

**Cwm Taf Statement of Strategic Intent**

**Children, Young People, Adults with Learning Disabilities (including autism and complex needs) and their families.**

**September 2016**

# Children, Young People, Adults with Learning Disabilities (including autism and complex needs) and their families.

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## 1 Introduction

This Statement of Strategic Intent is set within the context of the Social Services and Wellbeing (Wales) Act 2014 and it outlines the strategic approach to the commissioning of learning disability services by partners across Cwm Taf. Strategic commissioning is about analysing and prioritising needs in our communities and designing and delivering services that target our resources in the most effective way. A shift in local demographics, the new policy landscape and the changing expectations and needs of individuals with learning disabilities and their families necessitates an updated analysis of needs and a modernising of services.

This statement encompasses individuals with learning disabilities of all ages and those with complex needs and/or autism and their families. Individuals with learning disabilities are those who have:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:
- A reduced ability to cope independently (impaired social functioning)
- Which started before adulthood with a lasting effect on development

The degree of these difficulties varies considerably from mild to severe and each individual is different and therefore the range of support required varies from minimal to extensive. While some people with mild learning disabilities may have few significant problems, those with severe learning disabilities may have a variety of interconnecting needs that impact greatly on all aspects of their lives. People with a learning disability will often experience other difficulties. Autism itself, for example, is not a learning disability but around half of people with autism will also have a learning disability. For some people it is not the degree of learning disability that determines the level of support they need but the presence of some other significant factor, e.g. mental illness, offending behaviour or autism.

This statement summarises an agreed analysis of need, and describes a shared vision of strategic direction for service development for the future. The strategic approach described takes a whole systems perspective. This document underpins the individual agency implementation and action plans.

**“We have to do  
different things,  
not the same  
things  
differently”**

**(Gwenda Thomas,  
Deputy Minister for  
Social Services:  
January 2014)**

*Currently, too many people are in receipt of traditional residential and day centre style services. Too few people are supported to continue to live in their local communities. Not enough people access education and employment services. There are still too few children and adults accessing flexible support via direct payments.*

## 2 Key National and Local Messages

The Social Services and Wellbeing (Wales) Act 2014 that came into force in April 2016 also brings with it an emphasis on wellbeing. Key principles embedded within the Act include:

- Ensuring adults and children who need care and support and carers (including young carers) have a voice, more control over their lives and are at the heart of decision making
- Working in partnership, including the integration of services across health and social care with a focus on the delivery of preventative approaches, based on building strengths and promoting independence with the right level of care and support
- The provision of appropriate advice, information and assistance, strengths based and person centred assessment inclusive of young people and carers

The Cwm Taf Social Services and Wellbeing Partnership Board have committed to a range of strategic intentions across the region in line with the implementation of the Social Services and Wellbeing (Wales) Act 2014. Specific to learning disabilities is the commitment to developing new models for delivering care and support.

The Quality Strategy Cwm Taf University Health Board 2014-2017 has identified the need for effective care and improving health outcomes for people with a learning disability accessing general hospital care including the implementation of the 1,000 Lives guidance for improving the care of patients with a learning disability.

A fundamental principle for limiting the use of institutional (including hospital) settings is key to improving the life outcomes of people, as such settings remove individuals from their families and community thus reducing the voice and increasing isolation, provide significant environmental challenges for the individual resulting in distress and associated behaviours and institutionalised workforce cultures that can escalate to instances of abuse. The 'Forward Together Strategic Framework for South Wales Learning Wales Learning Disability Collaborative (Adult Services)' (2013) promotes the use of mainstream services through reasonable adjustments. The Mansell Report (2007) states that this approach not only improves the quality of life of individuals but also provides cost benefits which in this time of austerity is important.

In considering the specific needs of children, young people and adults with a learning disability (including autism) and behaviours that challenge, it is recognised that every effort should be taken to provide a person centred approach that provides services around the individual within a community setting. The Children Commissioner (England) 2015 undertook a study of the impact of young people placed in 52 week residential placements which identified a detachment from their families and local community. This often results in dependency on the unit and the staff, and an increased cost to commissioners.

### 3 Strategic Direction

Cwm Taf's strategy for learning disability services is focused on the following key messages:

- Maximizing the use of universal services
- Increased early intervention, prevention, information, advice and assistance
- Building community support and developing people's independence
- Sustaining people in their own homes
- Enabling people to live full lives and achieve their potential
- Keeping people safe
- Making best use of our resources

Our vision is that people with a learning disability will be able to access modern services that promote their independence, reduce reliance on long term services and emphasize choice and control. That children, young people and adults with a learning disability (including those people with autism and complex needs) will be able to access efficient and effective services that enable person centred outcomes and minimize escalation of need and risk through the promotion of early intervention prevention, greater independence and access to opportunities.

#### Evidence Base

The Statement of Strategic Intent is based on our analysis of intelligence gathered from a wide range of sources:

##### Predictive Intelligence

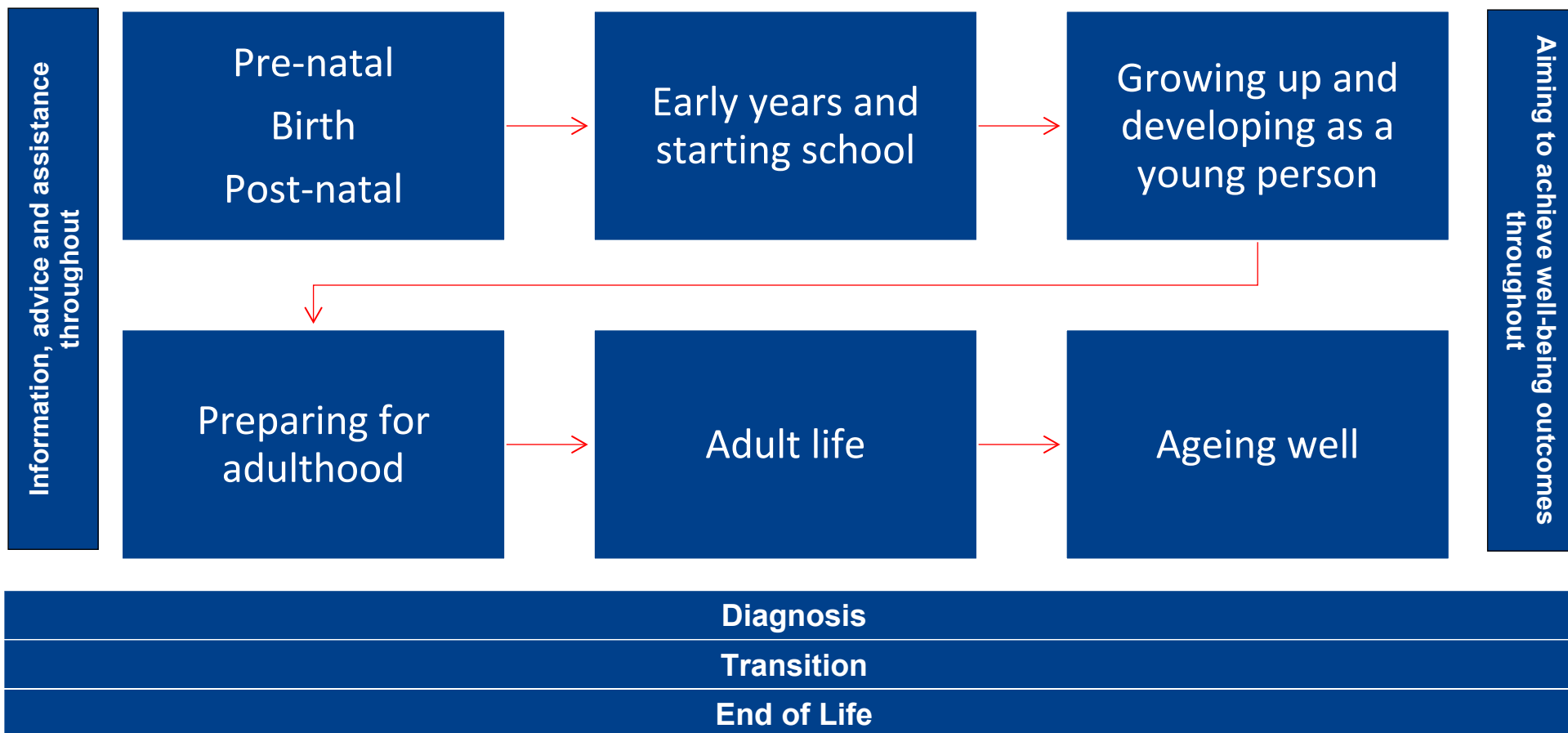
We use demographic analysis of the region's current and future population, applying prevalence and performance data to help forecast need.

##### System, Community and Personal Intelligence

We maintain links with a wide range of organisations through our contractual arrangements and through engagement networks. We will continue to use focus groups and ongoing dialogue to gather the views of people who use services and their families.

## 4 Pathway

Below is the regional support pathway that can be adapted for local use. A clear and effective support pathway will enable accessible information, and where required access to and provision of services and support. A lifelong support pathway shows a person's journey over time and is grouped into a series of key stages. The pathway indicates what should be happening at critical points in someone's life, and can help people with learning disabilities, their families and professionals navigate the complex system. There are a number of issues that can occur at any point in the pathway. These are depicted by the boxes running along the bottom.



## 4.1 Achieving Well-being Outcomes

The Social Services and Wellbeing (Wales) Act 2014 includes a National Wellbeing Statement (outlined below) which describes the wellbeing outcomes that people who need care and support and carers who need support should expect in order to lead fulfilled lives. The Cwm Taf regional approach aims to support people with learning disabilities and their families to experience these outcomes.

National Well-being Domains	Some example well-being outcome statements (taken from the National Well-being Statement)
Securing rights and entitlements	<ul style="list-style-type: none"> <li>■ My individual circumstances are considered.</li> <li>■ Control over day to day life.</li> </ul>
Physical and mental health and emotional well-being	<ul style="list-style-type: none"> <li>■ I am happy and do the things that make me happy.</li> <li>■ Physical, intellectual, emotional, social and behavioural development.</li> </ul>
Protection from abuse and neglect	<ul style="list-style-type: none"> <li>■ I am safe and protected from abuse and neglect.</li> </ul>
Education, training and recreation	<ul style="list-style-type: none"> <li>■ I do the things that matter to me.</li> </ul>
Domestic, family and personal relationships	<ul style="list-style-type: none"> <li>■ I belong.</li> </ul>
Contribution made to society	<ul style="list-style-type: none"> <li>■ I feel valued in society.</li> </ul>
Social and economic well-being	<ul style="list-style-type: none"> <li>■ I contribute towards my social life and can be with the people that I choose.</li> </ul>
Suitability of living accommodation	<ul style="list-style-type: none"> <li>■ I live in a home that best supports me to achieve my well-being.</li> </ul>

The full version of the Well-being Statement can be found at: <http://gov.wales/docs/dhss/publications/150722wellbeingen.pdf>

## 4.2 Information, advice and assistance

Information and advice is fundamental to enabling people to take control of, and make well-informed choices about, their care and support. Not only does information and advice help to promote people's well-being by increasing their ability to exercise choice and control, it is also a vital component of preventing or delaying people's need for care and support and carers need for support. Providing high quality and timely information and advice should be considered to be a preventative service in its own right.

Information is given to children, young people and adults with learning disabilities and their families along the whole pathway. Information needs to be set out clearly, be up to date, and be easy to get hold of. The provision of right information, given at the right time, at every stage, is very important. The range of information needed includes:

- Information about the process of support and care, including what will happen next and what is due to happen when
- Information about the disability including diagnosis and how it will/may change over time, plus trusted and reliable websites
- Health care arrangements
- Community support and options available
- Services available, including entitlement to services and waiting times
- Support options including short breaks, counselling and support groups
- Financial information

Advice is a way of working co-productively with an individual or family to explore the options available. This will require practitioners to undertake a proportionate assessment. Assistance involves another person taking action with the individual to access care and support. Assistance should follow the provision of information and advice where it is judged that an individual, or perhaps the family in the case of a child, will need extra help to enable them to access opportunities such as community resources or preventative services. Some individuals may also require advocacy to ensure they understand what is available to them so that they can engage and participate fully in decisions that affect them.

## **4.3 Pre-natal, birth, post-natal**

### **4.3.1 People Involved**

Parents know their children best and will often be the first to notice that their child may need additional help. The people involved will vary dependent where/when parents notice that something is not what they were expecting. Any of the following could be involved for example: Family member, Friend, Parent/carer support group, Midwife, Health visitor, Specialist health visitor, Specialist nurse, GP, Paediatrician, Hospital doctor, Teacher, Independent third sector provider e.g. playgroup leader.

### **4.3.2 The Aim**

The aim at this stage is to ensure that parents feel supported from the start. Parents should be given clear explanations about what is going to happen next, and where to get further information and help. Professionals should recognise the vulnerability of families where there is a child with disabilities, and be aware that for disability services 'one size does not fit all'. Parents will be provided with an



invitation to be placed on the Children with Disabilities Register which is used to inform planning of services and as a way of keeping in contact with families about events, offers and services. Parents are given an Early Support Developmental Journal to enable parents/carers, family members and the practitioners they work with to notice and celebrate everything that a child learns to do, as time goes by.

## **4.4 Early years and starting school**

### **4.4.1 People Involved**

Could be for example: Key worker, early years care providers, teachers, additional learning needs staff, nursing, independent third sector provider e.g. playgroup leader, children's centre staff.

### **4.4.2 The Aim**

The aim at this stage is to establish early networks and ensure smooth moves into child care and school, and to ensure that families continue to receive support and services early on to help minimise problems from arising in the future, in line with the Special Educational Needs (SEN) code of practice. We aim to ensure that services are outcome focused and when new services are started, the parents do not have to retell their journey. Services are outcome focused. Meetings are held, and services delivered, in appropriate venues which are convenient for families and where professionals are located.

## **4.5 Growing up and developing as a Young Person**

### **4.5.1 People Involved**

Could be for example: Key worker, teachers, school nurse, play/sport co-ordinators, national or regional disability sport organisations, club leaders.

### **4.5.2 The Aim**

The aim at this stage is to ensure that families know what is available and that children and young people have opportunities to engage in a range of activities appropriate to their wishes and needs. It is also to ensure that young people have a smooth route into secondary school and receive the information they need to support them growing up. Parents are regularly provided with up to date information about what opportunities are available via the keyworker, support groups, and also via mailings from the Children with disabilities register. A range of play and sport activities are available on a regular basis. Socialisation opportunities for parents are provided, for example music therapy groups for children include a space for parents to meet. Transport to and from activities is available, if required. Schools are community-focussed and provide opportunities for children without disabilities to act as mentors to

help support disabled pupils. Existing play facilities are accessible by children and young people with disabilities. Play work staff are trained to effectively support disabled children within community based provision to provide socialization opportunities both with other disabled children and with non-disabled children.

The key worker and the family meet together with teachers to plan the move to secondary school. This meeting is also used to review existing services and progress towards outcomes. Support for young people is provided during adolescence - sex and relationship education for young people with disabilities and support for families is given via the school and/or school nurse. True inclusion is experienced - the young person has social opportunities including after school activities, and is actively encouraged to access these.

## **4.6 Preparing for adulthood**

### **4.6.1 People Involved**

Could be for example: Key worker and transition team - this will include staff from the education department, schools, children and adult health and social services, careers services, housing, leisure, youth services, providers, further education.

### **4.6.2 The Aim**

The aim at this stage is to ensure that the family begins to prepare for the young person's move to adulthood. That they have clear expectations about what options and services are available and are able to make informed choices about the future. Annual school reviews involve the young person, parents and all professionals involved with the family. Reviews look at services and support currently being provided and outcomes are reviewed across all areas of the young person's life. Support needs for family are also reviewed. Services are available that together can support a meaningful life for the young person, and to help them make the transition to greater independence, including opportunities for further education, training, work experience and volunteering.

## **4.7 Adult Life**

### **4.7.1 People Involved**

Could be for example: Parents, other family members, friends, neighbours, GP, further education staff, employer, landlord, social worker, specialist healthcare staff, third sector providers.

### **4.7.2 The Aim**

The aim at this stage is to ensure that the adult with a learning disability has the same opportunities as anyone else to live a satisfying and valued life. They should have a home within their community, be supported to develop and maintain relationships and get the

help they need to live a healthy, safe and fulfilling life. They should have access to education, training, volunteering, paid employment, social and leisure activities and opportunities to be part of and contribute to their local community. They should have genuine choice and control over whom they live with and whether they live alone, with family or in a friendship group.

## **4.8 Ageing Well**

### **4.8.1 People Involved**

Could be for example: Parents, other family members, friends, neighbours, GP, further education staff, employer, landlord, social worker, specialist healthcare staff, third sector providers.

### **4.8.2 The Aim**

Older people with learning disabilities share many of the same experiences of growing older as everyone else and they have the same needs as other older people. Like others, people with learning disabilities have the potential to age successfully and so the aim at this stage is to ensure that older people with learning disabilities have choice and control over their lives to enable them to age well. Most people with learning disabilities live with their parents and these families are growing older together. The situation can be complex, as the person with learning disabilities may also be supporting the older family carer. Older people with learning disabilities and their carers therefore need a wide range of information, advice, assistance, person centred care and support options, and early planning for living arrangements in later life.

## **4.9 Diagnosis**

### **4.9.1 People Involved**

Could be for example: Consultant doctor, specialist nurse, GP, key worker, education psychologist, therapist, social workers, psychiatry.

### **4.9.2 The Aim**

The aim at this stage is to ensure that parents (and depending on age the person themselves) are given clear explanations about the disability, know what services are available and understand what support is available to them.

## **4.10 Transition**

### **4.10.1 People Involved**

Could be for example: Key worker and transition team - this will include staff from the education department, schools, children and adult health and social services, careers services, housing, leisure, youth services, providers, further education.

### **4.10.2 The Aim**

Transition planning is person centred with the young person's preferences, goals and aspirations taking centre stage. The transition process brings together the people who will ensure that families and young people with a disability can plan ahead for the future as they enter adulthood. The transition plan is focused on individual needs, regardless of what those needs might be, and agreed with young people and their parents. Early engagement is crucial in the preparation for transition as it helps to broaden views about what is possible and provides time to thoroughly investigate options.

## **4.11 End of Life**

### **4.11.1 People Involved**

Could be for example: Parents, other family, friends, chaplain, nurse, learning disability nurse, palliative carer/nurse.

### **4.11.2 The Aim**

People with a learning disability are as prone to the full range of ill-health conditions as the rest of the population, including malignant and non-malignant life-limiting conditions. The aim is for early diagnosis and effective health outcomes for everyone, including access to specialist palliative care services if appropriate. While some people with a learning disability recognise their own ill health, many cannot. Families and professional carers play a major role in noticing symptoms of potential ill health, and encouraging people to seek out medical advice. Once ill health is noticed, some people with learning disabilities need help to access clinics and attend appointments. Holistic care is central to the delivery of quality end-of-life care and support, regardless of disability, race, culture or creed. As death approaches, they should be given the opportunity to express their preferences about their end of life care. The person may wish to say goodbye to their friends, families and carers, and every opportunity to help them to do this should be made. All people involved with the person's life will need varying degrees of support to manage their sense of loss.

## 5 Demand Profile: What can we predict about the learning disability population across Cwm Taf?

There is forecast to be only a small increase in the number of children from 0 to 17 with a learning difficulty. The number with severe or profound learning disabilities is expected to increase by seven by 2025.

**Table 1: Children aged 0-17 predicted to have a learning difficulty, by age, projected to 2024**

	2016	2020	2025	% change 2016-2025	Actual forecast change in number 2016-2025
Children aged 0-17 with a moderate learning difficulty	2,245	2,283	2,282	1.65	37
Children aged 0-17 with a severe learning difficulty	290	295	295	1.72	5
Children aged 0-17 with a profound learning difficulty	71	73	73	2.82	2

Education services use a definition of learning difficulty which includes children with conditions such as dyslexia. Furthermore, some children with autism but without a learning difficulty will not be included. This is one of the reasons that it is important for local areas to have a learning disability register as a way of collecting more accurate data.

*Source: Daffodil. Numbers may not sum due to rounding*

Projections for those with a moderate or severe learning disability show an overall decrease of 20. However, as the overall figures suggest, there is expected to be a rise in the number of people aged 75 and over with a moderate or severe learning disability. This is a relatively low number but these individuals are more likely to need some degree of support. It is also worth noting the additional 19 people forecast to have a moderate or severe learning disability in the 55-64 age group, once again indicating that demand for some level of support is unlikely to reduce in the medium term.

**Table 2: People in Cwm Taf 18 and over estimated to have a moderate or severe learning disability**

	2016	2020	2025	% change 2016-2025	Actual forecast change in number 2016-2025
18-24	166	154	149	-10.24	-17
25-34	205	205	197	-3.90	-8
35-44	217	219	233	7.37	16
45-54	219	205	184	-15.98	-35
55-64	176	188	195	10.80	19
65-74	111	112	109	-1.80	-2
75-84	37	41	49	32.43	12
85 and over	12	14	17	41.67	5
Total	1,143	1,138	1,133	-0.88	-20

*Source: Daffodil. Numbers may not sum due to rounding*

2,269 adults and 726 children in Cwm Taf are predicted to have an autism spectrum condition. Approximately 50% of them will have a learning disability too.

Challenging behaviour usually begins in childhood or young adulthood and without effective intervention is highly persistent; around 30% of young children (aged 0-3) and 10-15% of adults with learning disabilities display behaviour difficulties. Not all of these people will have a moderate, severe or profound disability and hence not all of them will be in receipt of learning disability services. Many of these people will be at risk of offending and will come into contact with the criminal justice system, substance misuse services or mental health services.

A significant proportion of people with learning disabilities will not require social care services or specialist health services. Like the rest of the population they will come into contact with universal services which they will find more accessible if reasonable adjustments are made.

**Table 3: People in Cwm Taf predicted to have a learning disability (18 and over)**

	2016	2020	2025	% change 2016-2025	Actual forecast change in number 2016-2025
18-24	718	663	633	-11.84	-85
25-34	953	955	917	-3.78	-36
35-44	862	872	925	7.31	63
45-54	973	913	816	-16.14	-157
55-64	810	865	904	11.60	94
65-74	682	696	673	-1.32	-9
75-84	354	390	469	32.49	115
85 and over	130	148	180	38.46	50
Total population	<b>5,482</b>	<b>5,502</b>	<b>5,517</b>	<b>0.64</b>	<b>35</b>

*Source: Daffodil. Numbers may not sum due to rounding*

Overall, the population of people with learning disabilities in Cwm Taf is expected to increase by just 0.64%. There is a significant drop in the projected number of people aged between 18 and 34 predicted to have a learning disability. However, this does not reflect the expected changes within specific groups which are likely to affect demand for services. The most notable forecast change is that the number of people aged 75 and over with learning disabilities is predicted to grow considerably. There is also a notable increase forecast among the 55-64 age group, suggesting that demand among older groups will persist beyond the next ten years.

Better health and social care has meant that people with a learning disability are living longer than before. It is important for all older people to look after themselves and keep healthy to try to minimize age related illnesses like stroke, heart disease and diabetes. Older people with a learning disability may need additional support to do this.

### 5.1 How healthy are people with learning disabilities in Cwm Taf likely to be?

Children, young people, adults and older people with learning disabilities are at increased risk of experiencing physical health difficulties. People with learning disabilities die younger and experience poorer health than the general population. These differences are to a large extent avoidable and thus represent health inequalities (Emerson et al, 2011).

- People with learning disabilities are 10 times more likely to have a serious sight problem than other people. 6 in 10 people with learning disabilities need glasses and often need support to use them.
- 40% of adults with learning disability experience moderate to severe hearing loss.
- Overall, the proportion of people with learning disabilities who die from **cancer** in the UK is lower than among the general population (12-18%, compared with 26%), although they have proportionally higher rates of **gastrointestinal cancer** (48-59% vs 25% of cancer deaths). People with learning disabilities with cancer are less likely to be informed of their diagnosis and prognosis, to be given pain relief, to be involved in decisions about their care and they are less likely to receive palliative care.
- **Coronary heart disease** is a leading cause of death amongst people with learning disabilities (14-20%).
- **Respiratory disease** is possibly the leading cause of death for people with learning disabilities (46-52%) with rates much higher than for the general population. Adults with learning disabilities are 2.6 times more likely to die from asthma than those who do not have learning disabilities.
- The prevalence of **epilepsy** in the British population is between 0.5% and 1%: among those with moderate learning disability this prevalence rises to 15%. Among those with severe and profound disability the rate raises further to 30%, with seizures commonly being multiple and resistant to drug treatment.
- The prevalence of **mental health problems** in people with learning disabilities is considerably higher than in the general population (164 adults predicted to have LD & schizophrenia, 328 LD & anxiety disorder, 219 LD & depression). The prevalence of psychiatric disorders is 36% among children with learning disabilities, compared to 8% among children without learning disabilities. This equates to 935 children currently.
- The prevalence of dementia is higher amongst older adults with learning disabilities compared to the general population (22% vs 6% aged 65+) and they also tend to develop it at a younger age and at a faster rate. People with Down's Syndrome are at particularly high risk of developing dementia, with the age of onset being 30-40 years younger than for the general population.

## 6 Service Utilisation

Approximately 10% of the predicted population of children and adults with learning disabilities are known to G.P. surgeries across Cwm Taf. Data collected by the disabled children teams suggests that almost all children with a learning disability are known to social care services as children. However, there is a drop off after school of the number of people known to, and in receipt of adult social care.



23% of the predicted population of adults with learning disabilities are in receipt of social care services across Cwm Taf. There has been an increase in the number of people with learning disabilities in receipt of services since 2014. The exact increase is difficult to calculate as data has not been collected consistently over the years.

**In terms of the types of services being utilised we know that too few people access universal services. Too many people are in receipt of traditional residential and day centre style services. Too few people are supported to continue to live in their local communities. Not enough people access education and employment services. There are still too few children and adults accessing flexible support via direct payments.**

## **7 Resources: Meeting future demand and delivering financial sustainability**

As highlighted in the Cwm Taf Older Persons Joint Commissioning Statement (2015), advances in preventative medical interventions and the promotion of public health have led to the population as a whole living longer including the population of individuals with a learning disability. This means that significantly more people are likely to seek access to health and social care support over the next twenty years. This increase in demand will occur alongside challenges to the current pattern of services, as public sector spending also comes under increasing pressure. If care services were to simply increase in line with the population, this would lead to a near doubling of care costs between 2010 and 2026.

Currently the pattern of spend is to target resources at those in greatest need. For 2015/2016 Merthyr spent approximately 35% of the overall budget for adults with learning disabilities on residential and/or nursing care and 38% on supported living. Rhondda Cynon Taf spent 17% on residential and/or nursing care and 50% on supported living. Rhondda Cynon Taf spent only 5% on direct payments and Merthyr spent only 1%. Both Local Authorities spent only 3% of the overall budget on assessment and care management. In health there is increasing expenditure on continuing health care and spend on acute placements has not decreased.

The risk of targeting resources at those in greatest need is that whilst it meets the short term demand it does not reduce growing demand or provide a sustainable solution. The Social Services and Wellbeing (Wales) Act recognises this. It calls for the development of creative solutions such as community asset based approaches that enable individuals to access mainstream and universal services through appropriate reasonable adjustments and innovative support options. Delivering this will require investing less in residential provision and more in direct payments. Assessment and care and support planning is another area where more investment is needed so that staff can spend time helping those in need of care and support to find community solutions.

**Greater transparency and sharing of information in terms of numbers and expenditure across all services will support future demand management. It will also inform decisions about where to invest to facilitate sustainable outcomes for people**

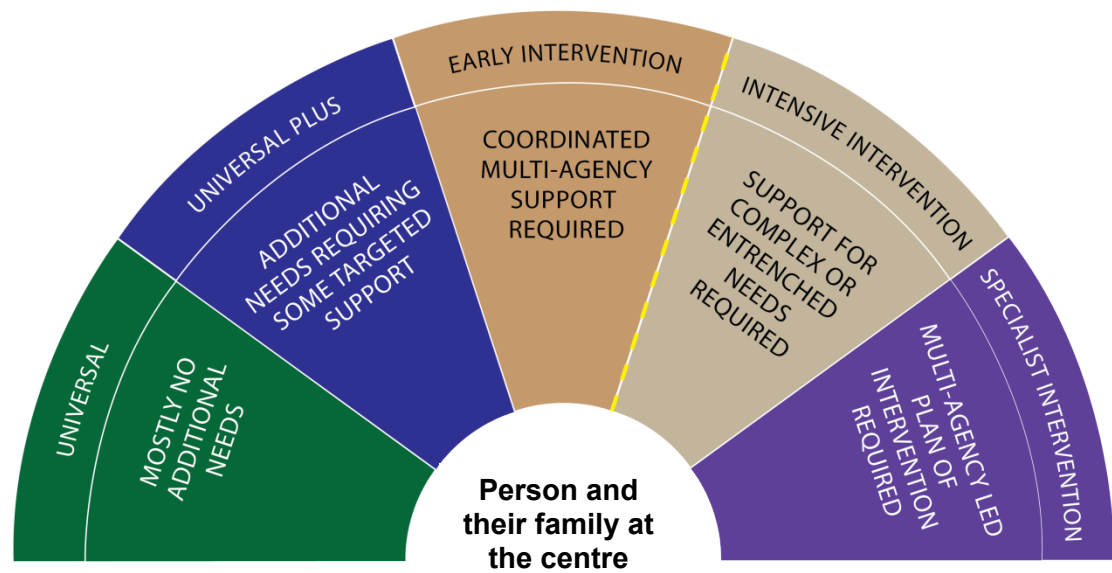
**effectively and efficiently. Pooling resources and commissioning specialist services at a regional level will help to make economies of scale.**

## 8 Regional Operating Model

The model for service provision is a dynamic one which responds to people's changing needs, provides targeted intervention and support where needed, enables individuals to return to independence as quickly as possible, and supports people by providing continuing access to universal services and community support.

### Achieving Personal Well-being Outcomes

- Protection from abuse and neglect
- Securing rights and entitlements
- Domestic, family and personal relationships
- Social and economic well-being



- Physical and mental health and emotional well-being
- Education, training and recreation
- Contribution made to society
- Suitability of living accommodation

Information, advice, assistance and advocacy

Commissioners understand their local population now and in the future

## 9 Market Shaping: Universal Services

Universal services include: leisure services (e.g. sports centre, cinema, social clubs, community and faith groups etc); information services (e.g. library, job centre, citizen's advice, charitable organisations etc); education services (e.g. college, adult education, etc); health services (e.g. dentist, optician, counselling, pharmacy, GP etc).

The vast majority of people with learning disabilities are not eligible for social care and hence live in the community with limited support. People with learning disabilities are at higher risk of many physical and mental health conditions, have fewer opportunities to work and often experience social deprivation. Supporting people with learning disabilities to lead healthy, meaningful lives and preventing the need for more intensive service provision requires universal services to be accessible. Making services accessible means that 'reasonable adjustments' need to be made to the service.

### 9.1 What are the implications for commissioning?

- Commissioners should work with those that commission and manage mainstream activities/services to find ways to make them accessible, in line with Equality Act duties. This should include playgrounds and other leisure activities that disabled children struggle to access.
- Commissioners will need to work with mainstream services to enable adults and children with a learning disability and/or autism who display behaviour that challenges to be included.

## 10 Market Shaping: Universal Plus

On average people with learning disabilities have poorer health and die younger than other people. In part this is because they are more exposed to causes of ill health through greater levels of material deprivation, poorer health-related behaviours and physical conditions often associated with causes of learning disabilities. But it is also partly a result of poorer understanding of physical changes and problems that indicate illnesses or conditions that could be treated and of how to get help from health services.

### Example

**Reasonable adjustments making access to primary care easier include:**

- **Desensitisation work/visits**
- **Car parking for carers/families**
- **Longer consultation slots**
- **Alternative arrangements in relation to using the waiting room**
- **Easy Read information leaflets**
- **Liaising with community learning disability teams**

People with learning disabilities should be able to access primary and community based secondary healthcare services in the same way as the general population. There is a need for support for people with learning disabilities across the life course to understand and express their needs in relation to their health and wellbeing, and to access health-based information together with support and opportunities to lead healthy lifestyles.

### 10.1 What are the implications for commissioning?

- Commissioners from social care should work with the local voluntary sector and GPs to consider what information, advice and assistance needs to be available in the community.
- Commissioners from health should develop pathways to support targeted interventions that will decrease health inequalities.
- Commissioners from Health should continue to commission the learning disabilities enhanced service. Currently there are 29 out of 42 practices providing the service but a focus should be made to encourage greater take up especially in Merthyr Tydfil where take up is the lowest.
- Commissioners from Health should continue to work with the local authorities to identify known patients with learning disabilities and to share the information with the GP Practices undertaking the enhanced service.
- Commissioners from Health should continue to provide the annual health check to patients who are registered with GP Practices who do not provide the enhanced service.

#### Example

Cornwall Cancer Screening Team have developed pathways for breast, cervical and bowel screening for people with learning disabilities. The pathways can be adapted to suit other areas and can be found at:

[www.improvinghealthandlives.org.uk/publications/1126/Making\\_Reasonable\\_Adjustments\\_to\\_Cancer\\_Screening](http://www.improvinghealthandlives.org.uk/publications/1126/Making_Reasonable_Adjustments_to_Cancer_Screening)

## 11 Market Shaping: Early Intervention

The provision of preventative and early intervention approaches can reduce the escalation of need and risk, improve personal outcomes and build capacity. Identifying need at its earliest point and providing the appropriate information, advice, assistance and where required intervention can delay or prevent escalating need that can often be costly. Being responsive to low level needs must be a consistent and collaborative approach across partners, in which the ability to share information and communicate effectively is key. The Social Services and Wellbeing (Wales) Act specifically mentions reablement and habilitation (i.e. the process of supplying a person with the means to develop maximum independence in activities of daily living through training, education, and/or treatment) as being key elements of preventative services. Reablement is about helping people, including children, to restore their skills and abilities they previously had in order to return to maximum independence. Habilitation aims to slow the progression of a disability or to enable an individual to gain new functional or communication skills. For people with complex needs who have always required a high level of input, prevention, and habilitation, is about enabling and progression. Examples include therapy for a child who is not walking or talking at the expected age or teaching adults with learning disabilities the fine motor coordination required to dress themselves. Most local authorities in Wales employ mobility specialists in education or Rehabilitation Officers Visual Impairment (ROVIs) in social services to support children and young people with visual impairment.

### 11.1 What are the implications for commissioning?

- Commissioners across children's and adult's services should ensure availability of early intervention programmes.
- Commissioners across children's and adult's services should ensure availability of a range of support and training for families and carers.
- Commissioners should provide flexible and creative short break/respite options.

## 12 Market Shaping: Intensive intervention

One important requirement of services is that they are able to retrieve crises; to manage them while they occur and to steadily bring the situation back to one in which the problems can be tackled over the longer term. This requires specialist support provided by a range of services, across children's services, Child and Adult Mental Health Services (CAMHS), and specialist community learning disability teams. Support should be built around the needs of the individual through a 'Collaborative Care' model. Individuals should expect continuity of care and support through close collaboration between services/agencies, including between specialist and mainstream services. Anyone who requires additional support to prevent or manage a crisis should have access to hands-on intensive 24/7 multi-disciplinary health and social care support at home, or in other appropriate community settings, including schools and short break/respite settings. This support should be delivered by members of highly-skilled and experienced multi-

disciplinary/agency teams. The interface between specialist routine multi-disciplinary support services and this type of intensive support service should be seamless.

People who present an immediate risk to those around them and/or to themselves may require admission to a hospital setting when their behaviour and/or mental state is such that assessment and/or treatment is temporarily required that cannot be provided safely and effectively in the community. Everyone who is admitted to a hospital setting for assessment and treatment should expect this to be integrated into their broader care and support pathway, with hospitals working closely with community services.

For all inpatient provision (secure or not) children admitted to hospital should be placed in an environment suitable for their age and must have access to education.

### **Example Positive Behaviour Support (PBS)**

PBS is built on a strong evidence base for supporting individuals with behaviour that challenges. PBS is a multi-component framework for delivering a range of evidence based supports to increase quality of life and reduce the occurrence, severity or impact of behaviours that challenge. The commissioning of services should be based upon the principles of positive behaviour support which is a framework used by all Providers in Cwm Taf.

The Positive Behaviour Support Academy is a collective of organisations and individuals in the UK who are working together to promote PBS as a framework for working with children and adults with learning disabilities who are at risk of behaviour that challenges. [pbsacademy.org.uk](http://pbsacademy.org.uk)

#### **12.1 What are the implications for commissioning?**

- Commissioners should ensure the availability of specialist integrated multi-disciplinary health and social care support in the community for people with a learning disability and/or autism, covering all ages. They should ensure alignment with local and national Autism Strategies, the CAMHS network and SEND.
- Within Cwm Taf secondary care learning disability health services are currently commissioned from a regional network managed by Abertawe Bro Morgannwg University Health Board. Commissioners of these services should maintain effective performance management to ensure that the needs of the local learning population are met and that these services provide value for money.

Commissioners should also ensure that all local partners are engaged in both the performance monitoring of the service, any plans for reconfiguration and future developments proposed for the network

- Commissioners should ensure this specialist health and social care support includes an intensive 24/7 support function to minimize escalation and manage crisis in the community.
- Commissioners should work with their local providers to develop models of alternative short-term accommodation.
- Commissioners should ensure inter-agency collaborative working, including between specialist and mainstream services.
- All professional involved should ensure that hospital admissions are supported by a clear rationale of assessment and treatment, and desired outcomes, and that services are as close to home as possible and Social workers should be working with individuals, families/carers, clinicians and local community services to ensure that the discharge planning process starts from the point of admission, or before.

### **13 Market Shaping: Specialist Intervention**

Everyone with eligible care and support needs should have a single person centred care and support plan, incorporating a range of other plans where appropriate, which they have been involved in developing and which they have a copy of. Plans should focus on what is important to the individual. For children and young people up to the age of 25 with a special educational need (SEN), this should take the form of an Education, Health and Care (EHC) plan.

Where people live, who they live with, the location, the community and the built environment need to be understood from the individual perspective. People with a learning disability can live successfully in different types of housing. They can cope with the full range of tenures including home ownership. There is a need to increase the use of assistive technology to support people to live as independently as possible.

Through increased use of direct payments people should have access to activities and services within the community; they should have opportunities to learn new skills, have new experiences, gain independence and employment and be supported to develop and maintain relationships. People should be able to access a range of services that meet their cultural and/or spiritual needs.



### 13.1 What are the implications for commissioning?

- Commissioners should work in a co-productive way to redesign services through robust person centred planning and use of direct payments. Commissioners should ensure that service specifications are based on person centred outcomes.
- Commissioners should ensure a multi-disciplinary approach to EHC plans, not leaving this only to education.
- Commissioners should work with the local voluntary sector to consider what additional or different local services are needed to ensure that people using direct payments have a range of services to choose from.
- Commissioners should co-produce local housing solutions leading to security of tenure, that enable people to live as independently as possible, rather than in residential settings.
- Commissioners should improve the quality of day services for people with profound and multiple disabilities or complex needs by training staff in and implementing person centred active support.
- Commissioners should incentivise the development of co-operatives.

#### Example Person Centred Active Support (PCAS)

PCAS is an approach that is fundamental to providing effective, person centred support. It isn't about supporting a particular person to get involved in a specific activity. It is about understanding that there isn't anything we shouldn't be supporting people to be involved in. We know when PCAS is being implemented because staff no longer have any discussions about WHAT they should be supporting people to be involved in, instead there is plenty of discussion about HOW they involve people in everything.

~~Our neighbours celebrated the good neighbour he recruited and paid a small retainer fee in return for providing help with support.~~  
This works well for people with a learning disability who need a fast response in a situation but do not need constant supervision.

## 14 Messages for Providers

We want to invest in better information and preventative services and encourage the development of community provision for a wider set of needs through reasonable adjustments, responding to emerging needs so that we can reduce or defer the need for care and support. We expect that opportunities will exist for a number of social enterprises to enter the market delivering new models of social inclusion that have a preventative element aimed at reducing need for both social and health care.

We want to develop services that better meet the needs of carers, including innovative approaches to short breaks. There will be opportunities for micro providers delivering schemes to teach skills, such as independent travel training, cooking, managing finances etc.

We aim to develop an approach that will lessen demand for residential services. We want to encourage the development of innovative models of high quality, local accommodation and the use of assistive technology.

We want to encourage a focus on the development of community provision for complex needs so that we can lessen demand for acute support and reduce the number who require crisis support. There are opportunities for providers who have creative, cost-effective local education, housing and support solutions to avoid the need to place individuals in specialist college placements.

We want to encourage the development of employment services e.g. job buddy support, work experience, on the job training opportunities to provide assistance to people with learning disabilities to gain paid employment.

We need services that can meet the needs of older people with learning disabilities, especially older people with learning disabilities and dementia.

**“We have to do different things, not the same things differently”.**

(Gwenda Thomas, Deputy Minister for Social Services: January 2014)