Cwm Taf Social Services and Wellbeing Partnership Board

Cwm Taf Joint Statement of Strategic Intent: Children, Young People and Adults with Learning Disabilities (that include autism and complex needs) and their families.

EQUALITY IMPACT ASSESSMENT

1. INTRODUCTION

The development of a Cwm Taf Joint Commissioning Statement for children, young people, adults with learning disabilities (that include autism and complex needs) and their families has been considered against the Equality Act 2010 and specifically the Public Sector Equality Duty, which came into force on 5th April 2011.

As part of this duty, public sector bodies in Wales are required to publish an assessment of impact in order to be transparent and accountable i.e. their consideration of the effects that their decisions, policies or services have on people on the basis of their gender, race, disability, sexual orientation, religion or belief, and age, to include gender re-assignment, pregnancy and maternity, marriage and civil partnership issues. These are classed as ‘protected characteristics’. Whilst deprivation does not constitute a ‘protected characteristic’ it is relevant because people from protected groups are more likely to experience it and because there are such high levels of deprivation in our local community. 36% of the Cwm Taf population live in areas which are among the most deprived 20% in Wales.

The need for the collection of evidence to support decisions and for engagement mean that the most effective and efficient impact assessment is conducted as an integral part of policy development or service re-design, with the assessment being commenced at the outset. These will help to eliminate discrimination, tackle inequality, develop a better understanding of the community, and target resources effectively.

Services for children, young people and adults with learning disabilities (that include autism and complex needs) and their families.

Research indicates that people with learning disabilities want to lead ordinary lives and do the things that most people take for granted.

They want to study at college, get a job, have relationships and friendships and enjoy leisure and social activities.

The key theme that has run through national policy and good practice guidance for almost 40 years is the need to provide services that support people to have healthy, meaningful, ordinary lives.

‘The concept that people with a learning disability have the same rights and aspirations as those without is the foundation upon which commissioners and providers should develop services that prevent the need for social care

The *Statement on Policy and Practice for Adults with a Learning Disability* laid out the rights for people with a learning disability living within Wales:

‘All people with a learning disability are full citizens, equal in status and value to other citizens of the same age. They have the same rights to:

- Live healthy, productive and independent lives with appropriate and responsive treatment and support to develop to their maximum potential.
- Be individuals and decide everyday issues and life-defining matters for themselves joining in all decision-making which affects their lives, with appropriate and responsive advice and support where necessary.
- Live their lives within their community, maintaining social and family ties and connections which are important to them.
- Have the support of the communities of which they are a part and access to general and specialist services that are responsive to their individual needs, circumstances and preferences.

This was mirrored in the 2011 commissioning guidance which set out guidelines for commissioning sustainable services which promote independence and encourage commissioners to think longer term about what might be needed for the learning disability population in Wales.

To date these still form central tenets of learning disability provision across Wales and as such there has been no subsequent review or update of policy. Therefore the most significant piece of policy and legislation impacting people with learning disabilities across Wales in recent years is the Social Services and Wellbeing (Wales) Act 2014.

For people with learning disabilities this Act has significant potential to improve their experiences of services as it provides a single legislative framework for the provision of services across the age ranges. This means that local authorities and their partners should be considering the wellbeing of individuals at all stages of their development, including through the traditional ‘transitions’ phase from children and young people’s services through to adult services, and through the provision of care and support into older age. It also legislates for the provision of advocacy services and for people to have strengths based assessments of need which considers all aspects of wellbeing as defined by the Act. It provides for carers through a right for their needs to be independently assessed beyond that of the person they care for

The Social Services and Wellbeing (Wales) Act 2014 includes a National Wellbeing Statement 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 approach to commissioning good lives aims to support people with learning disabilities and their families to experience these outcomes.

The following principles underpin the approach to commissioning good lives:

- Designing services from the individual up, but with their relationships right upfront as well.
- Designing services so that they reflect, and maintain or strengthen, the assets of the person and their relationships.
- Consequently, involving the person and their relationships fully in the design of the services.
- Designing services so that they reflect best practice in relevant professions.
- Consequently, promoting social inclusion, autonomy, choice, respect, and valued roles for the person, as well as effective specialist skills and techniques.

Rhondda Cynon Taf (RCT) County Borough Council, Merthyr Tydfil County Borough Council and Cwm Taf University Health Board have worked together to develop a Joint Statement of Strategic Intent for Children, Young People, and Adults with Learning Disabilities (that includes autism and complex needs) and their families which describes a shared commitment to deliver a new model of integrated health and social services.

2.THE VISION AND SERVICE MODEL

Together, we have adopted a common vision statement for integrated health and social care services for people with a Learning disability and autism:

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..

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

Universal Services

The vast majority of people with learning disabilities do not require 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 (e.g. leisure services, GPs, colleges, etc) to be accessible. Making services accessible means that 'reasonable adjustments' need to be made to the service.

Universal Plus

On average people with learning disabilities have poorer health and die younger than other people. People with learning disabilities should be able to access primary, community and 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.

Early Intervention

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 emotionally, socially and economically costly. Being responsive to low level needs must be a consistent and collaborative approach across partners.

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 Adolescent 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.

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 of which they have a copy. 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. 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.

3.OUR COMMISSIONING PRIORITIES

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

- Maximize the use of universal services
- Increase early intervention, prevention, information, advice and assistance
- Build community support and develop people's independence
- Sustain people in their own homes
- Enable people to live full lives and achieve their potential
- Keep people safe
- Make the best use of our resources

The outcomes we want to achieve

The definition of a Good Life is

Somewhere to live, something to do, someone to love
(home, occupation, relationships)

The outcomes we are seeking to acheive for people with a Learning disability and their families are

- that they will be able to access modern services that promote a sense of belonging to and inclusion in their local community.
- That services maximise independence, reduce dependency and emphasize choice and control.
- That children, young people and adults with a learning disability will be able to access efficient and effective services that enable citizen centred wellbeing outcomes
- That children, young people and adults with a learning disability will be able to access efficient and effective services that minimize escalation of need and risk

How that will feel for people with a learning disability in Cwm Taf (based on the WG outcome framework) is

- My individual circumstances are considered.
- I have control over day to day life
- I am happy and do the things that make me happy.
- I am safe and protected from abuse and neglect
- I do the things that matter to me.
- I belong.
- I contribute towards my social life and can be with the people that I choose.
- I feel valued in society.
- I live in a home that best supports me to achieve my well-being.

Current Service Utilisation

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.

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.

Resources: Meeting future demand and delivering financial sustainability

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 2014 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.

Within Cwm Taf, secondary care learning disability services are currently commissioned from a regional network managed by Abertawe Bro Morgannwg University Health Board. As the commissioner Cwm Taf University Health Board is currently undertaking a review to establish the current baseline position of the service relevant to the local population. Once complete this review will inform the commissioning work outlined within this statement of intent”.

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.

A Needs Assessment has been undertaken to inform the development of the Statement of Intent. In addition, the following information is relevant in relation to protected characteristics.

4. UNDERSTANDING THE DEMOGRAPHIC PROFILE

Better health and social care has meant that people with a learning disability are living longer than before. However, 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). 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.

In 2010, a review into health inequalities of people with learning disabilities in the UK highlighted striking differences between the general health of people with learning disabilities when compared to their non-disabled counterparts

They found there were potentially five key areas where health inequalities arose. These were:

- Social determinants such as poverty, poor housing conditions, and unemployment.
- Increased risk arising from genetic and biological factors associated with the learning disability.
- Communication difficulties and reduced health literacy.
- Personal health risks and behaviours.
- Difficulties in accessing services, including scarcity of services, poor understanding of needs particularly around communication, and potentially diagnostic overshadowing where the physical symptoms are seen to be issues arising from their learning disability.

Challenging Behaviour

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.

Gender

It has been noted that women with learning disabilities have markedly different patterns of contraceptive use to women in the general population, with greater use of long term methods such as depot injection, oral contraceptive, intrauterine device or sterilisation and significantly less use of barrier methods. Evidence suggests that women with learning disabilities are not given sufficient information or fully involved in decisions about contraception. Furthermore, there is evidence that women are prescribed contraception even when they are not sexually active or when they are past child-bearing age (McCarthy, 2009).

Studies in other countries have shown that women with learning disabilities and in particular women with Down’s syndrome tend to have earlier menopause than other women. A recent UK study found that women with learning disabilities had similar experiences of menopausal symptoms to other women but they had a poorer understanding of menopause and menstruation (Willis et al, 2011).

Age

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

Source: Daffodil. Numbers may not sum due to rounding

Projections for those aged 18 and over 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

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	**5,482**	**5,502**	**5,517**	**0.64**	**35**

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 10 years

Health

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.

Physical Disabilities

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 get used to them.

People living independently or with family are significantly less likely to have had a recent eye examination than people living with paid support staff.

The Foundation for People with Learning Disabilities states that around 40% of adults with a learning disability experience moderate to severe hearing loss

In some cases the hearing loss may exacerbate the effects of an individual's learning disability, because it may sometimes go unrecognised or undiagnosed, with the behaviours associated with hearing loss being instead considered part of the learning disability.

Untreated hearing loss can contribute to delayed speech and language development, difficulties with learning, and problems communicating with others, so a diagnosis as early as possible is vital, especially for people who may already experience difficulties in these areas.

Hearing problems are particularly common among people with Down's syndrome, and, as with the general population, become both more likely and more extensive as people age.

People who have a disability are twice as likely than people without a disability to have no access to a car (Office for Disability Issues 2009). Disabled people are also less confident in using public transport because of physical access issues but also because of staff attitudes (Framework for Action on Independent Living 2012).

Mental health

The prevalence of mental health problems in people with learning disabilities is considerably higher than in the general population.

The prevalence of psychiatric disorders is 36% among children with learning disabilities, compared to 8% among children without learning disabilities.

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.

Ethnicity

Cwm Taf has lower representation from ethnic groups other than white than Wales as a whole. However there are Polish, Portugese and Czech people living in the local community and their access issues will need to be considered in terms of language issues and availability of transport.

Language can represent a further barrier for people with learning disabilities in accessing public transport and services generally. It can also create further barriers to understanding during diagnosis, treatment and during recovery. The use of translation services may be appropriate and there are supportive policies in relation to these services.

Whilst there is no specific evidence available to examine the ethnicity of people with a Learning disability in Cwm Taf at this point it is worth noting that evidence shows that people from different ethnic groups respond differently to health promotion campaigns which may not be sensitive to language or cultural differences. In planning and delivering health and wellbeing activities, providers need to be mindful of these issues. However, the importance of family and community support networks is well recognised by many ethnic groups which will be helpful in building community capacity.

Marriage and Civil Partnership

Many people with a learning disability say that relationships are important to them - yet only 3% of people with a learning disability live as a couple, compared to 70% of the general adult population

Several barriers make it difficult for people with a learning disability to have personal and sexual relationships:

- Meeting people is more difficult.
- Social isolation is more common.
- The balance between risk and rights when it comes to people with a learning disability having intimate or sexual relationships is often skewed towards restricting their choices, both in the family home and other living arrangements.

These social attitudes are restricting, which means that people with a learning disability are often not getting the freedom or privacy to have intimate or sexual relationships.

Mencap have set out what is required to ensure people with a learning disability (relevant to people who have capacity to consent) are able to develop positive, informed, healthy and safe intimate relationships which are:

- Support to meet other people and form relationships
- Access to high quality and accessible sex education
- The opportunity to express their sexuality and have intimate relationships
- The right and wish to have an intimate sexual relationship balanced against any risk around safety and abuse

Religion

There is a lower representation in every religious group in Cwm Taf than is seen in Wales as a whole. Higher than average proportions of the population stated that they had no religion.

However it is important that services take cultural needs into account. A guide to cultural issues has been developed by Mental Health Advocacy Services (partly commissioned by the Health Board).

Sexuality and transgender

This information is not currently available. However in general terms, research has suggested there may be an association between harassment and poor mental health. Some evidence suggests lesbian, gay and bisexual and transgender people, are perhaps more likely than other groups to face hostility and misunderstanding, and are more likely to experience poor mental health.(How Fair is Britain?). Recent research looking at the mental health and emotional wellbeing of transgender people has found rates of current and previously diagnosed mental ill health are high.

The Isolation to Integration report found that gay men and lesbians are at greater risk of becoming lonely and isolated as they age because they are more likely to live alone and have less contact with family.

Lesbian, gay, bisexual and transgender (LGBT) people with a learning disability can face ‘double discrimination’, with their sexual rights denied on the basis of their learning disability as well as their sexual orientation or gender identity.

The Mencap requirements set out above in section 3.5 apply equally for LGBT people

Deprivation

Over 40% of residents in Merthyr Tydfil live in the most deprived fifth of Wales and within Rhondda Cynon Taf over 30% of residents live in the most deprived fifth of Wales. Higher levels of deprivation are evident in every category compared with the rest of Wales and this has implications for access to health generally, as well as other issues such as transport, unemployment and prosperity.

This has implications for our health and wellbeing given the association between deprivation and ill-health, which manifest in shorter life expectancy than the rest of Wales. There is also a gradient in life expectancy across Cwm Taf with higher levels of deprivation in valley communities, compared to the less deprived areas along the M4 corridor

The Office for National Statistics in 2011 found that across the UK, employment rates were lowest (at 12%) for those with severe learning difficulties.

According to the Foundation for People with Learning Disabilities over 65% of people with learning disabilities would like to be in paid employment but this contrasts with 2010/11 statistics which found only 6.6% of adults with learning disabilities were in some form of paid work.

Of those who were in employment they worked part-time, with men more likely to work 30+ hours than women.

Carers

More than half of adults with a learning disability live with their families. Even if they live away from the family home, their family carers are still likely to be involved in supporting them in various ways and unlike many other carers, family carers of people with learning disabilities are likely to have experienced a lifetime of caring and to care for decades. They may also of course have several caring roles as they age.

People with learning disabilities who continue to live with their families into middle age and beyond often find themselves in a mutual caring role as their parents get older. Like other carers people with learning disabilities are happy to care for others and proud of what they are doing. However, they may need some help in the role, and support to make decisions about the type and amount of caring they are doing. Its worth noting that the social services and wellbeing (Wales) Act 2014 gives Carers an equal right to assessment, this assessment should be carried out in the best way to meet an individual’s needs and focus on what matters to the person and how they can use their own strengths and resources to do those things.

People with disabilities are living longer and for their parents and carers this creates anxiety with regards to what will happen when they are too old to care, have a crisis or when they die. For some who are not currently involved with social services, services and support has changed beyond recognition from the days when people were offered the choice between leaving their relative in institutional care or taking them home. Working together to build more effective universal and community services could help ensure advice and information is more readily available outside of formal services and encourage older carers to begin developing contingency plans for the future

A comprehensive Cwm Taf Carers Strategy has been developed and formally agreed for the region which responds to the most common issues raised by carers. This can be found on the following link

http://cwmtaf.wales/how-we-work/plans-and-reports/cwm-taf-carers-strategy-2016-2019/

Welsh Language

In Cwm Taf, 12.3% of adults and 8.9% of children are able to speak Welsh. The proportion of those who are able to understand, speak and/or write Welsh varies within this.

More than just words…., the Welsh Government’s original strategic framework for Welsh language services in health, social services and social care, launched in 2012, has led to a number of improvements that have helped support Welsh speakers receive health, social services and social care services in their first language. This has been achieved by making the best use of the existing skills and resources across our NHS and social services.

One of the key principles of *More than just words*…. is the Active offer. An Active Offer simply means providing a service in Welsh without someone having to ask for it. It means creating a change of culture that takes the responsibility away from the individual and places the responsibility on service providers and not making the assumption that all Welsh speakers speak English anyway.

Human Rights

At its most basic, care and support offers protection of people's right to life under Article 2 of the European Convention by ensuring their most fundamental physiological needs, such as eating, taking medication, getting up in the morning and going to bed at night are met. But for those who require it, and those with whom they share their lives, the availability and organisation of care and support also determines whether they enjoy a number of other important human rights including freedom from inhuman and degrading treatment (under Article 3 of the Convention) and the right to respect for private and family life (under Article 8).

One crucial element of ensuring people are treated with dignity is for providers to understand the significance of human rights legislation. The legal framework of human rights law requires that health and social care workers, alongside other providers of public services, respect the dignity of people using services.

The ethics and values that underpin good practice in social care, such as autonomy, privacy and dignity, are at the core of human rights legislation. There are ongoing tensions between adherence to these values and the need to protect people from abuse, neglect and harm. For example, someone with a Learning disability may want to do something that presents a risk to themselves or others, and in such a case workers would need to consider whether this decision has been made with capacity. If so, then they should strive to find a way of ensuring the person’s safety while respecting their right to choose what they want to do. If the person may lack capacity, they should be assessed according to the Mental Capacity Act 2005 (MCA).

Whilst providers and commissioners in Cwm Taf must take responsibility for adherence to human rights and equalities legislation this is also enforced through external inspection and regulation.

4. STAFF WHO MAY BE AFFECTED BY THESE PROPOSED CHANGES

Analysis undertaken to develop the Statement has shown that the majority of partner resources, including staffing, are focussed on specialist services whereas we need a stronger emphasis in the future on Community, Universal and universal plus services.

We will need to consider the implications of the new service models for our staff. It is recognised that if staff are required to relocate or work differently, eg as part of integrating services, their personal characteristics and circumstances are taken into account, particularly if their journey is more difficult or their work pattern changes e.g. their age and family commitments.

There are appropriate organisational change policies in place within the local authorities and the University Health Board to manage any staff changes required as a result of this work

5. THE ENGAGEMENT EXERCISE

The initial draft statement of strategic intent for Children, Young People and Adults with Learning Disabilities (including autism and complex needs) and their families (referred from now on as the Statement) was developed in response to what service users, carers and other stakeholders had told us previously and with reference to good practice and research from elsewhere.

The engagement activity undertaken during 2017 was intended to make sure that we have correctly addressed the things that stakeholders told us and that the Statement is focussed on what matters

Over a 16 week period, between the 11th of May and the 31st of August a number of staff briefings, stakeholder focus groups and service user conversations have been undertaken across the region.

Stakeholder Briefing

At the start of the engagement process officers from across the Partnership created a comprehensive stakeholder map (attached as appendix 1) to ensure that all briefing materials could be widely distributed and operational staff updated and involved

To support effective service user engagement a focus group was facilitated on the 19th of May. This session was arranged for staff (from across the service) and the self advocacy group (Peoples First) to consider how best they could engage with and gather the views of the wide range of people with learning disabilities with differing levels of need and communication skills. The outcome of this session was to ensure effective conversations with service users about the plan and its content

The Focus groups

Focus Group	Participants
Parent Carers	8 participants
Council Staff outside Social Services	11 participants: libraries, leisure, adult education, customer services, community wellbeing, contact centre, youth engagement & participation,

	housing, integrated transport unit.
Adult Health	8 participants: therapies & health sciences, mental health, learning disability, primary care, OT, carers co-ordinator, nutrition & dietetics, substance misuse, patient care & safety, district nursing.
Children's Health	14 participants: OT, SALT, physio, dietician, neurodevelopment team, nursing, paediatrician, commissioning, psychiatrist, early years, planning, engagement & participation.
LD Community Groups	9 participants: Touch Trust, RCT, Mencap, Arts Factory, Autism for Children, Dewis, Viva
Wider Community Groups	7 participants

Each focus group lasted two hours and followed a similar procedure. Participants were asked to introduce themselves by stating who they were, what their role was and what that meant they were responsible for. The facilitator then spent ten minutes setting the context around the Social Services Well-being Act (SSWB Act) and the Cwm Taf Statement of Intent for Learning Disabilities. Each focus group was then asked the same set of questions:

- What impact has the SSWB Act had so far?
- Is there anything in the Statement of Intent that stands out to you?
- What things would you like to do differently?
- What impact would it have?
- What would it take to be able to do it differently?
- How would you like us to take the engagement forward?
- Who else could help us?
- Any other resources that could help us?

The discussions were allowed to flow naturally and the facilitator didn't move onto the next question until the discussion naturally paused. The focus groups were recorded, transcribed and the data analysed using Nvivo.

Focus Group findings

The findings are grouped under three themes (Universal, Universal Plus, and Early Intervention) that reflect the model for commissioning an ordinary life described in the statement of intent.

These findings are a summary of the key issues raised. A more detailed illustration of the discussion is available on request

Universal

- There is a direct correlation between families having a bad experience of universal services not coping with their family member with learning disabilities and the conclusion that the only solution therefore is a specialist service.
- There is a lack of community infrastructure
- There is a need for social prescribing
- There is a need to empower people with learning disabilities and their families
- There is a need to increase community presence and contribution so as to reduce stigma
- ‘There is a need to support and empower staff working in universal services
- Community environments need to be more accessible.

Universal Plus

Participants consistently stated that universal plus does not currently exist and is again the reason that people jump to the conclusion that the ONLY solution is a specialist service.

Early Intervention

Issues around early intervention consistently centred around challenging behaviour and the lack of access families have to support that helps them to manage and reduce such behaviors.

Meetings with service users (Peoples first)

People's first facilitated conversations with service users about the Statement of intent as part of a series of meetings during July.

These sessions were very well attended and utilised the 'easy read' document produced to support the engagement process

Service user participation at these meetings were as follows

Merthyr	18
Rhondda	8
Taf Ely	10

Findings from the meetings with service users (Peoples first)

These findings are a summary of meetings with service users, facilitated by Peoples first. The findings below reflect the structure of each meeting and identify the key themes recorded in the minutes. A more detailed record of each meeting is available on request

When asked if the statement of intent addressed the important things for them they noted particularly that it did not address:

- Transport as they felt particularly that transport was key to supporting access to the things they want to do
- Access to places to support people with learning disabilities feel more part of the community and help them be more independent

The things they identified as 'what matters' to them were (in summary):

- Healthy eating,
- Keeping fit and able to exercise (walking, swimming, dancing, going to the Gym, shopping, football, badminton, bowling, Zumba),
- Access to IT and communicating online with friends
- Being with partners, friends and family and socialising, going places with them
- Living with family,
- Learning and maintaining new skills Gardening, Arts and Crafts
- Working /having a job
- Having access to good local doctors and being confident to tell the doctor how you feel and having them listen to you
- Being Active
- Being happy
- Health and well being of family
- Having a break and a holiday

It was noted in particular during these meetings that communication with service users needs to be prioritised with regards to any changes to services and that they are concerned to ensure that they are fully engaged in any change to service delivery in the future

Online suggestion box

To further capture people's views and reflections, an online suggestion box was created on the Cwm Taf Hub. Officers from across the partnership publicised this online facility within their service areas, with stakeholders, service users and carers. This facility was also publicised through the stakeholder briefings and focus groups

Participants that recorded their views in the online suggestion box were as follows:

A person with a learning disability	1
A carer for someone with a learning disability	14
A professional working with people with learning disabilities	35
other	7
Total	57

Online suggestion Box findings

These findings are a summary of the responses recorded in the online questionnaire which was live from May to August 2017. A more detailed record of the online response is available on request

Of those who participated 90% recorded that they felt the statement of intent recorded the most important things for them

For those who didn't agree their comments referred primarily to the fact the document was written at a high level and lacked the detail of how it would be applied in practice

In addition there was specific reference to the fact the draft document does not refer to the Additional Learning Needs and Education Tribunal (Wales) Bill 2016 and its implications

When invited to provide further comment about the statement of intent and its content these included

- Support for the development of universal services
- Concern with regards to financial resources to manage both low level support and specialist care
- An emphasis on requests to improve communication both in terms of engagement and in relation to service delivery

When asked what they felt mattered the most to people with learning Disabilities the respondents identified the

- Having the right care and support when they need it
- Being independent
- Being with friends and family
- Being cared about
- Being able to take part in what's going on in the community
- Being active and involved in new things
- Having a safe and comfortable home
- Being able to learn new skills
- The health and wellbeing of their carer/parent
- Having good advice and support to keep themselves healthy
- Being treated as a respected individual

Outcome of the engagement activity

Generally the Statement of Intent has received widespread support particularly the service model for commissioning an ordinary life.

We have heard that access to universal and community services and activities is currently a challenge for people with learning disabilities, and service users in particular identified the practical difficulties they face whilst trying to live an ordinary life in the community.

We have noted that we need to continue to look at what matters to people with learning disabilities and their families and to engage them effectively in the design of the service going forward. This is because our understanding of accessibility to both universal services and community services has to be informed by the experiences of those who are trying to access them to ensure the key challenges they face are addressed

The Statement if Intent is intended as a strategic statement for partners to use as a framework for further commissioning and development but the nature of this high level document was frustrating for some as they are keen to understand how change will affect them directly

A strong message from all participants was the need to communicate more effectively with people and to engage them in any change and development of the service

To that end the Regional Steering group that involves representation from both Merthyr and RCT Local Authorities, Cwm Taf University Health Board, People First and third sector community groups will be responsible to ensure effective engagement and communication activities with service users, carers parents, staff and other stakeholders during the next steps are prioritised

Finally prior to embarking on the more detailed work to implement the model and to conclude the work on the actual statement itself we need to amend the draft to incorporate the Additional Learning Needs and Education Tribunal (Wales) Bill 2016 and its implications

6. POTENTIAL POSITIVE AND NEGATIVE IMPACT IDENTIFIED

Positive:

The primary beneficiaries are people with learning disabilities as the Statement provides a positive focus rather than a negative discrimination based on their disability

There will be a positive impact in terms of a culture change which promotes independence, social inclusion, greater choice and control.

The proposed service model (five interrelated levels) will improve health and social care outcomes eg by increased availability of services that promote health and wellbeing but also the opportunities to target support and care to those who need more intensive help. This will have a positive impact on both people with low level learning disabilities as well as those with more complex needs.

The emphasis on a 'good life' (*Somewhere to live, something to do, someone to love)* is likely to have a beneficial impact on people with a learning disability placing a greater focus on quality of life outcomes for people living in our communities.

The model will encourage the development of more opportunities to be available as locally as possible, at home or within local communities. This will have a positive impact by promoting accessibility and addressing the barriers currently experienced like transport.

Home based and community care can minimise disruption to people’s lives. It can also be easier to meet individual spiritual and cultural needs if people remain part of their own community and any groups to which they belong. Privacy eg LGBT status and family life, including marital and civil partnership status can also be preserved.

The improved coordination of services to be achieved by the collaborative approach taken by partners and the development of this Joint Statement of Intent will ensure people with learning disabilities can access the services they need in the right place at the right time, delivered by the right person.

Negative

There may be a negative impact on family members/carers who feel that they have to take on additional responsibilities and a significant unpaid caring role. This could particularly impact on certain cultures and/or where women are traditionally expected to take on that role.

As noted in section 3 the Cwm Taf Social Services and wellbeing Partnership are implementing a Carers strategy to support carers in the communities of RCT and Merthyr Tydfil and the Social Services and Wellbeing (Wales) Act 2014 provides carers with an equal right to assessment with a focus on what matters to the person

During the engagement activity it was clear that people with learning disabilities and their families are very anxious about changes to their services and are concerned to seek commitment that they will be engaged in any change that may have an immediate impact on their daily routine.

The steering group taking forward the co-ordination of work to respond to the statement of intent will endeavour to engage people with learning disabilities and their families in the work going forward paying attention to the communication of information as well as co-producing solutions with those who have a direct stake in the outcome

There is an expectation that suitable universal and community services will be available to support people with learning disabilities appropriately in the community but this will require resource particularly with regards to the training and development needs of staff across all agencies to ensure their understanding of the specific communication and engagement needs of this group of people are addressed effectively

In part some of the changes required to traditional service models will create efficiencies that can support new models of service; through utilising mainstream facilities for example. In addition the Social Care Workforce Development Grant is available to support the training needs of all staff groups across the statutory, independent and 3rd sector organisations working in social care - its allocation is influenced by Partnership priorities

Overall it is considered that the benefits to be gained from the implementation of the Joint Commissioning Statement for Learning Disabilities will outweigh any negative impacts. The potential negative impacts will be addressed as identified below and as the Strategy is implemented.

7. PLANS TO ALLEVIATE ANY NEGATIVE IMPACT

Support for carers

A comprehensive Cwm Taf Carers Strategy has been developed and formally agreed for the region which responds to the most common issues raised by carers

Engagement and communication

The steering group overseeing the next steps will comprise of partner representatives, Peoples First (self advocacy) service users and carers. This group will from the outset agree an engagement plan

The purpose of the engagement plan is for the group to think through how stakeholders are going to be appropriately informed and involved in each stage of the development of the business case and the implementation of the delivery model.

Effectively engaging and communicating with stakeholders including staff will help facilitate the change management process. It will also help identify as well as reduce the potential risk of stakeholders not engaging in or being committed to the changes. This plan is not a plan for consulting stakeholders about whether any changes should or should not take place. The case for change has been accepted and the focus now is to develop and implement the best solutions to deliver the agreed Vision and outcomes.

The objectives of the engagement plan is to

- Achieve a shared understanding of what we are doing and why.
- Ensure that a whole system approach is taken towards the agenda for change and that the relevant individual parts of the system understand their contribution towards its delivery.
- Maximise the opportunity for participation of stakeholders into the development and implementation of the changes.
- Build credibility and trust and create an environment that encourages openness and meaningful dialogue.

- Ensure all stakeholders know what is happening, when and how it will affect them.

This Statement of intent is a high level document that does not go into the detail of service change at an operational level

As a result it is anticipated that each significant service change undertaken within the services to people with Learning disabilities will require specific consideration with regards to a more detailed Equality Impact Assessment

8. MITIGATION

An effective EIA takes into account the views and opinions of those who may be affected by the policy and what is already known about how the policy might affect different groups. This includes national evidence, Public Health Wales information, census data, public and service user views wherever possible in order to identify and address issues.

The consideration of mitigating measures and alternative ways of doing things is at the heart of the Equality Impact Assessment process. Different options have been considered in the development of the Statement of intent as covered in this document. The consideration of mitigation of adverse impacts is intertwined with the consideration of all actions. Mitigation can take the form of lessening the severity of the adverse impact.

Ways of delivering services which have a less adverse effect on the relevant equality category or issue, or which better promote equality of opportunity for the relevant equality category, have been considered.

The preliminary issues and potential mitigations have been listed earlier in this document and will be revisited as the service changes are agreed and developed. This initial document represents stage one of the equality impact assessment.

10. SUMMATION – GENERAL DUTY

Due Regard to 3 elements of general equality duty

This Equality Impact Assessment is representative of a real attempt to address the following questions:

<u>Does this Statement Of Intent help to eliminate discrimination?</u>

Yes, although there is no perceived discrimination in the way services are currently provided, the move to this new model that supports an 'ordinary life' will help achieve the outcomes we are seeking to achieve for people with a Learning disability and their families to:

- access modern services that promote a sense of belonging to and inclusion in their local community.

- maximise independence, reduce dependency and emphasize choice and control.
- access efficient and effective services that enable citizen centred wellbeing outcomes
- be able to access efficient and effective services that minimize escalation of need and risk
- enable greater privacy and personalised care that meets their individual needs and lifestyles.

Does this service change help promote equality of opportunity?

Yes, this model of service provision should enhance the service offer to all people with a learning disability and their families , supporting an ordinary life in our communities

Does this service change help foster good relations between people possessing the protected characteristic and those that do not?

Yes we have considered the population as a whole from cradle to grave and looked particularly at the needs of older people with a learning disability and their carers to recognise their particular needs particularly now that people are living longer and with more complex care needs in the community

Where concerns relating to equality have been raised, these have been identified and explored in order to establish possible mitigation and to avoid discrimination against any particular groups and to promote equality of access to services. This has involved engagement with different groups in relation to the use of appropriate media, fora and by building on existing relationships.

The composition of the local population (2011 Census and Public Health information) has been analysed and issues considered.

11. MONITORING ARRANGEMENTS

The impact of this statement of intent will be closely monitored and careful consideration will continue to be given to the points highlighted in this equality impact assessment.

Further and as noted above specific service change resulting from our commitment to this high level statement will require further comprehensive equality impact assessment and as such this assessment is considered as the first step