

# POPULATION ASSESSMENT: LEARNING DISABILITY INCLUDING AUTISM

## 1. Introduction

Through the Understanding Our Communities project, public services are gaining a better understanding of the good things about communities, what matters to people and how their experiences and what they have to offer can help us to plan and provide services.

The Social Services and Well-being (Wales) Act has been put in place to make sure that public services are doing all that they can to support people using care and support services to have their say and get involved in managing their own well-being. The Act means that public services will need to make sure that the right support is available for the people who need it at the right time and in the right way.

Under this Act, public services must carry out and publish a Population Assessment, which looks at:

- the needs for care and support, and the support needs of carer;
- the extent to which those needs are not being met;
- the range and level of services needed to meet those needs; and
- how services are delivered through the medium of Welsh.

In Cwm Taf, we have been collecting lots of information for the Assessment, from the people making policy and commissioning decisions about services, the people delivering services and the people receiving services. In order to look at all of this information in an organised way, we used the seven 'themes' of the Act;

Carers;

Children and young people;

Learning disability;

Mental Health;

Older people;

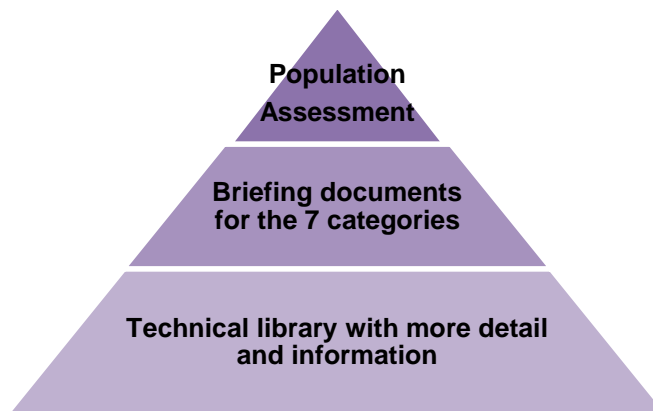
Physical disability and sensory impairment; and

Violence against women, domestic abuse and sexual violence.

We then spent some time, talking with these people about the headlines that emerged under this theme and really thinking about how they affect people and what we as public services can do to meet the needs of people using our services, in the best possible way, now and in the future.

A summary of the headlines relating to learning disability are contained in this document. The document shows how the learning disability headlines fit into the 'bigger picture' and the key messages which relate to *all* themes and what we currently do and/or could do to deal with these headlines.

The overall Population Assessment report contains the headline information across all themes.



The triangle shows the different parts of our work which taken together make up Cwm Taf's Assessment Report. Each level of this Assessment is supported by a more detailed level of data and information. The Assessment Report has been put together like this so that each reader can explore the information we have collected and analysed in as much or as little detail as they would like and can follow up any particular areas of interest. All of the information gathered throughout the project to inform the headlines in this briefing document is also available in an online library.

## 2. Learning disability

This document is about children, young people and adults with learning disabilities and / or Autistic Spectrum Disorders living in Rhondda Cynon Taf and Merthyr Tydfil (the Cwm Taf region).

If a person has a 'learning disability', it is usually said that they find it hard to understand new or complex information, to learn new skills and that they can't

always live their lives without the help and support of others. A learning disability usually starts before adulthood and has a long-lasting effect.

The term 'learning disability' is used to describe many different types of conditions and people with the same learning disability may experience it differently. This is also true for Autistic Spectrum Disorders, where some people might have difficulties communicating with others, problems with controlling their behaviour and a different way of seeing the world to people without Autistic Spectrum Disorders. So, it is very difficult to talk about people with 'learning disabilities' as one group and people with learning disabilities might talk about the same condition in different ways.

When children and young people are in school, the terms 'Special Educational Needs', 'Additional Learning Needs' and 'learning difficulty' are also used to describe the different levels of support they might get to help with their learning.

### 3. The current position in Cwm Taf

Most people with a learning disability or Autistic Spectrum Disorder will not use high-level, specialist services for their condition but will use the same services as everyone else. As well as the services that are for everybody, services in Cwm Taf for people with learning disabilities include:

- Education for children and young people with more serious Special Educational Needs, like learning support classes in mainstream (regular) schools, four special schools and two units for pupils that need extra help;
- Funding for schools to help them support pupils with Special Educational Needs;
- Services within the Council like Educational Psychology; Learning Support; Behaviour Support; Attendance and Well-being; Youth Engagement and Participation; and Supporting Education, Employment and Training support;
- Supported housing;
- Supported employment and things to do / places to go in the day;
- Services that give families / carers some time to rest from caring for the person who has a disability;
- Plans that help people to live the life they want to lead;

- Care in the home and Direct Payments, which give the money directly to disabled people and their families so they can choose the services they want;
- Support for people to speak on behalf of people with learning disabilities;
- Social work support;
- Charity and voluntary support;
- Health services support via the following means:
  - Children and adults with mild to moderate learning disability mainly receive their health care from paediatricians, GPs and primary care services. Cwm Taf Health Board has a principal role in providing high quality holistic health care to those with learning disabilities. Within Cwm Taf's general hospital settings, learning disability training is also provided to promote staff awareness and improve service delivery.
  - Secondary care Learning Disability services for adults within the Cwm Taf region are currently provided by Abertawe Bro Morgannwg Health Board (ABMU) as a network service with a close link to local mental health and primary care services. Currently there are typically between 75 and 85 adults with moderate to severe learning disability living within a variety of small home placements managed by ABMU in Cwm Taf. These people are supported by ABMU residential staff and Community Learning Disability Teams.

Across Cwm Taf work has been undertaken to develop a 'Cwm Taf Joint Statement of Intent for Learning Disability'. The document has been developed by statutory agencies that have responsibility for providing the local services on offer for people with learning disabilities. The plan is to share this document with the people and their families that use the services to make sure it is clear and a true picture.

The 'Joint Statement of Intent for Learning Disability' says that people with a learning disability should have more choice and control about what happens to them and be able to use modern and effective services that support them to live without too much support from services or their families – this is called 'independent living' and people have told us how important this is to them in their lives.

In the future, the 'Joint Statement of Intent for Learning Disability' will be used with this document and the finished Population Assessment to help services and the people using services make decisions.

## 4. Headlines

### People want to be able to be a part of their community.

Everybody we talked to told us how important it was to them to feel a part of their community – whether that was where they live, the people they spend time with or the things they take part in. People said that they enjoy being given the opportunity and support to live independently, which means different things to different people. Some people thought ‘being independent’ meant living in their own home, with little or no support from services, others linked independence to living away from their family members.

For example, even though some people lived in buildings where there are staff available to help, this represented ‘home’ to them. They talked about the staff and the other people they lived with as having a good effect on their independence. People also talked about making friends with family, partners and colleagues mentioned as things that make people feel good and improved their well-being.

Learning new skills, doing some training or getting a job was also seen as a good thing to do by people with learning disabilities and people who work with them. People told us that learning and having a job was good for their mental and physical well-being, helping them to achieve bigger and better things.

Many people with learning disabilities and / or Autistic Spectrum Disorders do not use specialist services, so it is important that all services are easy to use for people with learning disabilities too. For many of the people we spoke to, a ‘learning disability’ is not what leads how they feel from day to day, it is the other barriers to feeling well such as getting around, spending time with other people, feeling purposeful and feeling valued that were more important to everyone. As such, people told us about the things they are involved in through their local community like play schemes, music, bowls clubs, walking groups, dance and brass bands that are open to everyone, but make an effort for people with learning disabilities to take part in as well.

At the moment, not all services or communities are set up in the best way to do this and we need to raise awareness across businesses, members of the community and public services to help everyone enjoy activities in their community. This will involve time and patience in understanding what needs to change for everyone to get involved, learning from those activities that do this well to repeat this, and making sure that services are more flexible and use ‘common sense’ on what people might need.

*There seems to be more people with lots of different learning difficulties and what people expect from services is changing. This is creating challenges for everyone.*

We think that there are about 5,500 people in Cwm Taf who have a learning disability and about 2,500 of these are children and young people. About 600 children and young people have an Autistic Spectrum Disorder in Rhondda Cynon Taf and about 140 children and young people live with this in Merthyr Tydfil (some of them will also have a learning disability).<sup>1</sup>

Only a small number of these people are using services in Rhondda Cynon Taf or Merthyr Tydfil. At the moment, about 234 children and young people are using services through the Disabled Children's Team in Rhondda Cynon Taf but there are another 239 children and young people supported by the team who do not have a recorded disability. In Merthyr Tydfil, 87 children and young people are being supported by the Disabled Children's Team at the moment.<sup>2</sup>

But people who work with children and young people have said there seems to be more people with more complicated difficulties. For example, the number of young people that have needed a statement saying that they have a Special Educational Need has grown by 46% since 2012 (from 564 to 823 pupils in 2016). This is putting pressure on services and suggests that the number of people with difficulties is rising. This needs to be thought about in planning services for the future for adults with learning disabilities.

As well as this, the services people expect are changing. More people with learning disabilities and their families want to live in the same way as everyone else, with children going to mainstream schools, taking part in lots of things and being able to live independently. This has been a long process and is to do with the way we now live. Our communities and families have changed and this has meant that more traditional services are thought of as 'old-fashioned'.

Public services have not been able to move as quickly as people's expectations, so there are now some gaps in low level, community services such as housing, employment advice and social support. Instead, there are too many people still using traditional services like day centres. Although people enjoy visiting day centres and making new friends, as well as day centre services being a rest for families and carers, they are generally not helping people to reach their full potential and help them to live fuller lives. But there are some good examples of people getting

---

<sup>1</sup> [Daffodil Cymru](#)

<sup>2</sup> Data provided by Children's Services in RCT and Merthyr Tydfil Councils

involved in activities, training and getting work through supported services. There are also new models of housing called 'extra care accommodation' for older people, where people can live independently but still have support. People wondered whether these services might also be useful for younger people with learning disabilities too.

As well as this, the Welsh Government are working with local Council and Health services to bring in a National Joined-up Autism Service<sup>3</sup>. This will change the way children and young people with Additional Learning Needs have support in school; encourage employers and job centres to support people to get a job and help the wider community to understand Autistic Spectrum Disorders to best support the person.

Locally, we need to look at how organisations move funding from more 'traditional' services to focussing on what people want to achieve. This will involve thinking differently about the positive things already in the community that can be used and built upon to improve people's lives. To achieve this, services across Cwm Taf will need to be better at sharing information with each other to help decision making about where to invest money in future services.

*It is difficult to access support in times of urgency.*

As we have already said, most people with a learning disability or Autistic Spectrum Disorder will not need services for their condition. But, this is not to say that they might not need support and services at certain times of their lives. People with learning disabilities are more likely to suffer with their health and from mental health problems<sup>4</sup>. If services don't know about these people, their problems can get worse and worse until they reach a crisis point. We need to avoid this from happening.

The same is true for families who have been looking after their child or adult with learning disabilities. Sometimes they need support when things get really difficult or when something happens that pushes the whole family into stress. There are gaps at the moment in these 'intensive services', those services that help to manage a crisis, bring the family back from the brink and help problems to be tackled longer term.

Very often, these things relate to problems with behaviour and mental health. There are already some local services for children and adults with issues controlling their

---

<sup>3</sup> [Autistic Spectrum Disorder strategic action plan](#)

<sup>4</sup> [Cwm Taf Joint Statement of Strategic Intent](#)

behaviour, but people told us that they need more services, from an earlier age and a 'just in case' low level service, perhaps in the community through a voluntary organisation.

We also need to change the attitudes of services and families, so that people feel welcome and want to be helped. Everyone (not just families affected by learning disabilities or autism) said that they wanted to feel understood and listened to. They said it would help to have programmes around basic things like going to the toilet, sleeping habits and for this to be available throughout a person's life – not just for young children. Good examples of this include the 'Early Bird' Parenting Programme<sup>5</sup> that helps parents to understand behaviour of children who have an Autistic Spectrum Disorder and the specialist Flying Start Health Visitors.

*Services need to work more collaboratively to see the person, not the problem.*

This is a common theme running through the Social Services and Well-being (Wales) Act and other national laws at the moment. It was also something that staff and members of the public spoke strongly about during this process. People also said that this was hard because of all the different services, laws and pots of money; this stops staff from using their common sense for the person to reach their aims. And members of the public said that they just wanted services that made sense and gave them real choice and control over what they choose.

Some examples of this include how people with learning disabilities might want to spend their direct payments (money given directly to people and their families to buy the services they feel they need to help them). Some people might want to use this money to do activities that they enjoy, which will lead to new skills, more confidence and bigger things. But, at the moment, the system makes it quite difficult for Councils and Health Boards to allow this to happen.

Likewise, everyone is different and will need different levels of support at different times in their lives. At the moment, children and young people (up to the age of 18 or 25 years old) get certain services that adults might not be able to use. Different teams also work with children to those that work with adults, and they often work in very different ways. Sometimes, this isn't very helpful for the person who has one service up to the age of 18 and 364 days, and totally different services available to them from the age of 19 years old. This is true for families who foster a child with learning disabilities, who then might need an adult placement. This should be a quick and easy process, but can be challenging.

---

<sup>5</sup> [Programme through the National Autistic Service](#)



As we have already said, this can be true where people's conditions are getting more complicated. For example, elderly people might have a learning disability, poor physical health and dementia. This means they can be passed from service to service, which is confusing and difficult for the person and their family. Some of this is because national policy create divides in what services certain people can use. But this needs to change if we are going to support people to live the lives they want to lead.

In this way, everyone agreed that the system has to be more flexible to help staff to see the person and not the problem. This means that Welsh Government might need to make some changes, so that local services can do the things they need to do for the person.

Services will also need to work better together to understand what the person wants to achieve. Health, Social Services in the Council and voluntary sector will need to share information, work together to plan and deliver services to meet some of the complicated needs of people with learning disabilities and Autistic Spectrum Disorders. This is going to be difficult for some services and they will need to make brave decisions in trying new things. This is a 'culture change' across Cwm Taf. But listening to people with learning disabilities and / or Autistic Spectrum Disorders and their families, involving them in decisions and planning with them, will make this process a lot easier.

## 5. Links to other headlines and common themes

The things which affect people with learning disabilities do not stand alone. The same things are likely to affect other people who use care and support services, but who do not have a learning disability. Likewise, there are other headlines and common themes which will affect people who have a learning disability, but will not be related to that learning disability. Some of the common themes that have been brought forward by this work include:

The need for people to feel a part of their community is universal. Feeling alone seems to be a common problem for people with learning disability and Autistic Spectrum Disorders, but it is also the case the elderly, people with mental health problems and other people in society. Our population assessment is focussed mainly on health and social care but people's lives are about much more than social services and if we are to help people help themselves, there is a need for more services to understand the different barriers for people feeling part of their community. As

such, we need to think more about housing, leisure, transport, and planning, as the process develops in the future.

People also felt that services needed to be more modern and move away from day centres and more towards building provision around what's already there in communities, rather than fitting people into services. This is a culture change for services, which try to sort out a problem, rather than look at the person's whole life. This will involve working with the community and with partner organisations under the Social Services & Well-being (Wales) Act to focus on what can be achieved if people think outside their own services.

Across this work, it has been recognised that what we do next has to involve the people affected by these services and their communities. We need their help in shaping services for the future and to check how things will work in practice. We will also need to build strength in communities, as they surround a person and can make a big difference to their lives. Building good networks will help people connect and strengthen the community as a whole.

The parallel needs of carers have been brought up across chapters of the assessment because the well-being of individuals very often depends on the families around them. Any services that are put in place for any specific groups covered by the themes of the Act should think about what this means for carers – for example, learning disability day services must be planned in conjunction with respite services.

The need for services that respond effectively to a crisis are still needed across Cwm Taf, even though our aim is to build strength around families.

There is a strong case for collecting better data, sharing information in a better way and using data and information more to help plan services in the future.