POPULATION ASSESSMENT BRIEFING DOCUMENT

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 carers;
- 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 health and physical disabilities including sensory impairment are contained in this document. The document shows how these 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. Health, physical disability including sensory impairment

The information contained in this briefing document details the care and support needs of children, young people and adults with health and physical disabilities including sensory impairment, living in Cwm Taf (Rhondda Cynon Taf and Merthyr Tydfil).

A person with a 'health or physical disability including sensory impairment', may have difficulty carrying out everyday activities as their movement and senses may be limited. Sensory impairment is reduced or loss of sight, hearing or both. Those included are the blind, partially sighted, Deaf, and hard of hearing. A disability may be present from birth or occur during a person's lifetime. Health disabilities can include chronic conditions, for example obesity. For people who have suffered, for example, a stroke there may be long term effects on their movement, speech, hearing and sight.

As illustrated, there are many different types of conditions, this can make it hard to discuss common issues affecting these people, as they may not feel like, and self-identify as a group.

3. The current position in Cwm Taf

This is not a complete list of the services provided across the Cwm Taf area but gives examples of services currently being provided by public sector partners and the Third Sector.

- Care and Support plans for those with eligible needs;
- Carers Services services that give families and carers time off from their caring responsibilities to rest;
- Services provided by the local Council that allow people to remain in their home during later life, whilst still receiving assistance with their personal care needs;
- Payments made directly to service users to pay for their own care;
- Education based services including provision for Special Educational Needs and Additional Leaning Needs;
- Health services including joined up services for older people and support to pregnant women to deliver healthy babies;
- Housing solutions with varying levels of support depending on individual needs;
- Third Sector support including advice and assistance, to help people express their views, ensuring their interests are represented, further details available on the DEWIS web-site¹;

¹ Dewis

- Sports activities and projects which are tailored to the needs of those with disabilities and sensory impairment; and
- Community Equipment including Telecare, assisted listening devices and interpretation services that help individuals with disabilities maintain health and independence. This includes work being undertaken by Cwm Taf University Health Board with service users and staff to implement the "All Wales Standards for Accessible Communication and Information for People with Sensory Loss". Examples of progress are provided below and a range of actions are planned across the University Health Board and wider community:
- The roll out of hearing equipment throughout secondary care (hospital services) in order to improve communication for people who are hard of hearing and improve their patient experience. This will be extended to primary and community care.
- The Deaf Well-Being Project in conjunction with the local Deaf community, the British Deaf Association, New Horizons, Interlink and the Centre for Equality Human Rights. The aim of the project is to help Deaf people access services more easily and also better manage their physical and mental health.
- Following the success of the Deaf Friendly Education Programme for Patients, Depression Busting and Mental Health Awareness programmes are also being adapted to a Deaf friendly format.

There are a number of pieces of work developed or being developed across Cwm Taf by key people working with particular groups including older people and people with a learning disability.

The Joint Commissioning Statement for Older People ²seeks to ensure that older people live longer, healthier, fuller and happier lives; where they are encouraged and supported to maintain their independence for as long as possible, whilst recognising that some may become ill, frail or vulnerable, and ensuring that these people receive the respect, care and support they want and need at the right time and in the right place.

The Cwm Taf Joint *Learning Disability Statement of Intent*³ (a document put together by the key people in Cwm Taf working with those with learning disabilities) says that people with a learning disability should be able to access modern and effective services which they have identified as important and which support them to be more independent.

² Cwm Taf, <u>Joint Commissioning Statement for Older People's Services – 2015-2025</u>.

³ Cwm Taf, Learning Disability Joint Statement of Commissioning Intent

The increase in the number of older people in Cwm Taf is likely to result in an increase in dementia, chronic conditions such as cardiovascular, respiratory diseases and cancers. The Cwm Taf University Health Board has a number of plans to support people with specific chronic conditions including– cancer, heart disease, respiratory conditions, stroke, eye health and diabetes. Obesity can also be an underlying cause and impact upon on a number of these conditions. The Cwm Taf Healthy Weight, Healthy Valleys Strategy aims to help people to improve their nutrition and physical activity in order to maintain a healthy weight⁴. Public Health Wales has developed a 10 step approach to preventing childhood obesity, to ensure that future generations grow up to be a healthy weight⁵.

Despite the various documents outlined there remains a need for more strategic direction in Cwm Taf for future services for those specifically with physical disability including sensory impairment. This should also include, not only what is traditionally perceived as a disability, but also a range of chronic conditions, for example obesity, which may "disable" individuals and prevent them from living healthy and fulfilled lives.

This will allow a strong and shared commitment by organisations that provide services to ensure that people with these disabilities receive seamless, integrated health and social care services. Giving these people improved awareness and greater confidence in the services they will receive.

4. Headlines

Although a range of support services exist, people are unsure about what is available to them and how to access services, support and help.

People told us they don't know what services are available to them or how to access the support and help they need. This is despite the existence of a specialist directory style website (DEWIS), which has been designed to direct individuals to the services and support they might need. Service users and indeed a number of professionals remain unaware of and unfamiliar with DEWIS despite it having been available for a number of months. People instead report relying on family, carers and friends for advice, and value this support, however for some this support may be absent and for others, additional support may be required. The reliance on digital technology is an issue as it is often assumed that everyone has access to the internet, and therefore everyone can find out what they need to know. However, it is known that

⁴ Public Health Wales, Healthy Weight, Healthy Valleys Strategy 2012-2015

⁵ Public Health Wales, <u>10 steps to a Healthy Weight</u>

disabled people are less likely to live in households with internet access than nondisabled people. Further to this there are significant communication issues for those who are Deaf or blind or have some form of sensory loss. The format of information needs careful consideration, especially for those who were born Deaf, as English may be difficult for them to understand, with British Sign Language (BSL) their first language.

If people are more aware of the availability of support and services and are able to access them, the additional support and help received may improve their well-being. Without this people may not have access to what they need and their overall well-being may suffer as a result.

There are a range of services, support and help available. However, it is clear that people do not always know about the options available to them. It is important that those involved in the care and support of people, for example, GPs, need to direct people to these support services and increase awareness in order to ensure people get the help they require. This has to start with service providers, as there is a need to increase awareness among professionals, in order for them to be able to do this. By having information on a range of care and support services available in one place, in a location that people routinely visit, with staff available to offer help and guidance, people will be better supported to access the services they require.

<u>People do not identify with the language and definitions that are routinely used by</u> professionals and providers of services.

There are around 4150⁶ people in Cwm Taf registered as having some kind of physical disability or sensory impairment. Service providers believe this number is not a true reflection of the numbers affected as people do not identify with the language, definitions and terminology used. Deaf and blind, especially culturally Deaf and blind (those born Deaf or blind), service users feel particularly dis-connected with the term impairment, they do not feel they have an impairment or loss as they have never had that sense to impair or lose. There are also issues with under reporting as people do not want to be on registers as they are not sure how this information will be used, or they are worried about discrimination. The mechanism for reporting on these figures is a potential issue also, as the format of surveys is not always accessible to some, an example being, the culturally Deaf. As previously mentioned, English is not always well understood and they may therefore find it difficult to complete forms and surveys in English.

⁶ Welsh Government

As people do not identify with the language and do not define themselves using these words, they are not accounted for and go unnoticed. As a result, they are not directed to the support and help, which is available to them, and which they may need. This can impact on their quality of life and general well-being.

There are a number of services and third sector organisations who have a really good understanding of how these people define themselves. The people working in these organisations have a wealth of expertise in terms of what these people need, if we work with these people and listen to them when they talk about how people define themselves and what they need we can improve our understanding of this group. With improved understanding and more appropriate definitions, registers may be more accurate, so that service providers have a better understanding of who needs care and support, and also what type of care and support they need, and those that need that care and support can access it.

Services need to focus on the needs of individuals.

As previously mentioned, there are many different types of conditions, which can affect people, as such it is really important that the services available consider individual needs. For example, the needs of a Deaf person will be different from someone who has a physical disability and is in a wheelchair, or someone who has suffered a stroke which may have affected their movement and senses in a number of ways. Clearly having one type of service will not cater for all the individual needs that exist. Choice and independence⁷ are important to disabled people just as they are for non-disabled people. They want to feel involved, in control and listened to, and respected. Having a personal budget and receiving direct payments, can give them more choice and control to make decisions about what services they want and need to help them. For example, offering age appropriate respite services, to allow family to have a short break from their caring responsibilities, to include alternative and modern options, for example appropriately supported sports activities/clubs, rather than more traditional options as offered in day centre settings. This may be especially important for younger service users.

Due to the way services are set up, sometimes people with multiple needs, for example an elderly Deaf person, who is frail and has dementia, may need to access multiple services for their varied care and support needs. This may be further complicated due to the need for additional communication support, which it is reported service providers are not always aware of. Having to retell their story again

⁷ ONS, <u>Opinions Survey 2012</u>

and again, can leave them and their family feeling frustrated, confused and weary. This is not efficient for the service user or indeed services and service providers. There is a need for more joined-up working to better support these people and improve outcomes for them.

Service providers need to be aware of the full extent of a person's needs, and services need to be more flexible to ensure care and support is provided in the most logical way, so that a person is able to access all of the services they require in the most straightforward way (via as few service providers as possible).

To achieve this, changes need to happen at a higher level to allow local service providers to work together to better understand the needs of service users. It will be important that they share information, and plan and deliver services together to ensure that individual needs are met by their combined services. It is recognised that this will be a huge change and will require significant work and commitment, however the benefit and improvement for services users will be invaluable.

<u>People with physical disabilities including sensory impairment want to be part of</u> <u>their community removing the barriers that exist.</u>

People (not just those with physical disabilities and sensory impairments) talked about the importance of being an equal part of their family, social groups and communities. This includes being given the opportunity and the support to live independently; get skills and/or a job; being able to get out and about within their community, have a decent home, live and make friends and be involved in the things that are happening.

Disabled people and those with sensory impairment face significant barriers in fulfilling their potential and playing a full part in society⁸. These barriers include social isolation, and increased risk of depression, poverty⁹ and additional living costs¹⁰, reduced choice and independence across various areas of life (work, education and training¹¹, play and recreation, accommodation¹²). They may be more

⁸ DWP, <u>Disability Facts and Figures</u>

⁹ Save the Children, <u>Severe Child Poverty in the UK</u>,

¹⁰ Centre for Research in Social Policy, <u>Additional costs of living for people who are Deaf</u>

¹¹ ONS, <u>Labour Market Statistics</u>

¹² Department for Communities and Local Government, <u>English House Condition Survey</u>

vulnerable to discrimination and harassment^{13 1415}, and their access to the physical environment may be limited (transport¹⁶, buildings¹⁷, goods and services¹⁸ etc).

Most disabled children have the same wishes as all other children - to live at home, go to school and spend time with their friends and peers. Younger People with disabilities may face problems in education, and later employment, as well as in accessing technology to support independent living, they may also require additional support during transition from childhood to adulthood.

Deaf people told us that communication is a huge issue (that is not unique to just this group). Problems they experience include the lack of available interpreters, they also said that the increased and improved use of technology, e.g. remote interpreter service, was not always helpful. Others talked about the lack of accessible information and the available options for reporting problems, while also saying that information was hard to understand, especially when people use jargon.

Organisations providing services need to change the way in which they communicate with people who receive their services, it is also important that people are confident in communicating their needs to those who provide services.

This could be through developing common communication standards across a range of public services. Feedback from engagement with people who use services tells us that the following would be helpful; more visual, easy read information, drop in sessions for people through current One Stop Shop, Council One4All centres (or equivalents) with, for example, an interpreter available to deal with any queries, provide information etc. Involving existing groups that already provide support and advice across Cwm Taf, their experience and knowledge, will help to identify the improvements that are needed.

Establish early invention and preventative services rather than reactive services, which often come into play in times of crisis.

We know that our older generation will grow in the next 15 years, especially the over 80 population¹⁹, as a result we expect more people will need help, care and support from services. These people are likely to include those with health and physical disabilities, and sensory impairment, as it is known that these conditions

¹³ Home Office, <u>British Crime Survey</u>

¹⁴ Department for Business, Innovation and Skills, <u>Fair Treatment at Work Survey</u>

¹⁵ Equality and Human Rights Commission, <u>Enquiry into disability related harassment</u>

¹⁶ ONS, <u>Opinions Survey</u> 2011

¹⁷ ONS, <u>Life Opportunities Survey</u>.

¹⁸ ONS, <u>Opinions Survey</u> 2010.

¹⁹Cwm Taf, Joint Commissioning Statement for Older People's Services.

become more common as people get older²⁰. For some these are accepted as part of the aging process, however sensory loss, for example, can be prevented if people act quickly and seek help when they first notice a reduction in their sight or hearing.

Premature babies and those with a low birth weight are more likely to have multiple and complex disabilities^[xiv], positively medical advances in recent years mean that these babies will live longer. It is known that low birth weight can be linked to teenage pregnancy and mothers who smoke while pregnant. In order to reduce the risk of babies being born early, with a low birth weight, and the risk of disabilities that brings, it is important that help is available to those who may be at risk.

People told us about the importance of having help available to them when they need it. Whether that is, for example, when considering a move to supported housing for a person who is finding it difficult to continue living in their own home. Having that move available to them while they are still well enough to deal with it, rather than at crisis point when it is much more difficult and stressful for them to undertake.

As we have stated there will be increased demand for services in the future. If we don't take action at an early stage, the level of services people need will also increase. This will put more pressure on existing services, making it more difficult for those in need to access the care and support they require.

Some examples of simple early support services that could be put in place include a routine hearing screening programme for older people, which could have huge benefits, including cost ²¹, identifying hearing loss at an early stage and reducing that loss with hearing aids can reduce isolation²², depression, anxiety and improve emotional well-being and independence²³. Likewise, as hypertension is known to be the single biggest risk factor for stroke²⁴, the implementation of routine blood pressure screening could potentially reduce the risk of stroke for many people. Stroke can have long term effects on a person's movement, speech, hearing and sight, so the potential benefits of reducing the risk of stroke in the general population are clear.

²⁰ Welsh Government.

^[xiv] Children With Disability - An Overview, Orlagh Barnes, NHS Norfolk, 2 April 2008

²¹ RNID and London Economics, <u>Cost Benefit Analysis of Hearing Screening for Older People</u>

²² National Council on Aging, <u>The consequences of untreated hearing loss in older persons</u>

²³ Kochkin, Sergei and Rogin, Carole, <u>Quantifying the obvious: the impact of hearing instruments on</u> <u>guality of life</u>

²⁴ Stroke Association, <u>High Blood Pressure and Stroke</u>

5. Links to other headlines and common themes

The things which affect people with health and physical disabilities including sensory impairment do not stand alone. The same things are likely to affect other people who use care and support services. Likewise, there are other headlines and common themes which will affect these people but will not be related to their disability. Some of the common themes identified through this work include:

- Everyone wants to feel part of their community. Social isolation is not just an issue for people with physical disabilities including sensory impairment, but also for older people, people with mental health problems and people with learning disabilities. Feeling part of the community is not just about being able to access care and support, but also being able to live independently; having access to information and being able to communicate, developing skills and/getting a job; being able to get out and about within their community, having a decent home, living and making friends and being involved in the things that they enjoy.
- People told us they don't know what services are available to them or how to access the support and help they need. This is true for the general population, not just those with care and support needs. People report relying on family, carers and friends for advice, and value this support, however for some this support may be absent and for others, additional support may be required. The reliance on digital technology is an issue as it is often assumed that everyone has access to the internet, and therefore everyone can find out what they need to know. However, it is known that disabled people are less likely to live in households with internet access than non-disabled people, this is also the case for older people.
- As previously mentioned, there are many different types of conditions, which can affect people. As such it is really important that the services available consider individual needs. Clearly having one type of service will not cater for all the individual needs that exist. Choice and independence²⁵ are important to disabled people just as they are for all people. Everyone wants to feel involved, in control and listened to, and respected. People may have multiple needs but don't want to access multiple services, having to retell their story again and again. This can lead to feelings of frustration and confusion. This is not efficient for the service user or indeed services and service providers. To

²⁵ ONS, <u>Opinions Survey</u>, 2012

overcome this local service providers, need to work together to better understand the needs of service users. It is recognised that this will be a huge change and will require significant work and commitment, however the benefit and improvement for services users, across the board, will be invaluable.

 The predicted increase in our older generation will result in more people needing help, care and support from services. This will not just include people with health and physical disabilities, and sensory impairment. Having access to help when it is needed is important for everyone. If we don't take action at an early stage, and with the likely increased demand for services in the future from the older generation, whether they are physically disabled, a carer, or have a mental health issue, there will be more pressure on existing services. This will make it more difficult for those in need to access the care and support they require.