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**NORTH WALES** SOCIAL CARE AND WELL-BEING  
SERVICES IMPROVEMENT COLLABORATIVE

# North Wales Learning Disability Strategy

## Work in progress

### 2018 to 2023



## Version control

*Please note:* This draft document is a work in progress. Please send any comments to [sarah.bartlett@denbighshire.gov.uk](mailto:sarah.bartlett@denbighshire.gov.uk) by **26 September 2018**.

Version	Date	Changes	Author
0.10	05/09/18	Added findings from the consultation and restructured. Shared for further feedback.	SB

**An Easy-Read version of the draft strategy is available.**

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[\[Click to update page numbers before publishing\]](#)

# Contents

Our vision for North Wales.....	4
Introduction .....	5
Governance .....	14
What we know about the population.....	16
What people have told us.....	18
What we know about current services and the change we want to see .....	24
Early years .....	25
Having a good place to live .....	28
Having something meaningful to do.....	31
Friends, family and relationships.....	34
Being safe .....	34
Being healthy .....	36
Having the right support.....	40
Putting the strategy into action .....	46
Integrated structures .....	47
Workforce development .....	47
Commissioning and procurement .....	48
Community and culture change .....	49
Assistive technology.....	49
References .....	50
Appendix 1: Baseline data .....	54

People with learning disabilities will have a better quality of life; living locally where they feel 'safe and well', where they are valued and included in their communities and have access to effective personal support that promotes independence, choice and control.

(Mobius UK, 2008)

## Our vision for North Wales

The strategy promotes the principles of the Social Services and Well-being (Wales) Act 2014.

- **Voice and control:** putting the individual and their needs at the centre of their care and giving them a voice in and control over reaching the outcomes that help them achieve well-being.
- **Prevention and early intervention:** increasing preventative services within the community to minimise the escalation of critical need.
- **Well-being:** supporting people to achieve their own well-being and measuring the success of care and support.
- **Co-production:** encouraging individuals to become more involved in the design and delivery of services.

In the strategy we focus on how health and social care services can work better together and look at the areas people have told us matters to them:

- having a good place to live
- having something meaningful to do
- friends, family and relationships
- being safe
- being healthy
- having the right support

Within each of these areas we include:

- the needs of people with profound and multiple learning disabilities; and,
- support through changes in life from early years to ageing well, including the needs of older carers and the transition from children's to adult's services.

We are committed to strengthening Welsh language services and providing an active offer through the Mwy na geiriau/More than just words framework.

As a long term aim to provide the best quality services to everyone in North Wales we aim to integrate services across the region over the next 10 years.

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# Introduction

Support for people with learning disabilities is a priority in the [North Wales Regional Plan \(Area Plan\)](#) based on what people told us was important to them as part of the [population assessment](#) produced by the [Regional Partnership Board](#).

The Social Services and Well-being (Wales) Act 2014 includes a legal duty for Regional Partnership Boards to prioritise the integration of services in relation to people with learning disabilities (Welsh Government, 2015).

This strategy sets out how we will work towards integrated learning disability services in North Wales. It has been developed jointly by the six North Wales councils and Betsi Cadwaladr University Health Board (BCUHB) supported by Public Health Wales.

## About the strategy

The strategy focusses on the needs of children, young people and adults with learning disabilities in North Wales. It also includes the needs of autistic people who also have a learning disability. The strategy sits alongside other North Wales strategies and programmes including:

- The [North Wales Together for Mental Health Strategy](#)
- The [North Wales Integrated Autism Service](#)
- The North Wales Carers Strategy [\[add link\]](#)
- The work of the Children's Transformation Group as part of the Regional Partnership Board's children and young people's work-stream. This includes a priority for children and young people with complex needs.
- Additional Learning Needs strategies and plans
- Local Housing Strategies

### What do we mean 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 do we mean by the term *profound and multiple learning disabilities* (PMLD)?**

The term *profound and multiple learning disabilities* (PMLD) is used to describe a people with more than one impairment including a profound intellectual impairment (Doukas et al., 2017). It is a description rather than a clinical diagnosis of individuals who have great difficulty communicating and who often need those who know them well to interpret their responses and intent. The term refers to a diverse group of people who often have other conditions including physical and sensory impairments or complex health needs.

### **What do we mean 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 autistic people also have a learning disability.

### **What do we mean by the terms *parents and carers*?**

We use the term *parents* to mean those who bring up children including mothers and fathers, foster carers and adoptive parents, step-parents and grandparents.

We use the term *carers* to mean unpaid carers of all ages who look after family members, friends, neighbours or others because of a learning disability.

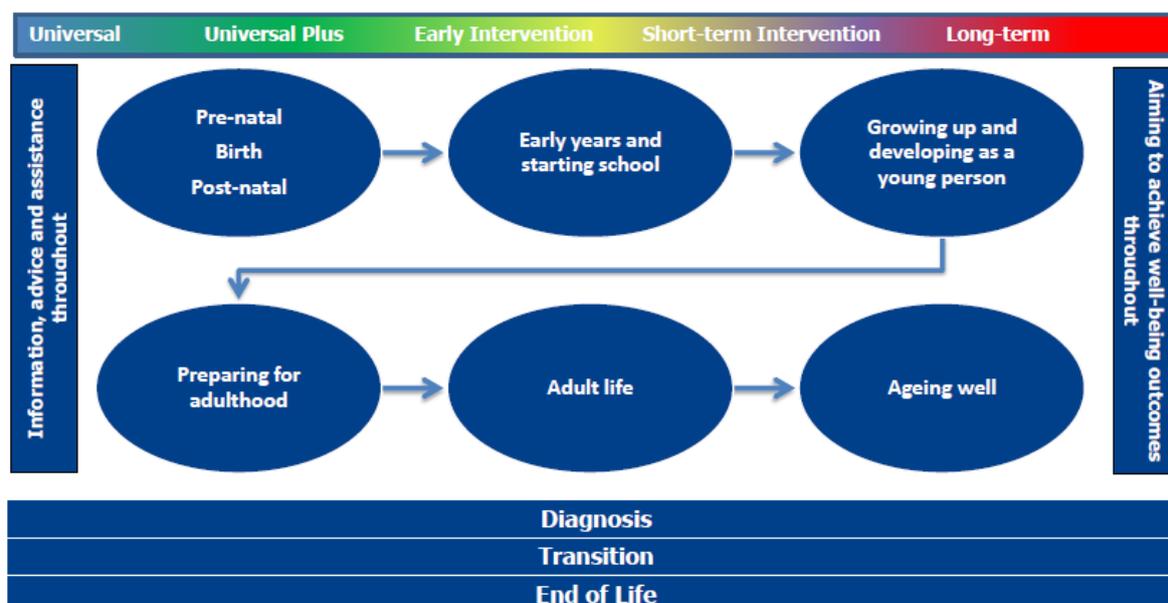
A *parent carer* is a parent or guardian who has additional duties and responsibilities towards their child because their child has an illness or disability. Parent carers will often see themselves as parents rather than carers, but they may need additional services to meet the needs of their child.

### **The social model of disability**

The strategy is based on the social model of disability, which recognises that disabled people are people with impairments who are disabled by their environment. We use the term *learning disability* in this strategy as it was the preferred term of the people with learning disabilities that we spoke to and it is widely recognised and used. We acknowledge that this language may not reflect fully the principles of the social model and that people have different opinions about the language they prefer to describe themselves that can change over time. The debate will be welcome and hopefully helps us towards a common understanding about the use of language.

## Whole system, lifespan pathway for producing good lives

The strategy takes a life span approach to Learning Disability Services based on the model below (National Commissioning Board, 2017). The model highlights the importance of pathways that move people from universal services to interventions and back again as well as the need to achieve well-being outcomes and provide information, advice and assistance throughout the pathway. Issues around diagnosis, transition and end of life care can occur at any point in the pathway.



## How we wrote the strategy

The strategy is based on the findings of the population assessment and regional plan produced by the Regional Partnership Board which both involved consultation with a wide range of people. The [Learning Disability Partnership](#) used this information to develop a set of themes for the strategy which we agreed with the [Learning Disability Regional Participation Group](#) before going out to a wider consultation about the themes, what works well at the moment and what needs to be improved. The consultation involved children, young people and adults with learning disabilities and their parents/carers, local council and health staff in children's and adults' services, third and independent sector providers, members of the North Wales Citizen's Panel and others.

Alongside the consultation we collated baseline data and research to inform the strategy and worked with a wide range of services to make sure the main messages in the strategy reflect the needs of the region and complement related strategies and plans. Throughout the process we worked closely with the [Learning Disability Regional Participation Group](#).

The consultation generated a lot of useful information which has been included in the strategy. All the reports produced have been made publically available so that they can be used to inform other work. The main consultation report brings together information about the consultation process, methods, promotion, response and findings. The reports are available here:

- North Wales Learning Disability Strategy Consultation Report [\[Add link\]](#)
- [North Wales Strategy: Local authority and health staff event 18 July 2018](#)
- [North Wales Provider Forum Event 9 April 2018](#)

The strategy is based on the principle of co-production, which is:

“An asset-based approach that enables people providing and people receiving services to **share power and responsibility**, and work together in equal, reciprocal and caring relationships” (Co-production Network for Wales).

We want to see co-production embedded at all stages of this strategy from the planning and commissioning to design, delivery and evaluation. While co-production is the aim that we are working towards it is likely to be an ongoing process of learning and experimentation. For example, while we involved a wide range people in writing this strategy, the size and scale of the project meant we used more traditional methods of consultation such as questionnaires and workshops. There are likely to be better opportunities to truly co-produce service design, delivery and evaluation as we put the strategy into action at a local level. This will mean focussing on co-production where it will make the greatest difference to people’s lives.

## Background

There is a long history of successful and innovative partnership working between learning disability services in North Wales arising from the All Wales Learning Disability Strategy in the 1980s. This provided dedicated funding for community care as the staged process of closing hospitals began. It was based on the rights of people with a learning disability to an ordinary pattern of life within the community; be treated as an individual; and, have additional help and support in developing their maximum potential.

In 2008 Mobius UK were commissioned by the North Wales Social Care and Well-being Services Improvement Collaborative to suggest how services should develop so that people with learning disabilities can enjoy life as citizens in their community rather than as less than fully engaged recipients of services (Mobius UK, 2008). This work developed a [vision for learning disability services](#) in North Wales with service users and carers and made recommendations under two strands. The first was about making the most of opportunities in council strategies for communities and citizens to ensure inclusion of people with learning disabilities. The second strand relates to the joint development of services between the six local authorities and health

in ways which support greater independence and choice, including joint commissioning. It included a review of good practice in the six local authorities.

One of the outcomes of the Mobius report was the creation of the North Wales Commissioning Hub in 2012 as a partnership between the six local authorities and BCUHB. The hub built on the work of a Regional Learning Disability Manager, a jointly funded post which resulted in improved procurement and service delivery for North Wales Adult Services. The original scope for the hub was to commission care home placements (including with nursing) and residential school services for all children, young people and adults with complex needs. Regional commissioning arrangements were reviewed in 2015 and it was agreed to transfer some commissioning activities back to local authorities and focus the regional commissioning function on strategic commissioning activities.

Currently, the North Wales Commissioning Board oversee the regional commissioning work supported by a Regional Business Manager and a Commissioning/Procurement Officer based within the North Wales Social Care and Well-being Improvement Collaborative.

## North Wales Learning Disability Partnership

The North Wales Learning Disability Partnership was set up to drive forward improved services based on mutual understanding across the six councils and health.

The group includes representation from:

- North Wales Head of Adult Services
- Head of Strategy Learning Disability & Mental Health Division (BCUHB)
- Six Local Authority Service Managers
- Senior Learning Disability Community Nurse (BCUHB)
- Senior Learning Disability In Patient Services Nurse (BCUHB)
- Regional Project Manager
- Psychology Clinical Lead (BCUHB)
- Psychiatry Clinical Lead (BCUHB)
- Therapy services (SALT, OT and/or Physio BCUHB)

## Participation

The Learning Disability Partnership recognise the vital contribution that the learning disability community across the region can make to shape and influence the services that they receive. This means working together; informing, listening, feeding back, acting, reviewing, and making ourselves accountable to the people we are working for and with.

The Regional Participation Strategy sets out a framework for ensuring that the work of the partnership is effective and citizen-focussed and that it meets the needs of the people with learning disabilities and their families (North Wales Learning Disability Partnership, 2015b). The strategy sets out a framework for how people with learning disabilities are involved in the work of the partnership.

Learning disability participation is coordinated across the six councils and each county has its own local participation network/forum supported by advocacy. The Learning Disability Regional Participation Group (LDRPG) was been supported by a Regional Participation Officer for two years, jointly funded by the six local authorities and health. The LDRPG reviewed the model of support during 2017 and agreed to employ a person with learning disabilities with support to co-ordinate the group. The co-ordinator will be based in a third/voluntary sector organisation.

## Legislation, policy and guidance

### **Social Services and Well-being (Wales) Act 2014**

The act aims to improve the well-being of people who need care and support, and carers who need support. The act changed the way people's needs are assessed and the way services are delivered - people will have more of a say in the care and support they receive. The law also promotes a range of help available within the community to reduce the need for formal, planned support.

This strategy is based on the principles of the act and it forms part of the Regional Partnership Boards approach to meeting its legal duty to prioritise the integration of services in relation to people with learning disabilities

### **A Healthier Wales: our Plan for Health and Social Care**

Welsh Government (2018a) have produce A Healthier Wales in response to the Parliamentary Review report (Welsh Government, 2018d). The plan set 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 a Quadruple aim:

- Improved population health and well-being
- Better quality and more accessible health and social care services
- Higher value health and social care
- 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.

The quadruple aim and design principles have informed the development of this strategy and the action plans.

### **Learning Disability Improving Lives Programme**

The Welsh Government programme has developed recommendations in the areas of early years, housing, social care, health and well-being and education, employment and skills for people with learning disabilities. 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 reflects the priority areas in Prosperity for All (Welsh Government, 2017b). The Improving Lives priorities have been incorporated into this strategy.

### **Additional Learning Needs and Education Tribunal (Wales) Act 2018**

The act will introduce the following changes.

- Introduce 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 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.

### **Well-being of Future Generations (Wales) Act 2015**

The Well-being of Future Generations (Wales) Act 2015 requires us to think about the long-term impact of our decisions, work better with people, communities and each other and to prevent persistent problems such as poverty, health inequalities and climate change.

There are four Public Services Boards (PSBs) in North Wales established by the Well-being of Future Generations (Wales) Act 2015. The purpose of the PSBs is to improve the economic, social, environmental and cultural well-being in their area by strengthening joint working across all public services in North Wales. Each PSB has a well-being assessment and a well-being plan which set out how the needs of the area and how they plan to work together to address them.

We have produced a Well-being Impact Assessment to help us consider the long-term impact of the strategy on the social, economic, environment and cultural well-being of the region, Wales and the world.

## **Equality and human rights**

The Equality Act 2010 introduced a public sector equality duty which requires all public bodies including the council to tackle discrimination, advance equality of opportunity and promote good relations. An Equality Impact Assessment has been undertaken to identify any potential inequalities arising from the development and delivery of this strategy.

A key part of the Equality Impact Assessment is consulting with people who may be affected by the strategy and in particular people with protected characteristics. The protected characteristics are:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race

- Religion and belief
- Sex
- Sexual orientation
- Welsh language

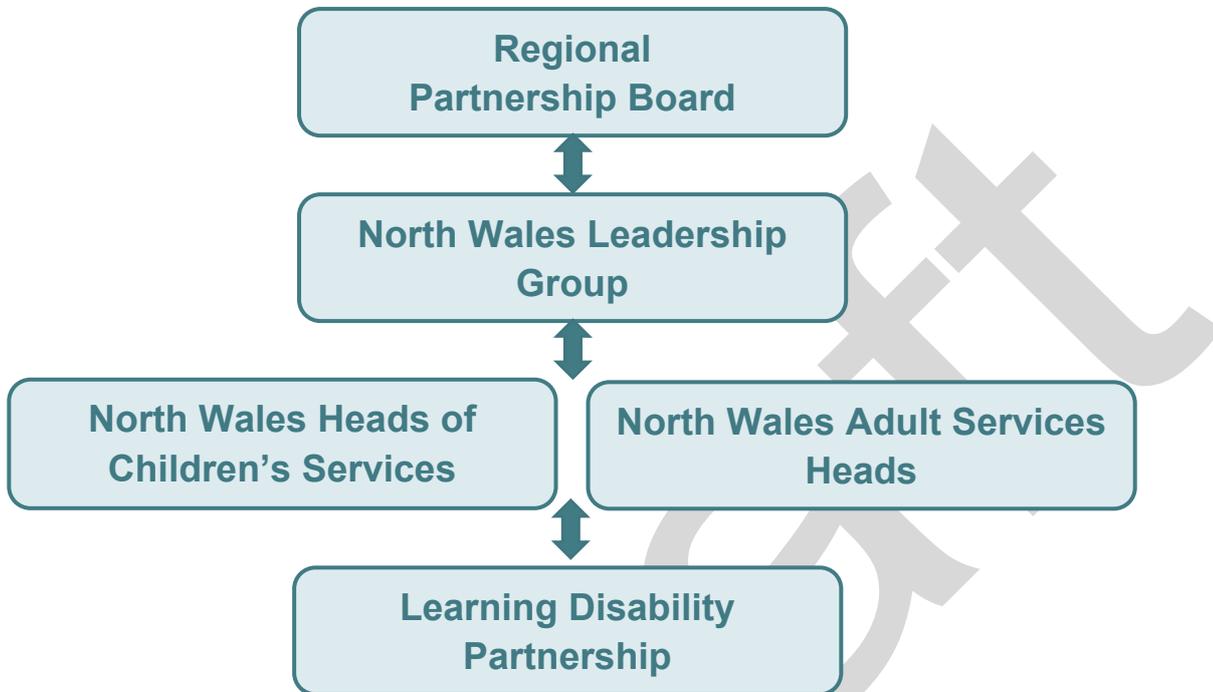
More information about the consultation and engagement that took place to develop the strategy is available in the consultation report [\[add link\]](#).

The strategy aims to tackle discrimination, advance equality of opportunity and promote good relations for people with learning disabilities. People with learning disabilities may have other protected characteristics and experience additional disadvantage because of these which we need to take account of. For example, older people with learning disabilities and people with profound and multiple disabilities and the use of the Welsh language.

The Human Rights Act 1998 sets out the basic rights we all have because we are human. They help protect people by giving public services, including health and social care services, a legal duty to treat people with fairness, equality, dignity, respect and autonomy. Services developed in response to this strategy also need to be based on the UN Convention on the Rights of the Child (UNCRC), the UN Principles for Older Persons (UNPOP) and the UN Convention on the Rights of Persons with Disabilities (CRPD).

## Governance

The [North Wales Learning Disability Partnership](#) will put the strategy into action in partnership with people with learning disabilities, parents, carers and organisations who provide care and support. Governance will be provided through the groups below.



### Regional Partnership Board

The Regional Partnership Board was established to meet Part 9 of the Social Services and Well-being (Wales) Act 2014. Membership includes:

- Lead members for Social Services from the six local authorities
- Directors of Social Services from the six local authorities
- Third sector representatives
- A service user and carers representative
- Health board representative
- Co-opted members from North Wales Police, North Wales Fire and Rescue Services, North Wales Ambulance Service, Local Authority Chief Finance Officer (section 151), and the Executive Director of Public Health (BCUHB)
- Head of Regional Collaboration – Business Management Support

More information about the board including a full membership list is available online here: [www.northwalescollaborative.wales/regional-partnership-board](http://www.northwalescollaborative.wales/regional-partnership-board)

## North Wales Leadership Group

The North Wales Leadership Group meets during Partnership Friday, a series of regional meetings that take place once a month. Membership includes the six Directors of Social Services and the three Area Directors from BCUHB.

## North Wales Adult Services Heads (NWASH)

NWASH also meet during Partnership Friday. Membership includes the heads of Adult Services from each of the six local authorities in North Wales.

## North Wales Heads of Children's Services (NWHoCS)

NWHoCs also meet during Partnership Friday. Membership includes the heads of Children's Services from each of the six local authorities in North Wales.

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# What we know about the population

## Population assessment: what we found out

- There are around 810 children with a severe or profound learning difficulty and 2,900 adults with learning disabilities receiving services in North Wales. The actual number of people with learning disabilities may be higher.
- The number of people with learning disabilities needing support is increasing and people with learning disabilities are living longer. These trends are likely to continue. There are also an increasing number of older carers (including parents and family) providing care and support for 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.
- There are likely to be more young people with complex needs needing support.

The full population assessment including an easy-read and audio-visual version is available online at: [www.northwalescollaborative.wales/north-wales-population-assessment](http://www.northwalescollaborative.wales/north-wales-population-assessment). The figures have been updated for this strategy and updated charts and tables are available on request.

## Children and young people

There are around 102,000 pupils in North Wales, the total school-age population but there is a lack of reliable data available about the number of children and young people who have a learning disability ([see appendix 1](#)). Estimates suggest there are around 5,000 children in North Wales with a moderate learning difficulty, 650 with a severe learning difficulty and 160 with a profound learning difficulty. Council's in North Wales currently support around 700 disabled children and young people assessed as in need of care and support. Around 5,200 children aged under 16 are in receipt of Disability Living Allowance in North Wales.

Projections based on trends in the overall population show that the number of children with learning disabilities is likely to increase slightly over the next 5 to 10 years and then decrease slightly by 2035 ([see appendix 1](#)) as the overall number of children and young people decreases.

The improved survival rates of pre-term babies and increased life expectancy for children with complex disabilities are likely to lead to an increase in the number of children in need of care and support and in the number of adults with more complex needs (Doukas et al., 2017)

## Adults

Table 1 below shows the number of adults with learning disabilities living in each local authority by age group in North Wales. These figures are 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 1: Number of adults with learning disabilities by age, 2016-17**

	Age 16-65	Age 65+	Total
Anglesey	270	40	310
Gwynedd	530	65	590
Conwy	440	55	500
Denbighshire	420	55	470
Flintshire	480	40	530
Wrexham	420	50	470
North Wales	2,600	300	2,900

**Source:** StatsWales, Disability Registers

Note: Data has been rounded and may not sum. The Disability Register also includes data for children under 16 but this hasn't been included here due to problems with data collection.

Since 2012-13 the number of adults aged 16 to 65 with learning disabilities has remained similar each year. The number of adults aged over 65 with learning disabilities has risen over the last five years by 23% across North Wales from around 230 in 2011-12 to 300 in 2016-17.

Projections suggest that the number of adults 18 and over with moderate learning disability is likely to increase in North Wales by around 6% by 2035 and the number of people with a moderate or severe learning disability is expected to increase by around 3% by 2035 ([see appendix 1](#)). The number of adults aged 18 to 64 is expected to decline slightly so this increase is due to an increase the number of people aged 65 and over. Due to increased life expectancy it is predicted that the number of people with learning disabilities aged 65 and over will increase by between 20% and 30% by 2035 ([see appendix 1](#)).

### Parents with a learning disability

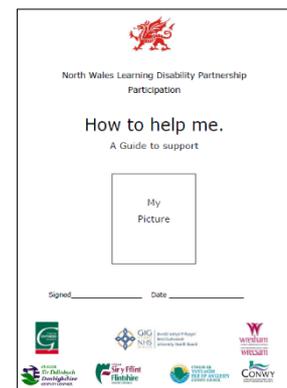
There is no data currently available on how many parents have a learning disability although this is something Welsh Government are planning to research further (Welsh Government, 2018b). A survey in England found that 7% of people with learning disabilities interviewed had children (Emerson et al., 2005). Using this figure estimates there could be around 200 parents with learning disabilities in North Wales. Just over half the parents in the survey looked after their children and other estimates suggest that between 40 and 60% of parents with a learning disability have their children taken into care (Stewart and McIntyre, 2017).

There are around 1,100 children looked after and the number is increasing year on year with a 13% increase in North Wales over the last five years compared with a 3% increase across Wales as a whole. [Improving support for parents with learning disabilities](#) may help to reduce the numbers becoming looked after.

## What people have told us

Learning disability participation is coordinated across the six councils and each county has its own local participation network/forum supported by advocacy. The regional participation group have been working on the topics below (North Wales Learning Disability Partnership, 2015a).

- 1. Leisure.** People with learning disabilities said they can 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. The group have been 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 leaflets about health checks designed to be easier to read
  - 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).

In March 2017 the group held a regional event on the theme of relationships. The purpose of the event was for people with learning disabilities to have their say about matters that are important to them. The group chose subjects that they would like to lead on which included: Lesbian, Gay, Bisexual and Transgender (LGBT); marriage; living with your partner; communication; confidence and relationships in a self-advocacy group; and, a speed dating event. The group also invited people to talk about keeping safe in general and keeping safe online. The event highlighted that attendees wanted help to meet new people, including making friends and dating, and to know more about relationships including sex, sexual health and keeping safe.

Discussion groups held to inform the population assessment highlighted the need for paid work to give people a feeling of self-worth and acknowledge their 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 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 parents of disabled children**

Feedback from engagement sessions with parents for the population assessment highlighted the following common themes:

- The time taken for assessments to take place and delays in accessing support was considered to be too lengthy. Need to “be quicker when a cry for help is given”. Support while waiting for assessments or confirmation of diagnosis was also cited as important.

- Concern about the lack of available help to care for their children, particularly for those who are full time carers and single parents, if they are ill and in the school holidays.
- Felt they needed more support to maintain their own emotional wellbeing – including extra help, respite/short-breaks, learning more coping strategies, baby sitters and support for emotional wellbeing. This was a concern when juggling work and caring for a disabled child and professionals who listen was suggested as being important. The physical and emotional impact of managing behaviour problems on parents was also significant. Including; temper, difficulties communicating and safety concerns.
- The impact of social isolation and support to get out of the home for both children and parents. Including direct payments for family outings, suitable afterschool clubs or day care was needed.
- Parents reported that it would help them to cope if there was better understanding from the wider community regarding disabilities and more acceptance of disabilities that you can't see.
- Better facilities for families of disabled children.
- More support from voluntary and charity sector.
- Issues managing their children's anxiety when in public or not in their care.

In depth interviews carried out with parents of disabled children in North Wales identified the importance of good support and information during the process of diagnosis, including the need for emotional support (Conwy County Borough Council, 2013). The study also highlighted the need for consistent, accessible support and efficient systems, for example to provide specialist equipment. Most of the families mentioned the need for carer breaks including frustrations with getting the kind of flexible breaks they need and the benefits to the whole family when it works well. Families mentioned the impact of caring on their finances and employment opportunities and the impact on siblings. They also spoke about their fears and anxieties including fears for their children's future, supporting them to be independent and what would happen when they were no longer there to care for them. Many of the families also spoke about the stigma associated with disability including their own reactions and reluctance to ask for help as well as the need to improve awareness and support from the wider society.

### **Feedback from disabled children**

- The children talked about the difficulties that they have meeting with friends outside school time. When you are younger there are special needs play scheme, they are not suitable if you are older. The children said they would like a club where they can meet their friends.

- Some children said they found noisy environments difficult such as going into large shops, swimming pools or sports centres.
- Some children would like to go out alone but parents are worried about other children bullying or taking advantage of them.
- The children said how difficult it was for them to make decisions.
- One child said because their mobility was not good they had difficulty getting around especially going downhill. This inhibits his social and leisure activities.
- The children said that they rely on their parents to help them with the things that they find difficult and one child had a social worker who took him out.
- The children would like a greater range of activities to do outside school such as art workshops, outdoor activities, trips to activity parks and somewhere to have fun, meet friends, to do cycling music and dance.
- The teachers said that they would like more information about what is available for children now that some of the play schemes have closed down.

### **Feedback from staff and partner organisations**

Feedback from staff highlighted the complexity and interdependency of issues facing disabled children and young people and their families, including difficulties around transition from children's services to adult's services. They also highlighted an increase in the number of disabled children with very complex needs.

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.

### **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.

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.

### **Learning Disability Strategy Consultation**

In January 2017 a meeting ‘Going Forward Together’ was held with staff and partners, facilitated by BCUHB, to inform the development of this strategy. The discussions looked at current strengths and challenges and what needed to change. The guiding principles discussed were:

- Shared responsibility to implement the legislation.
- Person first, learning disability second.
- Right support at the right time to the right people in the right place.
- No-one to experience delays in support due to disagreements between services. Shared responsibility to ‘fix it’.

In addition to the consultation findings above we asked a wide range of people for their views about what needed to be included in the strategy. Many of the findings have been incorporated within the strategy and a full report is available [\[add link\]](#).

Some of the main messages from the consultation were as follows.

- Need for real choice and control with a focus on rights and equality for people with learning disabilities. The importance of taking a person-centred approach.
- More inclusion and integration of people with learning disabilities into the wider community. Including the need for staff training about specific learning difficulties and an awareness that not all disabilities are visible. There was a lot of support for the idea that we should ‘help each other’ but there were also some concerns about the pressures this could put on people.
- The support people receive from family and providers often works well and there was praise for dedicated and committed staff. Specific services were mentioned as

working well including carer breaks, social services, health services, charities, third sector and independent organisations including advocacy services.

- Joint working between social care and health was highlighted as something that works well in some areas and something that needs to be improved in others including better information sharing systems and issues around funding.
- There were also mixed views about how well direct payments and support budgets worked for people. Some said they worked well for them and other commented that they need much more support to use them and shared difficulties of finding a direct payment worker.

The consultation also highlighted issues that can prevent people from experiencing good outcomes including:

- **Support for carers:** Carer breaks was mentioned by many people in the consultation. Some of the specific issues include a lack of short breaks for families, provision for people with more complex needs such as challenging behaviour and autism and regular and predictable provision that is open all year round. People mentioned the importance of considering the impact on families, including the needs of siblings of children with learning disabilities. Also the importance of listening to parents and supporting parents/carers to building resilience and develop coping mechanisms. People also mentioned the needs of older carers and planning for the future when they may be no longer able to provide care.
- **Funding:** There was concern about having enough funding available for services. A few people mentioned the need to work together and consider merging budgets to try and address these issues and the need to make better use of technology.
- **Transport:** People mentioned how important transport was to them for inclusion in activities including having someone who can drive them, bus passes and subsidised transport. People also mentioned the orange wallet system that helps people with using public transport.
- **Access to information:** A few people mentioned the need for more information about the services that are available, details of who is able to access support from them and availability of services in Welsh. The staff consultation highlighted the importance of promoting and developing [Dewis Cymru](#) as a source of information about the services and support available in local communities.
- **Workforce development:** People talked about the importance of training and support for staff, particularly support workers. Also the importance of training the wider workforce, such as training for GPs about the needs of people with learning disabilities and how to access community teams.

# What we know about current services and what needs to change

People with learning disabilities often need support with many aspects of their lives. 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 and can include help with:

- having a good place to live
- having something meaningful to do
- friends, family and relationships
- being safe
- being healthy
- having the right support

Within each of these areas we include:

- the needs of people with profound and multiple learning disabilities; and,
- support through changes in life from early years to ageing well, including the needs of older carers and the transition from children's to adult's services.

The current spend by social services and health directly on learning disability services in North Wales is over £130 million. This does not include additional services which provide support such as housing, leisure, third and voluntary sector support and so on.

**Table 2: Revenue expenditure, adults aged under 65 with learning disabilities**

	£ thousands	£ thousands
<i>Social services expenditure (2016-17)</i>		
Supported living / community living	36,000	
Residential care placements	20,000	
Day care	13,000	
Direct payments	8,200	
Home care	6,400	
Assessment and care management	5,800	
Other services to adults aged under 65 with learning disabilities	5,200	
Nursing placements	1,000	
Total social services		96,000
<i>BCUHB expenditure (2015-16)</i>		
Mental health and learning disabilities division (including continuing health care)	37,000	
Primary care and other contracts	590	
Total BCUHB		38,000
Total spend learning disability services		130,000

Please note this information is taken from Welsh Government returns and does not include spending on children and older people with learning disabilities because of the way the data is collected.

Local authorities also spend around £220 million of capital each year in North Wales for personal social services. This includes spending on buildings and housing related to all kinds of personal social services, not just for people with learning disabilities.

## Early years

Support for parents with a learning disability is included in [the right support section](#).

We want every child with a learning disability to have the best start in life.

### Diagnosis and assessments

In the consultation parents mentioned challenges around waiting for assessments, the time taken and issues around needing to wait for a certain age for an assessment. Parents also said they needed better support and understanding from professionals while waiting for an assessment. Support is also needed following a diagnosis, which may include counselling for parents.

### Support for parents

Support should begin before birth with good information and support available from midwives and health visitors.

It's important that parents have access to parenting courses that are specifically geared towards parents of young children with learning disabilities. Courses need to be sensitive to the needs of parents awaiting diagnosis as a parent in the consultation said that being sent on parenting courses felt like being blamed for their child's additional needs.

Parents told us there was a need for good information and advice. This information should be joined-up so health, social care and education staff are giving the same messages. It should also be available to people early on. At one of the strategy workshops the following guide was recommended: '[A Parent's Guide: Improving the well-being of young children with learning disabilities](#)' produced in collaboration between the University of Warwick, Cerebra, Mencap, the Challenging Behaviour Foundation and parents of children with learning disabilities. There is also information available and through Family Information Services and on [Dewis Cymru](#).

### Childcare and short breaks

Each local council in North Wales produced a Childcare Sufficiency Assessment in 2017, which includes an assessment of the provision for disabled children. These

highlight that in all areas there is a need for childcare for children with additional needs and the action plans set out how this will be addressed. Initiatives to support childcare for disabled children include pre-school referral or pre-school support schemes to support children with additional needs in pre-school settings; a Childcare Brokerage officer post which supports parents / carers of children with a disability to access suitable childcare and play provision; using the Welsh Government Out of School Childcare Grant to fund assisted places or 'helping hands' scheme; and, providing training for childcare staff.

Short breaks are activities for children and young people, usually occurring away from the home, that allow them to have a good time with others – peers and adults, while also giving a break to parents/carers from their caring role.

The short breaks can range from an hour or more planned activity to overnight stays with alternative carers. Some short breaks can involve the whole family having quality time together, by having assistance for trips out or leisure activities.

A report by the Children's Commissioner for Wales (2014) highlighted the importance of appropriate, accessible and good quality short breaks. The report found that the provision of short breaks is a complex matter due to different eligibility criteria and range of provision in each council and because each family has a different set of circumstances and needs. Some of the issues identified include issues around transition and support for children and young people aged 18-25 such as young people wanting to continue using the residential facility they were used to after they turn 18 and suggest continuing until they finish education. Other barriers included the accessibility of universal services, transport and awareness of the support available. The report also highlights the importance of the language used around short breaks, the perception and understanding of it among children and young people and the importance of independent advocacy. They found that some children and young people believe the main purpose of a short break is for parents/carers to have a break from them, whereas it should be for mutual benefit.

Childcare and short breaks also a priority in the Welsh Government (2018c) Improving Lives Programme:

'To ensure there is adequate childcare and short break solutions for children with a learning disability to enable families to live an ordinary life including going to work where possible.'

### **Early intervention**

Family-focussed support is available in some areas from Flying Start and across North Wales from Families First and Team Around the Family (TAF), known as Together Achieving Change (TAC) in Wrexham.

Early intervention is also a priority in the Welsh Government (2018c) Improving Lives Programme:

- To improve life chances by building on the team around the family approach to reduce the number and impact of Adverse Childhood Experiences (ACEs) experienced by children with a learning disability.
- To reduce inappropriate use of medication and restraint through increasing the use of a range of evidence based interventions for example Positive Behavioural Support and active support to ensure early intervention of challenging behaviour and prevention where possible

### Speech, language and communication needs

Speech, language and communication needs (SLCN) are common in children and young people who have other diagnoses such as an autism spectrum disorder and learning difficulties (The Communication Trust, 2010). It is estimated that around 3% of children have SLCN as part of another condition such as autism, hearing impairment, general learning difficulties; and, 1% of children have the most severe and complex SLCN which prevents them from expressing their basic needs.

A study to map the current provision of speech, language and communication support in Wales (Holtom and Bowen, 2016) looked at the continuum model for meeting SLCN below which where needs are met through actions around prevention, identification, assessment, intervention and review.

Level	Examples
Universal (Tier 1)	Education settings and health visitors
Targeted (Tier 2)	Targeted intervention within education settings
Specialist (Tiers 3 and 4)	Speech and language therapists (SLTs), specialist advisory teachers working directly with children and supporting universal and targeted services (for example, training)

The review identified that for this model to be effective the services needed:

- Capacity and consistency at each level including skills and knowledge; a sufficient workforce (size and funding); and clear roles and responsibilities.
- Those involved need to use the right tools such as which are effective, accessible, appropriate and implemented well.
- Those involved need to work together as no single service or person can meet a child's SLCN.

## Children with complex needs

Children with complex needs are a priority for the Children's Transformation Group as part of the Regional Partnership Board's children and young people's work-stream so we have not duplicated this work in this strategy.

### Early years: the change we want to see

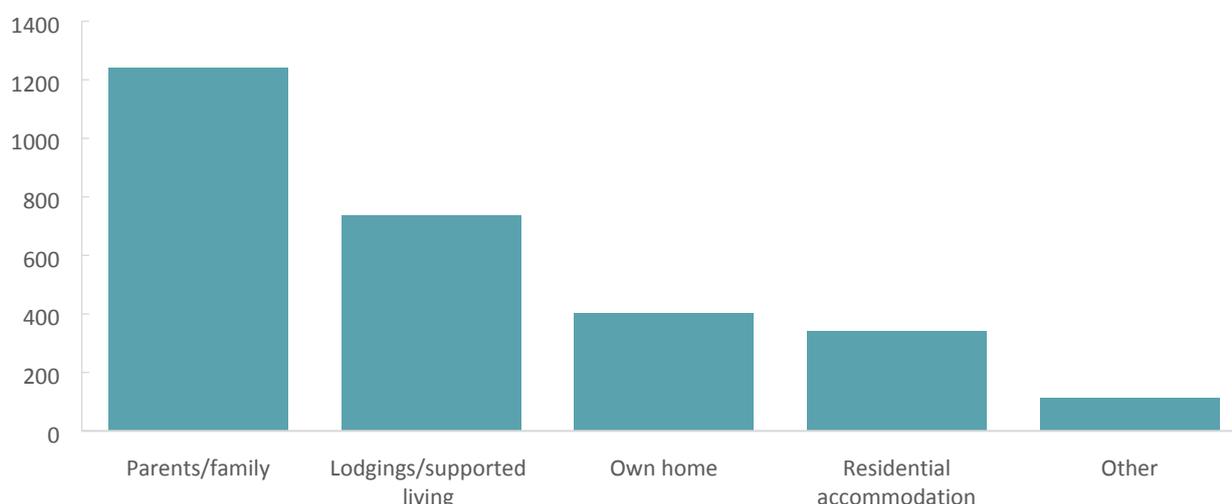
- Fewer people will fall between the gaps in services.
- Carers will have access to a range of flexible carer breaks.
- People with learning disabilities and their parents/carers will have access to good consistent information and advice.

## Having a good place to live

Most children and young people with learning disabilities live with their parents/family. There is no data available showing how many children with learning disabilities live in foster placements but in total there are around 120 disabled children looked after in North Wales ([see appendix 1](#)).

Figure 1 shows that the most frequent living arrangement for adults with learning disabilities is in community placements with their parents/family.

**Figure 1: Community, residential and other accommodation placements, 2016**



**Source:** Adults receiving services at the 31st March 2016 and range of services during the year, Welsh Government

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

Welsh Government is currently developing guidance in the commissioning of supported living services and regional procurement exercise is taking place for supported living providers in North Wales.

## Housing for people with profound and multiple learning disabilities (PMLD)

The Raising our Sights guide to housing (Mencap and PMLD Network, 2013) says that people with PMLD have very complex housing needs including:

- **The physical environment** including adaptations, equipment and the space needed to meet the person's needs
- **The location** of the housing to allow people to remain close to family, friends and their communities
- Wherever they are living, the person will need **individualised and skilled support** for their health, social and well-being needs from appropriately trained staff.

There should be a range of options and a person-centred approach to planning to find the model of housing and care that is right for the individual. This may include supported housing, extra care housing, shared lives, residential care, home ownership and different types of tenancies.

### Community based, residential services and nursing care

In North Wales there are around 1,900 adults with learning disabilities who receive community-based services, around 280 who receive residential services and around 26 who receive nursing care within a care home ([see appendix 1](#)).

The North Wales Adult Services Heads (NASH) have agreed to explore the use of the national Integrated Health and Social Care Collaborative Commissioning Programme framework agreement for younger adults (18-64 years) with mental health and learning disabilities in residential and nursing care homes.

### Deprivation of Liberty Safeguards

Under the Human Rights Act everyone has a right to liberty unless a legal process has been followed. The aim of the Deprivation of Liberty Safeguards (DoLS) is to provide legal protection for vulnerable people who are deprived of their liberty, to prevent arbitrary decisions and to give rights to appeal. The safeguards apply to people who lack capacity to consent to care or treatment and are living in residential or nursing homes or hospital in-patients. There were 160 DoLS referrals made by each local authority for people with learning disabilities during 2016-17 ([see appendix 1](#)).

### Out of area placements

**[The numbers will need updating once the final returns are received]**

Data collected for the strategy found that there were around 15 children and young people aged under 18 who were placed out of county or region. Less than five of these were placed out of county by choice, for example, because they are closer to family or because have been placed with family (Connected Person) out of county for

safeguarding reasons. Ten of the children had a severe learning disability. The most common need was around challenging behaviour followed by autism, physical disability and hearing impairment. Most of the out of county placements were in foster placements or specialist residential schools. The most common placement length was for between 2 to 4 years with less than 5 placements for over 10 years.

For adults there were around 130 people placed out of county or region, with 10 of these placed out of county by choice, for example to be closer to family. The numbers are split fairly equally between people with a severe, moderate or mild learning disability. Around half of the people placed out of county had needs around challenging behaviour. The next most common need was autism followed by mental health (dual diagnosis), forensic and physical disability. Less than 5 people were placed out of county with needs relating to visual and hearing impairments and dementia in each category. The majority of placements were residential and around a quarter of the placements were in hospital. Around 10 of the placements were tenancy based with less than 5 placements in each of shared lives and specialist residential school. There were a range of placement lengths with no real differences in placement lengths between people in placements by choice and others. There were around 20 people who had been in a placement out of county for 10 years or more.

### **Supporting People**

The Supporting People programme is a Welsh Government programme providing housing-related support to help vulnerable people to live as independently as possible. The total budget for Supporting People in North Wales for 2018-19 is around £30 million of which £8.2 million has been allocated to supporting people with learning disabilities.

There is a North Wales Regional Collaborative Committee (RCC) to drive forward effective and efficient delivery of the programme at a regional and local level and is linked to the Regional Partnership Board. Learning disabilities is a priority area for the RCC in the 2017-20 strategic plan.

### **Planning for future accommodation needs**

The Wales Audit Office (2018) estimate that local councils in Wales will need to 'increase investment by £365 million in accommodation in the next twenty years to address both a growth in the number of people with learning disabilities who will need housing, and the increase in the number with moderate or severe needs'. This figure includes increases in costs due to inflation.

For North Wales, this will mean we need to plan for between 80 and 190 additional placements by 2035. The increase is estimated to be greatest in Wrexham followed by Gwynedd and then Denbighshire. Anglesey are estimated to see a decline in the

number of placements needed. Conwy and Flintshire are estimated to either have a small increase or small decrease.

The cost of these additional placements at current prices is estimated to be between £2.4 million and £7.3 million by 2035 and would be around 10 times as much if estimated inflation is included.

### Having a good place to live: the change we want to see

- There will be fewer out of area placements.
- More people with learning disabilities will have choice and control over where they live and how they are supported.

## Having something meaningful to do

This section is about having something to do that's meaningful and is chosen by the individual. It includes play, leisure and sport; education and training; day opportunities, work opportunities and paid employment.

### Play

Play is a fundamental part of a healthy childhood and it is every child's right to be able to play. Play is defined in the Welsh Government Play Policy as freely chosen and personally directed. The right to play is enshrined within article 31 of the United Nations Convention on the Rights of the Child (UNCRC) and further defined within General Comment 17. The comment on article 23 about the rights of disabled children states:

“Play has been recognised as the best source of learning various skills, including social skills. The attainment of full inclusion of children with disabilities in the society is realised when children are given the opportunity, places and time to play with each other (children with disabilities and no disabilities)”

Children with learning disabilities can face additional barriers to accessing play opportunities, the Bevan Foundation found:

“Disabled children and young people face barriers from lack of provision, lack of support, poor access to buildings and negative attitudes which, notwithstanding legislation and policies, prevent them from participating like non-disabled children and young people”

Each local council in North Wales has produced a play sufficiency assessment as part of their play sufficiency duty. A survey undertaken for one of the assessments found that 46% of disabled children said that they were satisfied with their play opportunities compared to 70% overall. Another found that parents of children with complex needs

were particularly concerned about the attitude and actions of others and people's understanding of 'hidden' impairments like autism and ADHD.

The assessments show that a lot of work has taken place to understand and provide for the needs of disabled children and to make sure play projects and providers have access to a range of resources to support inclusion. For example, delivering inclusive play training to providers, activity programmes for disabled children, providing one to one support workers in mainstream provision, providing small grants for equipment training or resources and buddy schemes.

The play sufficiency assessments also set out the actions which each area is planning to improve play opportunities for disabled children including better partnership working, providing disability inclusion training, sharing resources and mentoring mainstream clubs who want to become more inclusive. Challenges to providing inclusive play opportunities include lack of accessible transport, particularly in rural areas and funding for services.

A list of resources available to support inclusive play is available from [Play Wales](#).

### **Sport and leisure**

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.

In the consultation people told us that they were involved in many different kinds of sport and leisure activities including:

“volunteering, snooker, tennis, wheelchair basketball, ten pin bowling, playing pool, Men's Sheds, magazines, star wars figures, art and art classes, cinema, shopping, watching TV and films, swimming, colouring, computer games, newspapers, ironing, watching and playing football, music, theatre, dancing, going out every night, sports clubs, buzz club, curry night, going out for meals, walking and holidays.”

People said that there needs to be more leisure activities and opportunities for people with learning disabilities, more integrated community-based activities and mixed groups.

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.

[Disability Sport Wales](#) provides an online database of disability-specific or disability-inclusive sport opportunities.

### Education and training

There are 9 special schools in North Wales with a total of 1,300 pupils, including Ysgol Plas Brondyffryn, the North Wales regional centre of excellence for teaching children on the autistic spectrum. Many children and young people with learning disabilities attend mainstream schools ([appendix 1](#)).

For more information about support for pupils with Additional Learning Needs in North Wales please see each council's strategies and plans.

### Day opportunities and work 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.

### Paid employment

We would like to see more people with learning disabilities in paid jobs. We don't know how many people with learning disabilities in North Wales currently have paid jobs but estimates suggest they are far less likely to have a job than the general population. Estimates from England suggest around 6% of adults with learning disabilities known to their local authority have a paid job. In the consultation many of the people who had paid jobs said that they were important to them although some people said they were concerned that they would struggle to find work. There is some support available at the moment, for example from:

- Disability Advisers in the Jobcentre
- Careers Wales
- [Supported employment agencies](#)

## Active support for people with profound and multiple learning disabilities

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).

### Having something meaningful to do: the change we want to see

- More people with learning disabilities will be involved in their local community.
- More people with learning disabilities will have paid jobs.
- Increased take-up of support budgets / direct payments.

## Friends, family and relationships

The [what people have told us](#) section highlights the need for more opportunities for people to develop friendships and relationships. This includes opportunities to join in socially with groups from all parts of the community, not just events arranged for people with learning disabilities.

### Friends, family and relationships: the change we want to see

- More people with learning disabilities will be involved in their local community.

## Being safe

### Children and young people

Often as a result of their disability, disabled children are more vulnerable to abuse and neglect in ways that other children and the early indicators of abuse or neglect can be more complicated than with non-disabled children (HM Government, 2006).

Young people with learning disabilities may be more vulnerable to county lines drug gangs and child sexual exploitation.

County lines drug gangs are those where an urban criminal gang travels to smaller locations to sell heroin/crack cocaine. The gangs tend to use a local property, generally belonging to a vulnerable person, as a base for their activities. This is often taken over by force or coercion (cuckooing). They pose a significant threat to vulnerable adults and children who they use to conduct and/or facilitate this criminality.

The Sexual Exploitation Risk Assessment Framework (SERAF) tool includes learning disability as a vulnerability factor for child sexual exploitation.

## Adults

Each year there are on average around 210 safeguarding concerns raised in North Wales concerning adults with learning disabilities ([appendix 1](#)). In the last five years there have been around 50 crimes in North Wales where the victim had a learning disability, including people with Down's syndrome, ADHD and Autism ([appendix 1](#)).

Children and adults with learning disabilities may be at risk of financial abuse. This is any theft or misuse of a person's money, property or resources by a person in a position of, or expectation of, trust to a vulnerable person. Common forms of financial abuse are misuse by other of a vulnerable adult's state benefits or undue pressure to change wills.

Forced marriage statistics show that there was a year on year rise in the number of people with learning disabilities being reported who may be at risk or subject to a forced marriage from 2010-16 (North Wales Safeguarding Board, 2017). Forced marriage is where one or both people do not consent or lack the capacity to consent to the marriage and pressure or abuse is used.

## North Wales Safeguarding Boards

The [North Wales Children's and Adults' Safeguarding Boards](#) are in place to make sure the citizens of North Wales are adequately prevented and protected from experiencing abuse, neglect and other kinds of harm. They have produced 7 minute briefings for professionals about the issues described above including warning signs and advice about what to do in response.

## Positive risk taking

Safeguarding children, young people and adults from the risks described above also needs to be balanced against the risk of overprotecting people which can affect their well-being (Community Care, 2015).

The importance of positive risk taking was highlighted in the consultation. People spoke about how other elements of this strategy can support safeguarding in a way that promotes independence. Such as the importance of people with learning disabilities being involved in their community so that there are people around who know them and can look out for them and the potential uses of technology.

The [Safe Places scheme](#) is now running in some parts of North Wales. A safe place helps vulnerable if they feel scared or at risk while they are out and about in the community and need support right away.

### **Criminal justice system**

An estimated 20-30% of offenders have learning disabilities or difficulties that interfere with their ability to cope within the criminal justice system (Talbot, 2008). This group is at increased risk of reoffending where support services and programmes don't meet their needs and can be targeted by other prisoners when in custody (Talbot, 2008).

A multi-agency task and finish group in Wales have developed a guidebook called 'Access to Justice' (2013) to support the 'responsive and appropriate management of adults with a learning disability in the criminal justice system in Wales. This work aims to take forward the recommendations of the Prison Reform Trust No One Knows programme.

The North Wales Police and Crime Commissioner (2017) is working with the health board to improve the response to vulnerable people that present to criminal justice agencies and target services and support to help people in crisis.

#### **Being safe summary: the change we want to see**

- More people with learning disabilities will be involved in their local community.
- More people with learning disabilities will use technology safely to help them be more independent.

## **Being healthy**

### **Mental health**

Children with learning disabilities are more likely to have mental health needs than the general population and these can start early in life (Toms et al., 2015). An estimated 30% to 50% of children who have a learning disability will also have mental health needs (National Institute for Health and Care Excellence, 2016). Research suggests that there's a high level of unmet need for mental health services for children with learning disabilities (Toms et al., 2015). This was highlighted in the consultation where people commented that access to mental health needed to be quicker for children with learning disabilities and also more support for their parents.

Research suggests that the prevalence of mental health needs in adults with learning disabilities was 41% or 28% when behaviours that challenge were excluded (Cooper et al., 2007). There is a risk that mental health needs in people with learning disabilities may not be identified due to assumptions that behaviour and symptoms are because of their learning disability (National Institute for Health and Care Excellence, 2016).

The Children's Commissioner for Wales (2018) identified a persistent and serious gap in mental health provision for young people with a learning disabilities. They found that continuity of care issues are often address by child services continuing to work with young adults, although this creates issues around suitability of services and costs. They also found that joint clinics between children's and adult health care providers were perceived as positive by young people and their families.

The Together for Mental Health in North Wales strategy sets out how we plan to improve mental health services in North Wales (Betsi Cadwaladr University Health Board, 2017).

### Screening programmes

The uptake of screening programmes in North Wales for everyone eligible was as follows.

- Cervical screening: 70% of women eligible (25 to 64 year olds) were tested within 3.5 years and 77% were tested within 5 years at 1 April 2017. This is similar to the all Wales take up (Public Health Wales, 2017c).
- Breast screening: 71% of women eligible (50 to 70 year olds) took up the invitation in 2015-16. The all Wales take up was 74% and the minimum standard for update is 70% (Public Health Wales, 2017b).
- Bowel screening: 51% of men and women eligible (60 to 74 year olds) were screened within 2.5 years at 1 October 2016. The all Wales take up was 52% (Public Health Wales, 2017a).

The uptake of screening tests for people with learning disabilities who are known to the Health Liaison Team was as follows.

- Cervical screening: 6% of women eligible were tested during the year (17 out of 305)
- Breast screening: 10% of women eligible were tested during the year (10 out of 102). This figure may be slightly undercounted as it is not always filled in on the annual health check.
- Bowel screening: 9% of men and women eligible were tested during the year (6 out of 65).

Although some of the differences in the level of uptake may be due to undercounting there is still a large difference between the take up of screening by people in the whole population and people with learning disabilities.

### Healthy lifestyles

There is a record of Body Mass Index (BMI) for 454 adults with learning disabilities in North Wales (excluding Conwy) and 178 of those had a BMI in the obese range (30 or higher). No adults had a BMI in the underweight range. The data was not available from Conwy GPs.

These figures suggest around 39% of the population of people with learning disabilities in North Wales have a BMI in the obese range. In the population as a whole, around 20% of people in North Wales have a BMI in the obese range (Welsh Health Survey, 2015).

This suggests that we need to do more to make sure that people with learning disabilities have opportunities for physical exercise and healthy eating.

### Chronic conditions

Adults with learning disabilities may also have a chronic condition such as coronary heart disease; diabetes; asthma; dysphagia (swallowing problems) or epilepsy. The data we have about the number of people who have a chronic condition and a learning disability in North Wales is incomplete. A study of GP records of adults with learning disability in England found that people with learning disabilities had higher prevalence of epilepsy, severe mental illness and dementia as well as moderately increased rates of underactive thyroid and heart failure (Carey et al., 2016). They found that the prevalence of chronic heart disease and cancer were approximately 30% lower than in the population as a whole. This is surprising as people with learning disabilities have a higher prevalence of risk factors for chronic heart disease, so researchers think it may be that these conditions aren't being identified as well. They also suggest that lower rates of smoking and alcohol use among people with learning disabilities may contribute although there isn't any evidence to confirm this at the moment.

### Dementia

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).

## **Mortality**

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, there has been a dramatic change in life expectancy for people with Down's Syndrome since the 1930s rising from age 10 to around age 50 over the course of 70 years (Holland, 2000).

However, people with learning disabilities are still at more risk of dying early compared to the general population and are more likely to die from causes that could have been prevented (Mencap, 2012, Hosking et al., 2016).

## **Annual health check**

In North Wales 2,900 people with learning disabilities aged 18 and over are eligible for an annual health check and around 1,700 people (57%) had the health check in the last year.

There are 116 GP practices in North Wales, of which 71 are signed up to delivering the learning disability annual health check.

## **In-patient units at Bryn y Neuadd**

The inpatient learning disabilities services within Mental Health and Learning Disabilities Division provides highly specialised person centred care for people with learning disabilities within a safe environment. They provide a range of specialist services, inclusive of assessment and treatment; rehabilitation; assessment and treatment for people with profound and multiple needs and therapeutic support services in a specialist learning disability hospital setting. There are currently three wards within the Learning Disability Inpatient Service at Bryn y Neuadd hospital. During 2016-17 there were around 50 admissions to these units due to mental health needs, challenging behaviour and/or physical health needs.

## **Continuing health care**

There are 280 people with learning disabilities in receipt of continuing health care funding in North Wales. Of these, 224 are jointly funded between health and social services and 56 are fully funded by health.

## **Admissions to an Acute Hospital**

There is a North Wales shared care agreement for carers supporting patients with a learning disability in hospital for use when the ward has identified that there is a need for additional support. Some people with learning disabilities will benefit from having their own familiar support while in hospital which can reduce anxiety, prevent diagnostic overshadowing and help support the hospital to make reasonable adjustments.

## Communication standards

The Royal College of Speech and Language Therapists (2013) have produced five good communication standards, which are reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings. The document includes links to useful resources. The standards are are:

- **Standard 1:** There is a detailed description of how best to communicate with individuals.
- **Standard 2:** Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.
- **Standard 3:** Staff value and use competently the best approaches to communication with each individual they support.
- **Standard 4:** Services create opportunities, relationships and environments that make individuals want to communicate.
- **Standard 5:** Individuals are supported to understand and express their needs in relation to their health and well-being.

## Being healthy: the change we want to see

- More people with learning disabilities will take up cancer screening opportunities when offered.
- Reduced demand on specialist learning disability services.
- Fewer people will fall between the gaps in services.

## Having the right support

We want to provide the right support at the right time to the right people in the right place. To provide support that helps people to do what they want, gives them choice and control over their own lives and promotes positive risk taking.

### Having the right support with changes and transitions

The services people need will change throughout their lives. These changes, or times of transition, can include:

- moving from school to college;
- moving from school or college into work; or,
- moving from living with parents into their own place;

The services available to support people may also change at specific times, for example, moving from children's services to adult services at age 18. Some services in

North Wales co-produce transition plans to support young people age 14 to 17 with this change and others have a lifetime disability service so they don't use formal transition plans. In this case the outcomes (what matters to people) in relation to the transition are recorded in the statutory care and support plans.

The Children's Commissioner for Wales (2018) has spoken to young people, parents and carers and professionals throughout Wales about their experiences and views about transitions to adulthood for young people with learning disabilities. The key messages from young people and their families were:

- Young people's participation in planning and decision-making appears to be very low – this means that their different priorities and specific interests can get missed.
- 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.
- 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.

### **Support for people with profound and multiple learning disabilities (PMLD)**

People with profound and multiple learning disabilities (PMLD) need a high level of support to lead good lives as described in this strategy. A group of family members, education, health and social care professionals have developed a set of Service Standards to be used by commissioners and providers of services for people with PMLD (Doukas et al., 2017). The standards have been developed to be used as an internal auditing tool and they recommend that they are used as part of an annual

self-assessment process with action plans developed to address areas that need improving. They include standards for organisations around leadership, quality, staff development (skills and confidence), physical environment, communication, health and well-being, social, community and family life.

Additional resources on how to improve services for adults with PMLD are available in the Raising Our Sights guides available from [www.bit.ly/raising-our-sights-guides](http://www.bit.ly/raising-our-sights-guides).

### **End of life care**

The [lifespan pathway](#) included at the start of the report highlights how end of life care may be needed at any point in the pathway.

A report by the Care Quality Commission (2016) identified inequalities in end of life care for people with learning disabilities. This included a lack of understanding of people's individual needs; not identifying people who are approaching the end of life at an early enough stage because of poor access to physical healthcare; poor communication, for example, health and social care staff making assumptions about people's ability to 'cope' with discussions about end of life. The Welsh Government (2017a) has published their Palliative and End of Life Care Delivery Plan which sets out how they plan to improve the delivery of all aspects of palliative and end of life care including support for people of all ages and the needs of those experiencing bereavement.

The service standard for people with PMLD is that 'The organisation ensures each person has an End of Life Plan in place, in consultation with the person, their family and other appropriate members of the circle of support' (Doukas et al., 2017).

### **Carer breaks**

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.

There is a North Wales Carers' Strategy [\[add link\]](#) and carers journey mapping carried out to inform the strategy highlighted how important it was to have the right support in place for the person cared for in order to support the carers. We have reviewed the provision of respite/short-term break resources for individuals with a learning disability or complex needs and their carers in North Wales (Hay, 2017) and developed a set of recommendations which we will implement as part of the strategy.

Carer breaks have traditionally been referred to as 'respite' although the term has also been associated with respite from something that is a burden so we are starting to use the term 'carer breaks' in preference.

See the [early years section](#) for more information about short breaks for children with learning disabilities.

## Advocacy

The Welsh Government describes advocacy as having two main themes:

“speaking up for and with individuals who are not being heard, helping them to express their views and make their own informed decisions and contributions, and, safeguarding individuals who are at risk”.

There are different forms of advocacy which include:

- **Self-advocacy** when individuals represent and speak up for themselves.
- **Informal advocacy** when family, friends or neighbours support an individual to have their wishes and feelings heard, which may include speaking on their behalf.
- **Independent volunteer advocacy** involves an independent and unpaid advocate who works on a short term, or issue led basis, with one or more individuals.
- **Formal advocacy**, which can refer to the advocacy role of staff in health, social care and other settings where professionals as part of their role consider the wishes and feelings of an individual and help make sure they are addressed properly.
- **Independent professional advocacy** involves an independent professional advocate who is trained and paid to undertake the role. They must make sure individuals' views are accurately conveyed irrespective of the view of the advocate or others as to what is in the best interests of the individuals.

There are self-advocacy groups for people with learning disabilities in each county in North Wales.

It is important to involve and ‘listen to’ people with profound and multiple learning disabilities (PMLD). Advocacy for people with PMLD may involve ‘representational advocacy’ where an independent advocate speaks on their behalf and families are also important advocates for people with PMLD. When commissioning advocacy services for people with PMLD we need to take into account the observational and listening skills of the advocate and ability to communicate in a variety of ways with the individual and family members, a good understanding of human rights as well as giving the right amount of time (Mencap and PMLD Network, 2013).

## Support for parents with a learning disability

The research suggests that best practice for supporting parents with a learning disability should include the following (Stewart and McIntyre, 2017).

- Early identification of parents with learning disabilities so that appropriate support can be put in place. This will need to address concerns parents may have about discrimination and assumptions about their ability to parent.
- Good partnership working to make sure parents with learning disabilities don't fall between services. For example, a person may not have been eligible for learning disability services before having parental responsibility. Also need to make sure staff are aware of the needs of people with learning disabilities, how to support them and make reasonable adjustments. This includes GPs, midwives and health visitors, social workers working in child protection and family support services and advocates and others working in family courts.
- Early assessment of parenting skills that identifies strengths as well as support needs and gives people time to develop their skills. For example, by using the Parents Assessment Manual (PAMS). Multi-disciplinary support should be available to help people address any issues identified.
- Make sure information is accessible including information about pregnancy and childcare and especially any information about child protection proceedings.
- Support should be family focussed, adapted to the family's needs and take a strengths-based approach. Some families will need on-going or long-term support.
- Promote the use of independent advocacy and self-advocacy. In child protection proceedings generic advocacy may not be sufficient as advocates will need knowledge of child protection law and the needs of people with learning disabilities. In our consultation parents with a learning disability said it was important that they get to have their say too.

One of the childcare sufficiency assessments mentioned the importance of access to childcare for parents with learning difficulties.

As part of the Improving Outcomes for Children Ministerial Advisory Group phase 2 work programme (Welsh Government, 2018b), *Workstream 2: Assessment of Risk and Edge of Care Services* includes actions to:

- Undertake research to identify the number of children who have parents with a learning disability who no longer live at home and the reasons behind their change of status.
- Develop guidance for reducing the number of looked after children taken from parents with a learning disability.

Looked after children are also a priority in the Welsh Government (2018c) Improving Lives Programme which aims to 'improve the outcomes of parents with a learning disability and their children to ensure a good quality of life'.

There is a network for parents with a learning disability in North Wales supported by [Learning Disability Wales](#). It is open to parents whether their child lives with them or not and provides an opportunity to share experiences and stories with each other with each other and also with social services and Welsh Government.

**The right support: the change we want to see**

- Fewer people will fall between the gaps in services.
- No-one will experience delays in support due to disagreements between services.
- Increased take-up of support budgets / direct payments.
- People with learning disabilities and their parents/carers will have access to good consistent information and advice.

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## Putting the strategy into action

To achieve our vision and provide services based on what matters to people (a good place to live, something meaningful to do and so on) we have planned five work packages that will set out *how* we will change things in order to achieve good lives for people with learning disabilities. The work packages will include actions to improve support throughout people’s lives and meet the needs of people with profound and multiple learning disabilities. They will take an asset-based approach to build on the skills, networks and community resources that people with learning disabilities already have. The diagram below shows how the different parts of the project will fit together.

Putting the strategy into action will include not just people who provide specific learning disability services. To achieve our vision we need to co-produce services with people with learning disabilities and their parents/carers and share power and responsibility for making these changes. We also need to work closely with staff in the six local authorities and the health board outside of specific learning disability services such as GPs to improve communication and understanding of the reasonable adjustments that people with learning disabilities may need to access health care and other public services. The key to achieving our vision will be to work with local communities to make sure people with learning disabilities are truly valued and included in their communities.

### North Wales Together: Seamless services for people with learning disabilities

#### Co-produced work packages

- Integrated structures
- Workforce development
- Commissioning and procurement
- Community and culture change
- Assistive technology

#### The citizen and what matters to them

- Early years
- A good place to live
- Something meaningful to do
- Friends, family and relationships
- Being safe
- Being healthy
- The right support

## Integrated structures

### **Making sure health and social services work together better to support people with learning disabilities.**

We want an integrated service where no citizens fall between the gaps in services with seamless transitions through changes in life. We will build on current good practice across North Wales with integrated health and social care teams and lifespan approaches to disability services to develop models and structures that provide seamless care to the individual.

#### **Actions**

- Review current models of integration and share best practice across the region.
- Reduce any duplication of record systems so people only have to 'say it once'.
- Make sure there is sufficient support for the health issues of older people with learning disabilities, including people with dementia.

#### **How we will know if we've made a difference**

- New integrated structures will be in place.
- Fewer people will fall between the gaps in services (identified through consultation and engagement, feedback and complaints).
- No-one will experience delays in support due to disagreements between services.

## Workforce development

### **Making sure staff know how to communicate well with people with learning disabilities in Welsh or English and can make changes to support them well. This will help people get the health care they need.**

We want to see more awareness of disability issues among the wider public sector workforce including the reasonable adjustments that can be made to provide people with learning disabilities fair and equitable access to services and other community resources.

#### **Actions**

- Bring different parts of the workforce together to share best practice.
- Develop a consistent value-based skill set for staff across the region.
- Provide support for the wider workforce, including GPs and healthcare assistants about reasonable adjustments and preventative measures.
- Work with Public Health Wales to improve the take-up of cancer screening by people with learning disabilities.

### **How will we know if we've made a difference**

- More people with learning disabilities will take up cancer screening opportunities when offered.
- Reduced demand on specialist learning disability services.
- People with learning disabilities and their parents/carers will have access to good consistent information and advice.

## **Commissioning and procurement**

### **Work with other organisations to make sure we have the types of housing and support people need.**

We want to move towards person-centred, outcome models of commissioning where the process is led by the person to deliver services that develop self-reliance, improve quality of care, reduce demand and re-invest in new forms of care.

### **Actions**

- Explore and pilot pooled budgets between health and social care in a locality.
- Provide sustainable models of support jointly by health and social care to meet the needs of individuals with complex needs. 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.
- Increase recruitment to the shared lives / adult placements scheme.
- Continue to explore and develop housing options to meet the needs of people with learning disabilities in partnership with other organisations.
- Improve the use of and support available for support budgets / direct payments.
- Support older carers and make sure they have the support and carer break (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.
- Implement the recommendations of the *Development of Respite/ Short-term Break Resources across North Wales for Individuals with a Learning Disability or Complex Needs and their Carers* report (Hay, 2017)

### **How will we know if we've made a difference**

- There will be fewer out of area placements.
- More people with learning disabilities will have choice and control over where they live and how they are supported.
- Increased take-up of support budgets / direct payments.
- Carers will have access to a range of flexible carer breaks.

## Community and culture change

**Work with the local community to make sure people with learning disabilities can access lots of different activities and meet new people if they want to. Help more people with learning disabilities to get paid jobs.**

We want to raising awareness and build friendships and relationships within an inclusive community to make the most of the assets, resources and skills available.

### **Actions**

- Work with local employers to develop employment opportunities for people with learning disabilities as well as other day opportunities.
- Build on the work of community navigators, local area coordinators and social prescribing models to develop a co-productive, scalable structure for community inclusion.

### **How will we know if we've made a difference**

- More people with learning disabilities will be involved in their local community.
- More people with learning disabilities will have paid jobs.

## Assistive technology

**Find ways to use technology like alarms and mobile phones to help people be more independent.**

### **Actions**

- Developing skills, knowledge and training about the potential of existing technologies (such as mobile phones and voice controlled personal assistants like Alexa) to support people with learning disabilities.
- Develop the provision of assistive technology for people with learning disabilities.
- Provide more support for people with staying safe when using the internet.

### **How will we know if we've made a difference**

- More people with learning disabilities will use technology safely to help them be more independent.

## References

- Betsi Cadwaladr University Health Board 2017. Together for Mental Health in North Wales.
- Care Quality Commission 2016. A different ending: Addressing inequalities in end of life care.
- Carey, I. M., Shah, S. M., Hosking, F. J., DeWilde, S., Harris, T., Beighton, C. and Cook, D. G. (2016) 'Health characteristics and consultation patterns of people with intellectual disability: a cross-sectional database study in English general practice', *British Journal of General Practice*.
- Children's Commissioner for Wales 2014. Full Lives: A study of short breaks provision for children and young people with disabilities and their carers in Wales.
- Children's Commissioner for Wales 2018. 'Don't hold back' Transitions to adulthood for young people with learning disabilities.
- Community Care (2015) *Decisions to safeguard adults with learning disabilities can make them less safe*. Available at: <http://www.communitycare.co.uk/2015/04/21/decisions-safeguard-adults-learning-disabilities-can-make-less-safe/>.
- Conwy Connect (2014) *Reducing Stigma*. Available at: <http://www.conwy-connect.org.uk/category/engagement-service/reducing-stigma/>.
- Conwy County Borough Council (2013) *Families First Research*. Available at: <http://www.conwy.gov.uk/doc.asp?doc=31283&cat=10032&Language=1>.
- Cooper, S.-A., Smiley, E., Morrison, J., Allan, L. and Williamson, A. (2007) 'Prevalence of and associations with mental ill-health in adults with intellectual disabilities', *British Journal of Psychiatry*, 190, pp. 27-35.
- CSSIW 2016. National inspection of care and support for people with learning disabilities.
- Department of Health 2001. Valuing People: A new Strategy for Learning Disability in the 21st Century. London: Department of Health.
- Doukas, T., Fergusson, A., Fullerton, M. and Grace, J. 2017. Supporting people with profound and multiple learning disabilities.
- Emerson, E. and Heslop, P. 2010. A working definition of Learning Disabilities. Improving health and lives: Learning Disabilities Observatory.
- Emerson, E., Malam, S., Davies, I. and Spencer, K. 2005. Adults with Learning Difficulties in England 2003/4. NHS Health and Social Care Information Centre.

- Hay, A. 2017. Development of respite/short-term break resources across North Wales for individuals with a learning disability or complex needs and their carers.
- HM Government 2006. Working Together to Safeguard Children. *A guide to inter-agency working to safeguard and promote the welfare of children*. London: TSO.
- Holland, A. J. (2000) 'Ageing and learning disability', *The British Journal of Psychiatry*, 176, pp. 26-31.
- Holland, A. J., Hon, J., Huppert, F. A., Stevens, F. and Watson, P. (1998) 'Population based study of the prevalence and presentation of dementia in adults with Down's syndrome.', *British Journal of Psychiatry*, 172, pp. 493-498.
- Holtom, D. and Bowen, R. 2016. Study to map the current educational provision of speech, language and communication support in Wales, for learners aged 0-25. Welsh Government.
- Hosking, F. J., Carey, I., Shah, S. M., Harris, T., DeWilde, S., Beighton, C. and Cook, D. G. (2016) 'Mortality among adults with intellectual disability in England: comparisons with the general population', *The American Journal of Public Health*, 106(8), pp. 1483-1490.
- Isle of Anglesey County Council, Gwynedd Council, Conwy County Borough Council, Denbighshire County Council, Flintshire County Council, Wrexham County Borough Council and Betsi Cadwaladr University Health Board 2016. North Wales population assessment: Analysis of feedback from organisations.
- Jones, E., Perry, J., Lowe, K., Allen, D., Toogood, S. and Felce, D. 2014. Active Support: A handbook for supporting people with learning disabilities to lead full lives. ARC Cymru.
- Kerr, D. 2007. Understanding Learning Disability and Dementia: Developing Effective Interventions. London: Jessica Kingsley Publishers.
- Mencap 2012. Death by indifference: 74 deaths and counting. *A progress report 5 years on*.
- Mencap and PMLD Network 2013. Raising our Sights guides.
- Mobius UK (2008) *Developing 'citizen centred' services for people with learning disabilities*: North Wales Social Services Improvement Collaborative. Available at: [http://www.asdinfo.wales.co.uk/resource/q\\_s\\_NWSSIC\\_-\\_Final\\_report.pdf](http://www.asdinfo.wales.co.uk/resource/q_s_NWSSIC_-_Final_report.pdf).
- Multi-agency task and finish group 2013. Access to justice. *In*: Royal College of Psychiatrists, Public Health Wales, Welsh Government, Learning Disability Wales, Mencap Cymru, NHS Wales, HM Prison Service, National Offender Management Service, CPS, All Wales Criminal Justice Board, North Wales Police, South Wales Police, Gwent Police, Dyfed Powys Police, Prison Reform Trust, Wales Probation & Service, H.C.a.T. (eds.).

- National Commissioning Board 2017. Commissioning Services for People with a Learning Disability: Good Practice Guidance. *In*: Institute of Public Care (ed.).
- National Institute for Health and Care Excellence 2016. Mental health problems in people with learning disabilities: prevention, assessment and management.
- North Wales Learning Disability Partnership 2015a. Evaluation report: North Wales Learning Disabilities Event 26 March 2015.
- North Wales Learning Disability Partnership 2015b. Participation Strategy.
- North Wales Safeguarding Board 2017. Safeguard People with Learning Disabilities from Forced Marriage - 7 Minute Briefing.
- Office of the Police and Crime Commissioner North Wales 2017. Police and Crime Plan 2017-2021.
- Public Health Wales 2017a. Bowel Screening Wales Annual Statistical Report 2015-16.
- Public Health Wales 2017b. Breast Test Wales Annual Statistical Report 2015-16.
- Public Health Wales 2017c. Cervical Screening Wales Annual Statistical Report 2016-17.
- Royal College of Speech and Language Therapists 2013. Five good communication standards. *Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings.*
- Stewart, A. and McIntyre, G. 2017. Parents with learning disabilities. Glasgow: Institute for Research and Innovation in Social Services.
- Talbot, J. 2008. Prisoners' voices: Experiences of the criminal justice system by prisoners with learning disabilities and difficulties. *No One Knows: Report and final recommendations.* Prison Reform Trust,.
- The Communication Trust 2010. Don't get me wrong. *Information for supporting children and young people with speech, language and communication needs.*
- Toms, G., Totsika, V., Hastings, R. and Healy, H. (2015) 'Access to services by children with intellectual disability and mental health problems: Population-based evidence from the UK', *Journal of Intellectual and Developmental Disability*, 40(3), pp. 239-247.
- Wales Audit Office 2018. Strategic Commissioning of Accommodation Services for Adults with Learning Disabilities.
- Ward, C. 2012. BILD Factsheet: Older people with a learning disability. British Institute of Learning Disabilities.

Welsh Government 2015. Social Services and Well-being (Wales) Act 2014: Part 9 Code of Practice (Partnership Arrangements).

Welsh Government 2017a. Palliative and End of Life Care Delivery Plan.

Welsh Government 2017b. Prosperity for All: the national strategy.

Welsh Government 2018a. A Healthier Wales: our Plan for Health and Social Care.

Welsh Government 2018b. Improving Outcomes for Children Ministerial Advisory Group.

Welsh Government 2018c. Learning Disability: Improving Lives Programme.

Welsh Government 2018d. Parliamentary Review of Health and Social Care in Wales. *A Revolution from Within: Transforming Health and Care in Wales.*

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## Appendix 1: Baseline data

This appendix includes the baseline data gathered to inform the strategy.

### Children and young people

There are reliability issues with much of the data collected about children with learning disabilities due to differences in the definitions used and the way data is collected.

There are around 102,000 pupils in North Wales, the total school-age population. Table 2 below shows the number of pupils who have a learning difficulty. The way education services define learning difficulties as moderate, severe or profound is different to the way social services assess whether someone needs support from learning disability services. These figures can't therefore be used to tell how many young people are likely to need support from learning disability services as adults.

**Table 1: Number of pupils with a learning difficulty, 2016-17**

	Moderate	Severe	Profound	ASD
Anglesey	335	135	20	125
Gwynedd	820	130	50	115
Conwy	360	45	30	325
Denbighshire	250	85	30	375
Flintshire	885	95	40	245
Wrexham	695	115	30	295
North Wales	3,345	605	200	1,480

Source: PLASC, Welsh Government, [Stats Wales](#)

*Numbers have been rounded to the nearest 5.*

**Table 2: Estimated number of children aged 0-17 with a learning difficulty**

	Moderate	Severe	Profound
Anglesey	777	100	25
Gwynedd	700	91	22
Conwy	1143	148	36
Denbighshire	818	106	26
Flintshire	494	64	16
Wrexham	1,095	142	35
North Wales	5,027	651	160

Source: Daffodil, estimates based on prevalence in the population

Table 3 shows the number of children receiving care and support who have a disability or Statement of Special Educational needs.

**Table 3: Number of children receiving care and support with a disability or Statement of Special Educational Needs (SEN) (2017)**

	Children with a disability	Children with a Statement of SEN
Anglesey	75	65
Gwynedd	245	175
Conwy	155	120
Denbighshire	90	35
Flintshire	65	40
Wrexham	65	75
North Wales	695	505

Source: Children Receiving Care and Support Census, Welsh Government, StatsWales

Numbers have been rounded to the nearest 5.

**Table 4: Number of children aged 0-17 with a moderate learning difficulty, 2017 to 2035**

	2017	2020	2025	2030	2035	Predicted change between 2017 and 2035
Anglesey	490	505	505	480	450	-46
Gwynedd	820	820	830	840	860	38
Conwy	780	790	780	750	700	-76
Denbighshire	700	720	730	710	690	-15
Flintshire	1,140	1,150	1,140	1,080	1,030	-120
Wrexham	1,100	1,130	1,150	1,130	1,120	29
North Wales	5,030	5,100	5,130	4,980	4,840	-190

Source: Daffodil, estimates based on prevalence in the population

Numbers have been rounded so may not sum.

**Table 5: Number of children under 16 in receipt of Disability Living Allowance (DLA) February 2018**

	Age under 5	Aged 5 to under 11	Aged 11 to under 16	Total
Anglesey	50	190	180	420
Gwynedd	70	300	290	660
Conwy	80	410	410	900
Denbighshire	100	380	480	960
Flintshire	120	490	490	1,100
Wrexham	100	510	620	1,230
North Wales	510	2,270	2,460	5,240

Source: ONS (from Nomis)

Numbers have been rounded so may not sum.

**Adults****Table 6: Number of adults aged 18 and over predicted to have a learning disability, 2017 to 2035**

	2017	2020	2025	2030	2035	Predicted change between 2017 and 2035
Anglesey	1,300	1,300	1,300	1,300	1,300	-20
Gwynedd	2,400	2,400	2,400	2,500	2,500	170
Conwy	2,200	2,200	2,200	2,200	2,200	20
Denbighshire	1,800	1,800	1,800	1,900	1,900	120
Flintshire	2,900	2,900	2,900	2,900	2,900	60
Wrexham	2,600	2,700	2,800	3,000	3,100	440
North Wales	13,100	13,300	13,400	13,700	13,900	780

Source: Daffodil

**Table 7: Number of adults aged 18 and over predicted to have a moderate or severe learning disability, 2017 to 2035**

	2017	2020	2025	2030	2035	Predicted change between 2017 and 2035
Anglesey	260	260	250	250	250	-20
Gwynedd	480	490	490	500	510	30
Conwy	430	430	420	420	420	-10
Denbighshire	360	360	360	370	370	10
Flintshire	590	590	580	580	580	-10
Wrexham	550	560	580	610	630	80
North Wales	2,680	2,680	2,690	2,730	2,750	80

Source: Daffodil, estimates based on prevalence in the population

Note: The number of adults aged 18-64 is predicted to decline by around 25 people, which is why the increase in the total adults aged 18 and over is lower than the increase in the total adults aged 65 and over.

**Table 8: Number of adults aged 65 and over predicted to have a learning disability, 2017 to 2035**

	2017	2020	2025	2030	2035	Predicted change between 2017 and 2035
Anglesey	370	390	420	440	460	90
Gwynedd	580	590	620	660	690	120
Conwy	660	680	730	790	840	190
Denbighshire	480	500	540	590	630	150
Flintshire	680	720	770	850	920	240
Wrexham	570	600	660	730	800	230
North Wales	3,330	3,490	3,730	4,060	4,350	1,010

Source: Daffodil, estimates based on prevalence in the population

**Table 9: Number of adults aged 65 and over predicted to have a moderate or severe learning disability, 2017 to 2035**

	2017	2020	2025	2030	2035	Predicted change between 2017 and 2035
Anglesey	50	50	50	60	60	10
Gwynedd	80	80	80	90	90	10
Conwy	90	90	90	100	110	20
Denbighshire	60	70	70	80	80	20
Flintshire	90	100	100	110	120	30
Wrexham	80	80	90	90	100	30
North Wales	450	470	490	520	550	110

Source: Daffodil, estimates based on prevalence in the population

### Expenditure on services

Local authorities had spent around £85 million a year in North Wales on services for people with learning disabilities as shown in table 4 and 5 below. This increased to £96 million in 2016-17 due to transfers to meet the cost of providing support to former Independent Living Fund (ILF) recipients.

**Table 10: Social services revenue expenditure, adults aged under 65 with learning disabilities**

	2011-12	2012-13	2013-14	2014-15	2015-16	2016-17
	£ thousands					
Anglesey	8,134	6,936	6,812	7,180	7,763	8,373
Gwynedd	12,733	12,223	13,105	13,386	14,931	15,911
Conwy	16,791	16,095	16,401	16,362	16,729	18,676
Denbighshire	11,685	12,001	12,045	12,781	9,993	14,230
Flintshire	18,676	17,650	17,697	17,959	20,194	21,814
Wrexham	16,368	16,096	15,811	15,163	14,440	17,122
North Wales	84,387	81,001	81,871	82,831	84,050	96,126

Source: Revenue outturn data collection, Welsh Government, StatsWales

**Table 11: Social services capital expenditure on personal social services**

	2011-12	2012-13	2013-14	2014-15	2015-16	2016-17
	£ thousands					
Anglesey	21,619	25,428	24,105	21,288	43,976	36,640
Gwynedd	35,752	42,470	41,461	32,417	35,534	29,309
Conwy	28,009	28,704	38,630	27,966	19,426	30,478
Denbighshire	39,733	38,345	42,003	35,662	88,562	42,964
Flintshire	43,026	39,821	38,058	40,401	140,301	63,493
Wrexham	56,042	42,250	45,144	54,847	219,453	84,208
North Wales	224,182	217,018	229,401	212,581	547,252	287,092

Source: Capital outturn (COR) data collection, Welsh Government, StatsWales

## Compliments and complaints

Overall during 2016-17 local council and health services received around 40 formal complaints about learning disability services. Most complaints are resolved informally. The numbers are too few to identify any trends or issues developing across North Wales.

The number of formal complaints received by local authority learning disability services is listed in the table below. The numbers can't be compared against each other or year to year as they are counted differently. For example, some services include children and adults while others include adults only and some figures are for a whole disability service rather than the learning disability service. The data shows how the number of complaints increases when services change or are reduced.

**Table 12: Number of formal complaints received, Learning Disability, 2016-17**

	2014-15	2015-16	2016-17
Anglesey	<5	<5	<5
Gwynedd	10	<5	<5
Conwy	5	5	10
Denbighshire	5	5	5
Flintshire	20	60	10
Wrexham	30	10	10
BCUHB	<5	10	<5
North Wales	80	90	40

Source: Local authority data collection

*Numbers have been rounded to the nearest 5.*

Local authorities and health services also receive compliments about the work they are doing well.

## Children in need of care and support

There is no consistent data available about the number of children with a learning disability in foster placements. The number of children in North Wales on the learning disability register in foster placements is 23 in 2016-17 which seems like an undercount. The table below shows the total number of looked after disabled children.

**Table 13: Number of disabled children looked after at 31 March 2017**

2014-15	
Anglesey	15
Gwynedd	25
Conwy	15
Denbighshire	30
Flintshire	30
Wrexham	<5
North Wales	120

Source: Children receiving care and support census, StatsWales.

Numbers have been rounded to the nearest 5

### Community based, residential services and nursing care

Please note, the data is not available for 2015-16 due to reduced data collection.

**Table 14: Number of adults (over 18) with a learning disability who receive community-based services**

	2010-11	2011-12	2012-13	2013-14	2014-15
Anglesey	170	126	154	172	174
Gwynedd	246	255	275	203	332
Conwy	324	358	393	398	381
Denbighshire	222	256	277	288	295
Flintshire	422	368	398	418	424
Wrexham	281	271	268	285	276
North Wales	1,665	1,634	1,765	1,764	1,882

Source: StatsWales

**Table 15: Number of adults (over 18) with a learning disability who receive residential services**

	2010-11	2011-12	2012-13	2013-14	2014-15
Anglesey	37	37	29	34	28
Gwynedd	15	23	34	41	49
Conwy	73	83	74	75	69
Denbighshire	55	50	49	49	52
Flintshire	44	42	46	42	52
Wrexham	43	39	40	36	34
North Wales	267	274	272	277	284

Source: StatsWales

**Table 16: Number of adults (over 18) receiving nursing care (Independent sector care homes)**

	2010-11	2011-12	2012-13	2013-14	2014-15
Anglesey	2	2	3	4	3
Gwynedd	0	0	0	2	2
Conwy	10	15	16	17	15
Denbighshire	0	0	0	0	1
Flintshire	1	3	4	7	4
Wrexham	16	4	2	1	1
North Wales	29	24	25	31	26

Source: Stats Wales

### In-patient units at Bryn y Neuadd

- Mesan Fach Assessment and Treatment Unit
- Tan y Coed rehabilitation provision
- Foelas assessment and treatment unit for people with PMLD.

The number of admissions of people with learning disabilities who were admitted to in-patient units in Bryn y Neuadd in 2016-17 were as follows.

- 16 admissions to Mesen Fach due to challenging behaviour.
- 22 admissions to Mesen Fach due to mental health needs.
- Less than 5 admissions to Mesen Fach with additional physical health needs and 5 admissions to Foelas with physical health needs.
- 5 people were admitted once or more to both in-patient and mental health and learning disability care for management of challenging behaviour during the year.

### Deprivation of Liberty Safeguards

The table below shows the number of DoLS referrals made by each local authority for people with learning disabilities during 2016-17.

**Table 17: Number of Deprivation of Liberty Safeguards (DoLS) referrals, 2016-17**

	2016-17
Anglesey	14
Gwynedd	25
Conwy	65
Denbighshire	27
Flintshire	21
Wrexham	8
North Wales	160

Source: Local authority data collection

## Schools

**Table 18: Number of special schools and pupils in North Wales, 2017-18**

	Number of schools	Number of pupils
Anglesey	1	92
Gwynedd	2	215
Conwy	1	221
Denbighshire	2	277
Flintshire	2	209
Wrexham	1	295
North Wales	9	1,309

**Source:** Pupil Level Annual School Census (PLASC), Welsh Government, Stats Wales

## Safeguarding

The table below shows the numbers of crimes in each county although the numbers are not large enough to show any trend over time or significant differences between counties.

**Table 19: Number of crimes linked to victims with learning disabilities**

	2012-2016	
	North Wales	
Anglesey	5	2012 5
Gwynedd	5	2013 10
Conwy	10	2014 15
Denbighshire	10	2015 5
Flintshire	10	2016 20
Wrexham	10	Total 50
North Wales	50	

**Source:** North Wales Police

*Numbers have been rounded so may not sum.*

The table below shows the number of safeguarding concerns in each county in North Wales.

**Table 20: Number of adult safeguarding concerns concerning adults with learning disabilities**

	2012-13	2013-14	2014-15	2015-16
Anglesey	20	30	20	25
Gwynedd	20	35	15	30
Conwy	55	60	60	50
Denbighshire	20	30	15	40
Flintshire	30	55	50	35
Wrexham	30	30	30	50
North Wales	180	240	190	230

**Source:** StatsWales

*Numbers have been rounded so may not sum.*