community based day services and the establishment of community living schemes.

'Community living' enables people to live as tenants in 'ordinary' properties, within their own community. In North Wales the impact of the All Wales Strategy has been considerable, particularly in relation to the shift away from institutional care, with community living now well established as the preferred option for most people who need to live away from the family home.

In terms of day time activities, we have also seen a move away from large, isolated, day services and towards more community based 'businesses'.

**2001: Fulfilling The Promises:** In 2001, the Learning Disability Advisory Group published their proposals for a framework for services for people with learning disabilities. The report 'Fulfilling The Promises', outlined a vision for services based upon the principles of the All Wales Strategy. It laid down a number of key principles in areas such as employment, Community living and health needs.

**2004: Section 7 Guidance- Service principles and Service Responses:** Although considerable progress had been made in Wales since the All Wales Strategy was first established there was recognition of the need for further development. In response to this Welsh Government (WG) issued Section 7 Guidance on Service principles and Service Responses in 2004 and allocated grant funding for projects which supported this guidance.

The white paper **Sustainable Social Services for Wales: A Framework for Action** published in 2011 set out the Welsh Government's vision and highlighted the challenges facing public services in Wales.

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