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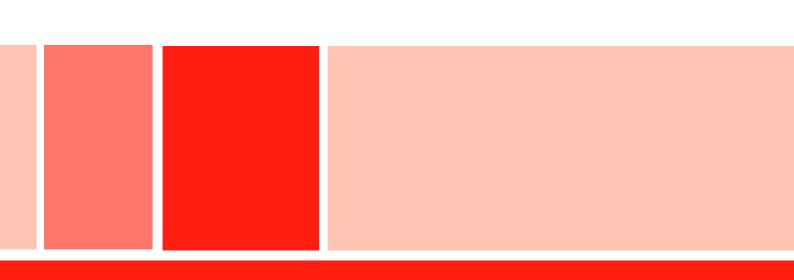
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Review of Evidence of Inequalities in Access to Healthcare Services for Disabled People in Wales



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Shaun Smith ESRC PhD Internship Scheme

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Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government.

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Acronyms

AIDS acquired immune deficiency syndrome

ALAC Artificial Limb and Appliance Centre

ALAS Artificial Limb and Appliance Service

AWSSIC All Wales Stroke Service Improvement Collaborative

BBC British Broadcasting Corporation

BME black and minority ethnic

BSL British sign language

CRPD Convention on the Rights of People with Disabilities

DLA disability living allowance

DWP Department for Work and Pensions

EHRC Equality and Human Rights Commission

GP General Practitioner

HIV human immunodeficiency virus

HQIP Healthcare Quality Improvement Partnership

ILO International Labour Organisation

LHB Local Health Board

NHS National Health Service

NICE National Institute for Health and Care Excellence

NRAS National Rheumatoid Arthritis Society

NSF National Service Framework

ODI Office for Disability Issues

ONS Office for National Statistics

PIP Personal independence payment

RNIB Royal National Institute of Blind People

SCI spinal cord injury

UN United Nations

UK United Kingdom

Executive Summary

Introduction

This report was undertaken to review inequalities in access to healthcare services associated with the protected characteristic of disability. This report therefore presents a synthesis of such evidence based on a scoping review of published literature.

Methodology

This report is comprised of a literature review of 355 published sources of evidence which show inequalities in access to healthcare services for disabled people. The papers/reports used in this report are drawn from a variety of sources including government documents, academic literature, and independent reports. The scope of the review was to search for evidence published in the preceding 10 years specifically relating to, or having relevancy for, the working-aged adult population in Wales. A consultation exercise was also conducted to gather the feedback and responses of leading disability organisations in Wales.

Main Findings

This report finds wide-ranging evidence to suggest that disabled people in Wales experience considerable general and more specific healthcare access issues. Background evidence suggests there is a strong correlation between poverty and disability and that such poverty is compounding already existing inequalities in access to better health. For example, many disabled people have considerably shorter life-expectancies and there is evidence to suggest that this is caused by inequitable levels of healthcare provision.

Evidence also suggests that there is a general under-provision of many services which could potentially be beneficial to disabled people in Wales including rehabilitation services and mental healthcare provision. There is also a surprising amount of geographical variation in the provision and uptake of key healthcare services. Such variations often correlate with area deprivation or the urban rural divide, but in many instances indicate a simple imbalance in the provision of care.

Specific evidence suggests that people with different forms of sensory loss in Wales have difficulties accessing healthcare services due to inappropriate contact methods. Evidence suggests that many people with chronic conditions are not aware of the rehabilitation services available to them. The majority of people with learning disabilities do not benefit from the annual health check scheme despite the benefits being well-documented in the literature. Lastly, there is a stigma preventing men from seeking help for mental health conditions even though there is a gender imbalance in the rate of suicide in Wales.

Summary of Evidence – general findings

- The inequality gap in 'disability free life expectancy' in Wales is now 14.8 years for males and 12.5 years for females between the most and the least deprived groups.
- There is evidence from international sources to show that people with certain impairments have considerably shorter life-expectancies in comparison to the general population and that some of these differences are due to inequitable levels of care.
- There is an association between poor health literacy and adverse health outcomes and the evidence shows that people who report long-term limiting illnesses or disability perform lower than average in literacy and numeracy assessments – often a background determinant of levels of health literacy.
- Carers have disproportionately poorer health in comparison to the general population and there is also specific evidence which suggests that caring, considered independently, can have adverse health outcomes.
- Evidence suggests that reforms contained under the Welfare Reform Act will disproportionately and negatively affect Wales, will disproportionately and negatively affect disabled people and will have adverse health outcomes among people in Wales.
- There is a lack of research concerning the efficacy of both telehealth services and personalisation approaches for disabled people in Wales.

Specific Findings

Physical Disability

- There is geographically uneven access to wheelchair fitting services in Wales
 with people in North Wales experiencing particularly long waiting times. The
 wheelchair fitting service often does not meet people's needs in terms of
 maintenance and training in the use of wheelchairs.
- There is a lower ratio of trained Prosthetists per head in Wales than any other UK country.
- There is currently no Muscular Dystrophy Care Co-ordinator exclusive to Wales.
- Public awareness of different types of arthritis is poor and people avoid seeking healthcare through a perceived need to struggle with pain and a perception that nothing can be done about symptoms.
- Only 60% of chronic pain services in Wales meet the 'multidisciplinary' status of providing all of a trained Physician, Psychologist, and Physiotherapist.
- Due to a lack of objective criteria for defining pain, there is often a stigma surrounding the experience of pain with many people, particularly women feeling they are not believed by healthcare staff surrounding their experience of pain. There is also evidence to suggest that men avoid seeking healthcare in relation to pain.

Sensory Loss

- Many deaf and hard of hearing people are forced to make contact with their GP in a method that is not optimal and 90% of GP surgeries in Wales do not offer suitable alternatives for making appointments.
- People with different forms of sensory loss are missing appointments due to not hearing being called in waiting rooms and appointment letters sent in the wrong format.
- There are multiple sources of evidence to suggest that many people with sensory impairments feel socially isolated, avoid social situations and lack a feeling of independence.
- There are a number of barriers to the early detection of degenerative eye disease among the most deprived income groups and BME populations.

Chronic and Long Term Conditions

- There are variable screening rates for different types of cancer and variable screening uptake rates geographically across Wales. Targets are currently not being met for uptake of cancer screening programs in Wales.
- Only 57% of people with type 1 diabetes and 37% of people with type 2 diabetes receive all nine aspects of the recommended annual health check.
- There is evidence to suggest that certain chronic conditions such as diabetes, chronic kidney conditions and HIV are all under-diagnosed and that cancer is frequently diagnosed late in the UK.
- Evidence suggests that, directly following diagnosis, many people with chronic conditions do not receive written information regarding the management of that condition.
- People with neurological conditions are not receiving recommended multiple aspects of rehabilitative care and are often unaware that certain services are available to them, such as physiotherapy.
- There is a general under-provision of rehabilitation services for many chronic conditions.
- Rehabilitation services are poorly integrated and services such as home modification, assistive technology, and financial support are often not incorporated into the rehabilitation process.
- 44% of stroke patients do not receive a recommended single joint assessment of needs and 64% of stroke patients do not receive an individual care plan in Wales.
- There is evidence to suggest that certain people with chronic conditions (e.g. cancer) feel isolated and 'left alone' after leaving clinical care.

Learning Disability

 The majority of people with learning disabilities in Wales do not receive an annual health check and the uptake rates vary by a considerable margin geographically across the country.

- The quality and consistency of annual health checks for people with learning disabilities varies across Wales and some GPs are reluctant to undertake annual health checks.
- The uptake rates for most cancer screening programs, vision and hearing assessments and routine dental care are lower among people with learning disabilities when compared to the general population.
- There is evidence to suggest that diagnostic overshadowing could be a barrier to people with learning disabilities receiving correct diagnoses for underlying health problems.
- Access to out-of-hours healthcare is particularly problematic for people with learning disabilities.

Mental Health Conditions

- Spending on mental health services is not keeping pace with the expected increase in the prevalence of mental health conditions.
- Mental health conditions are generally under-treated; only 24% of people with depression and anxiety disorders receive any form of treatment, only 8% of patients with depression have seen a psychiatrist and only 3% of patients with depression have seen a psychologist.
- The provision of staff specially trained in mental health conditions is sporadic across Wales.
- Public awareness of the symptoms and consequences of postnatal depression is poor.
- There is a clear and consistent gender imbalance in the rate of suicide in Wales with more men committing suicide than women. Despite this, the evidence consistently shows that a higher proportion of women report depression when compared to men, suggesting that mental health conditions are under-reported among men.
- There is an embarrassment and stigma attached to men seeking help for mental health conditions.
- 20% of people who commit suicide in Wales do so within 3 months of discharge from a healthcare point and 28% missed their last appointment before committing suicide.

1. Introduction

- 1.1 This report aims to synthesise published research showing inequalities in access to healthcare services associated with the protected characteristic of disability to contribute to the evidence base. This review will inform the Welsh Government's Strategic Equality Objectives towards advancing equality and eliminating discrimination for protected groups in Wales, of which, disabled people are an important example.
- 1.2 This report is based on a scoping-review of published evidence drawn from government documents, academic literature and independent reports which show inequalities in access to healthcare services for disabled people in Wales. Where possible, evidence specific to Wales has been identified and included but it is clear that such evidence is unavailable in many areas and a separate aim of this report was also to highlight such gaps in knowledge as to inform future research agendas.
- 1.3 A 'scoping-review' is not intended to be a comprehensive review of all aspects of access to healthcare for disabled people and this report does not review current practice.
- 1.4 'Disability' is a protected characteristic under The Equality Act (2010) meaning that the Welsh Government has a duty and responsibility to protect and safeguard disabled people's equal access to public services such as healthcare services. The Welsh Government was also the first United Kingdom (UK) government to explicitly adopt the social model of disability which commits the Welsh Government to working towards removing the disabling barriers created and sustained by society.
- 1.5 This report starts by providing a contextual picture of the different ways in which disability has previously been defined, the general interaction between disability and inequality in Wales and the interaction between disability and other demographic factors. It then progresses to present general evidence showing general health and health access inequalities experienced by disabled people when compared to other groups and the general population. Lastly, the report considers specific evidence relating to inequalities in access to healthcare services experienced by five specific groups of impairment including physical disability, sensory loss, chronic and long-term conditions, learning disability and mental health conditions.
- 1.6 The report acknowledges the contested nature of disability and the complexity of research concerning access to healthcare services, particularly under the social model of disability. Given this complexity, and the evidence available, this report concludes that there is now a sufficient body of evidence to suggest that disabled people face a number of particular and more general healthcare access issues which point towards clear inequalities.

2. Methodology

The Purpose of the Research

- 2.1 The main aim of this research was to undertake a review of evidence outlining inequalities and inequities in access to healthcare services for disabled people in Wales. The main method of this research was to conduct a scoping-review of published reports and literature detailing such inequalities.
- 2.2 The author of the report also attended a number of meetings with disability groups such as the Disability Equality Forum hosted by the Welsh Government and also had individual meetings with the NHS Centre for Equality and Human Rights and Mencap Cymru. The author also had personal correspondence with a number of disability groups and relevant institutions such as Local Health Boards and the Royal National Institute of Blind People (RNIB). A consultation exercise was also conducted to gather the responses and feedback of a broad range of organisations and individuals concerned with policy and access to healthcare services for disabled people in Wales.

Scope of the Report

- 2.3 The scope of the research and the methodology used was determined, in part, by areas of particular interest and relevance to the Welsh Government's Strategic Equality Objectives but also, in part, by issues of practicality in terms of what could be achieved in the four month period of the research. A brief outline of the scope of the report is included as follows;
 - A commitment to finding evidence specific to Wales and, where appropriate, evidence from the UK and internationally which has, by implication, direct relevancy for Wales.
 - A focus on data and evidence published in the preceding 10 years.
 - A focus on the working-age adult population (16-64) (although, where appropriate, the report has seen fit to report on issues relating to young and older age groups, particularly where the boundary between age classifications has little usefulness for specific issues, such as in the case of dementia or age related macular degeneration, for example).
 - A commitment to including robust and rigorous evidence published by reliable sources.
 - Attempt to find models presented under or applicable to the social model of disability.

Literature Search Strategy

- 2.4 The primary search strategy for this research was to conduct exploratory searches of online databases (such as Web of Knowledge and PubMed) for academic literature and online search engines (such as google) for public or third-sector published reports. Individual searches were then conducted directly through the websites of relevant organisations and institutions known to publish evidence in the area of healthcare inequality (such as National Health Service (NHS) evidence, Public Health Wales, The King's Fund etc.). From these initial exploratory searches, more detailed searches were then conducted relating to specific areas of concern (such as 'mental health'). The general search terms included in the initial exploratory phase included terms (or truncated terms¹) such as; 'health', 'healthcare', 'services' 'inequality', 'disability', 'impairment', 'Wales', 'access' and 'uptake'.
- 2.5 The sources which comprise the literature used to inform and referenced directly in this report can be categorised as follows;
 - Academic literature (e.g. published journal articles by researchers affiliated to universities)
 - Review and audit reports (e.g. those published by the Wales Audit Office)
 - Governmental research and reports (e.g. governmental inquiries)
 - Public-body reports (e.g. reports published by the Office for National Statistics)
 - Independent third-sector reports (such as those published by Action on Hearing Loss or The King's Fund)
- 2.6 Although the search strategy and broader methodology of this research may not be considered as fully 'comprehensive' for disability and healthcare access inequality in Wales, they can be considered as representative for published literature relating to Wales in the previous 10 years. Thus, due to practical constraints, the aim of the research was to conduct a 'scoping' exercise and/or a 'rapid evidence review' to draw out the main issues concerning healthcare access for disabled people and to discuss as many of these issues in as much detail as possible. A rapid scoping review can perhaps best be described as providing a thematic and explanatory overview of relevant and recent data which can be used to inform policy in the broad subject area at hand.
- 2.7 One of the key issues in terms of the scope and methodology of the research is the availability of data specific to Wales. In many cases, data specific to Wales was found to be lacking. This sometimes reflects reviews of specific healthcare services which take as their geographical basis the 'UK' or

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¹ A truncated search term is where an asterisk* is used to shorten a word to its root so that different versions of the same word are presented in the search results. E.g. a search for inequ* would include results for both 'inequity' and 'inequality'.

'England and Wales' and do not tend to disaggregate data by individual country. Secondly, due to the relatively small population of Wales, the number of people with certain specific impairments (such as human immunodeficiency virus (HIV) or muscular dystrophy, for example) is often relatively low, therefore finding large-scale (or robust) evidence in specific areas such as this is often difficult.

2.8 This means that the methodological approach taken by this research has been to use data from both the England and Wales or UK level and to attempt to draw out the implications specific to Wales implied within such evidence. In some areas, evidence specific to the UK is also lacking and in such instances international literature (mainly academic publications) has been used where it is felt to be of relevance to Wales.

Consultation Exercise

- 2.9 A consultation exercise was also conducted as part of this research to gather the responses and feedback of a number of expert individuals, groups and organisations concerned with healthcare inequality for disabled people in Wales. Over 50 such groups were invited to take part in the consultation exercise and 23 eventually responded stating that they wished to participate. Those who attended the workshop or who replied with written responses included; Local Health Boards (LHB), the Welsh Ambulance Trust, Disability Wales, Public Health Wales, Action on Hearing Loss, RNIB, Mencap Cymru, the Stroke Association, Arthritiscare Wales and the South West Wales Neurological Alliance.
- 2.10 The consultation exercise involved sending advanced recommendations and initial findings from the research and inviting participants to respond in writing to the recommendations or attend a workshop which was run at the Welsh Government on the 18th February 2014. Feedback from this consultation exercise has been incorporated into the report in three main ways. Firstly, specific comments have often been included directly in the content of the report. Secondly, general comments have been incorporated in the overall approach and scope of the report. And lastly, more formal written responses have been included in appendices attached to this report (see appendices A to E).

Research Aims

2.11 This research therefore concerned itself with three main aims;

 To review evidence showing inequalities in access to healthcare services for adult² disabled people in Wales and assemble this evidence in a single document.

² In this report, adults are defined as those aged 16-69. The specific nature of access to healthcare for children and older people means that discussion of these groups has not been included.

- 2. To use the above evidence as a basis to examine research gaps concerning access to healthcare for disabled people in Wales.
- 3. To draw meaningful general and specific conclusions based on this evidence which can be used to inform a broad range of policy areas and future research agendas.

The Structure of This Report

- 2.12 The report which follows is structured into three distinct sections. These sections are:
 - 1) Contextual issues (e.g. the interaction between inequality and disability)
 - 2) General evidence (i.e. inequalities for 'disability' as a category)
 - 3) Specific evidence (i.e. inequalities for distinct groups of medical conditions or impairments such as sensory loss)
- 2.13 It is important to give a rationale for why such an approach has been taken. In general, it can be said that such an approach has been taken as a compromise between the way in which evidence pointing to inequalities in healthcare access is presented in the literature and the social model of disability.
- 2.14 During the research it became clear that much of the evidence outlining inequalities in access to healthcare services for disabled people in Wales was either aggregated or written on the basis of either one single impairment (or medical condition such as cancer, for example) or a distinct group of impairments (e.g. 'neurological conditions'). This is further supported by audit reports, governmental inquiries, clinical reviews, wider academic research and specialist healthcare services which are often structured in a similar way. This means that such evidence and data are often not easily generalisable for the category of 'disability' as a whole.
- 2.15 The social model of disability, however, implies that disability is not inherent to the individual condition but to wider issues of access and ability in society. This, in many ways, is a unique problem to the question of the social model of disability when applied to the question of healthcare access as healthcare services are often designed solely to treat individual conditions. The approach this research has taken, and which is reflected in the structure of this report, is first to outline the context in which unequal access to healthcare might be understood, secondly (where available) to draw together the evidence generalisable to disability as a distinct category, and thirdly to also draw on that evidence which is written on the basis of specific impairments, thereby attempting to capture the totality of the problem.
- 2.16 On this last issue, there was a concerted effort in the approach taken by this report to avoid referring directly to medical conditions or impairments and instead to refer to cross-cutting themes applicable to more than one group.

Inevitably, this problem has not been fully overcome and much of the evidence in the specific evidence sections is presented based on specific conditions. In some senses, however, such an approach is potentially relevant under an equality agenda if it is clear that there are particular inequalities referring to the lack of attention or provision given to one particular impairment or group of impairments.

3. Contextual issues

Defining Disability, Access, Equity and Equality

3.1 The following sections provide a background to the evidence presented in this report by discussing a number of contextual issues such as the definition of disability, the relationship between inequality and disability and lastly the interaction between disability and a number of demographic factors.

Access and Need

- 3.2 In the literature concerned with inequalities in access to healthcare (across different characteristics such as material wealth, gender, age, ethnicity and disability etc.) there are a number of different ways in which equality and access have been defined. It is important to examine some of these distinctions between definitions and also outline the way in which this current research has defined and approached the issues of 'access' and 'equality'.
- 3.3 The current *Standards for Health Services in Wales* (Welsh Government 2010) define 'access' to healthcare as:
 - 'The extent to which people are able to receive the information, services or the care they need.' (pp 15)
- 3.4 The above definition corresponds closely to a key 'equality objective' under the Welsh Government's *Strategic Equality Plan and Objectives* (Welsh Government 2012a) which aims to
 - 'Put the needs of service users at the heart of delivery in key public services, in particular health, housing and social services, so that they are responsive to the needs of people with protected characteristics' (pp 19).
- 3.5 A key element of both of the above definitions is the issue of 'need' and, in particular, aligning healthcare services to meet people's needs. The issue of how 'need' is defined, however, is often a contentious one in the literature, as there is no common agreement on what exactly constitutes need (Oliver and Mossialos 2004). Typically, 'need' has been defined based on an examination of the factors leading to healthcare *utilisation*, which some have contended may not fully correspond to a true picture of need, which is often a complex interaction between people's expressed and personal needs, and needs more rooted in societal norms (ibid.).
- 3.6 There may, in fact, be little convergence on how 'access' to healthcare is defined in general (ibid.). Kovandzic et al. (2011) in a review of the literature find two key strands to how healthcare access has previously been defined. The first is what they call the 'functionalist view' which defines access based on 'entrance' into the formal system of care and incorporates such issues as

demand, availability and utilisation. The second is what they term behavioural or societal approaches which focus more on health seeking behaviour, attitudes, and beliefs of people before entering formal systems of care. One approach which has sought to reconcile these two different perspectives regarding 'access' is offered by Gulliford (2001) who attempts to define access as follows:

- 1. If services are available, in terms of an adequate supply of services, then a population may 'have access' to health care.
- The extent to which a population 'gains access' to health care also depends on financial, organisational and social or cultural barriers that limit utilisation. Thus utilisation is dependent on the affordability, physical accessibility and acceptability of services and not merely the adequacy of supply.
- 3. The services available must be relevant and effective if the population is to 'gain access to satisfactory health outcomes'.
- 4. The availability of services, and barriers to utilisation, have to be evaluated in the context of the differing perspectives, health needs and the material and cultural settings of diverse groups in society.

(quoted directly from Gulliford 2001: 3)

- 3.7 This research takes many of the key principles from the above definition and adapts them for use in this report and to inform the methodology. In particular, Gulliford's definition consolidates a number of key aspects of access under one definition. The first is a focus on 'having access' to services which already exist which raises questions of which services do not exist in areas where there may be a pre-existing need. The second is the issue of 'gaining access' which pays closer attention to social factors preventing access, which may be more appropriate to the social model of disability. Lastly, Gulliford successfully incorporates 'need' into his definition but does not give it preference over the wider (societal) factors which may determine access to health.
- 3.8 It is important to highlight that although 'access' can have a general connotation in relation to healthcare, it often has a very specific connotation when relating to disabled people and access to public services in general. One example of this in a Welsh context is the formulation of the *All Wales Standards for Accessible Communication and Information for People with Sensory Loss* (NHS Wales 2013). This document claims the purpose of the standards' is to:

'Ensure that the communication and information needs of people with a sensory loss are met when accessing our healthcare services' (pp 1).

- 3.9 Furthermore, they state that:
 - 'There is a legal duty under the Equality Act 2010 to ensure that reasonable adjustments are made to deliver equality of access to healthcare services for disabled people' (pp1).
- 3.10 The immediate point to recognise is that, although the 'needs' of people are once again the predominant focus of access, such needs are situated within an equalities framework which suggests that 'reasonable adjustments' may be required to meet the needs of disabled people such as people with different forms of sensory loss. Such specific connotations of access can be extended to other areas of disability such as physical disability, although there is a surprising lack of research surrounding the question of how physical access is to be defined in a Welsh context.

Equality and Equity

- 3.11 The All Wales Standards for Accessible Communication' are one example of how 'equality' has been linked to the issues of access in a Welsh policy context. It is therefore important to examine how equality has previously been defined in relation to access and the particular approach taken by this research. The definition of equality is perhaps best approached by also offering a definition of 'equity'. Equity, at its most basic level, is an ethical concept with means either fairness or justice in the distribution of resources and public goods (Braveman 2003, Braveman and Gruskin 2003). The concept of equity is therefore normative: or a concept predominantly based on the values attributed to what constitutes a 'fair' or 'just' society.
- 3.12 As Braveman (2003) has highlighted, because equity is a normative concept it cannot be directly measured in relation to health or healthcare access. What can be measured, however, is health(care) *inequalities* which are considered as differences between more or less advantaged groups in society (whether that be based on material wealth, gender, or disability etc.). A health inequality is a systematic disparity based on underlying social (dis-)advantage whereas a health inequity is a systematic disparity based on underlying social (dis-)advantage which is unjust or unfair. As some researchers have highlighted 'not all health disparities are unfair' (Braveman and Gruskin 2003:255).
- 3.13 This means that the approach taken for this research inevitably involves questions of both inequality and inequity. The main method of the research is to search for literature showing an inequality in access to healthcare for disabled people when compared to the other social groups or the 'general population'. However, the decision of what constitutes an 'inequality' inevitably involves questions of equity. In some cases, healthcare services may actually

be disproportionately designed and configured for people with particular impairments, based as they are on the medical model of treating certain illnesses and conditions. This research therefore approaches (and considers) the question of access and equality in the following interrelated ways:

- 1. extent to which disabled people can 'gain access' to already existing equitable healthcare services (e.g. rehabilitation, wheelchair fitting).
- 2. Inequalities in access to healthcare services more generally based specifically on disparities relating to disability (e.g. physical access, organisational barriers, staff knowledge and attitudes)
- Inequalities in access to better health, and therefore the implications of inequities in the type and level of healthcare that is available and accessible. (e.g. people's attitudes and health seeking behaviour).

Contextual Issues - Situating Disability

- In 2002, the Welsh Government adopted what is termed the 'social model of disability'³. The social model of disability is both a way of defining disability and method of critique of the barriers preventing disabled people from fully taking part in society on an equal basis. In line with the Welsh Government's position, the social model of disability is used as the most relevant definition of disability within this report. Moreover, the principles of critique implied by the social model⁴ are also the principles which inform the methodology of this report specifically in terms of how the social barriers to healthcare are viewed and framed.
- 3.15 The social model of disability is neither the only theoretical model of disability nor the only way in which disability is defined through governance. As such, it is important to draw attention to, and discuss the implications of, the different ways in which disability has previously been defined. In terms of governance, two of the most relevant ways in which disability is defined are through various criteria to receive welfare benefit supports and through anti-discrimination laws such as the Equality Act (2010). As will become clear, neither of these aspects necessarily define disability under the social model, yet both have important implications for accessing healthcare and better health for disabled people in Wales.

⁴ The term 'social model' is simply used as an abbreviated form of 'social model of disability' throughout this report.

³ Sometimes also referred to as the 'British social model' or 'social-political perspective' (Bickenbach et al 1999).

What is the Social Model of Disability?

3.16 The social model of disability is widely acknowledged to have emerged through the activism of disability groups in the 1970s culminating in a number of documents produced by the Union of the Physically Impaired Against Segregation (UPIAS 1975, UPIAS 1974). The social model of disability is best captured by one of its early proponents, Mike Oliver, who claims the social model:

"Does not deny the problem of disability but locates it squarely within society. It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation" (Oliver 1990).

- 3.17 As such, one of the key theoretical tenets of the social model is the distinction between 'impairment' and 'disability'. Impairment is the broad term used to encompass any number of chronic conditions, diseases, illnesses, congenital conditions or injuries which produce potential individual limitations. Disability is the term used to describe the effects resulting from social relations and organisations which discriminate against people with an impairment. Thus, the social model shifts the 'problem' of disability away from the individual and on to social institutions and social relations (Riddle 2013).
- 3.18 Anastasiou and Kauffman (2013) have reviewed the main contentions of various strands of theory underpinning the social model of disability and have condensed five key arguments as follows:
 - 1. The social model makes a sharp distinction between impairment and disability.
 - 2. Impairment refers to physical/bodily dysfunction, whereas disability refers to social organization.
 - 3. Disability is not a product of bodily pathology.
 - 4. Disabled people are an oppressed social group.
 - 5. Disability is not a matter of personal tragedy.

(quotes taken directly from (Anastasiou and Kauffman 2013: 442-443))

3.19 In 2002, following the advocacy of leading disability groups in Wales (Disability Wales 2013), the Welsh Government explicitly adopted the social model of disability. The Welsh Government contends that under the social model: 'disability occurs when a person is excluded by barriers affecting people with impairments, from something that other people in society take for granted' (Welsh Government 2013). The social model of disability is now explicitly adopted in Welsh Government policy documents such as the

- Framework for Action on Independent Living (Welsh Government 2013b) which establishes a vision for disabled people in Wales.
- 3.20 Many of the ways in which the social model is defined, including those contained in the list by Anastasiou and Kauffman above, emerge in direct criticism of what is often called the 'medical model of disability'. It is therefore important to situate the social model in relation to such criticisms and this is done in the following sections.

What is the Medical Model of Disability?

- 3.21 The medical model of disability⁵ is in many ways not, in fact, a model which is actively constituted by any ongoing or consistent theoretical tradition but rather the orthodox ways in which disabled people are treated in healthcare settings. As such, the medical model 'assumes that a lack of ability in any functional area, which has arisen as a result of impairment, stems from the limitations of the individual to 'adapt', 'cope', or 'cure' their conditions (Woodhams and Corby 2003:164). Disability, under such assumptions, is approached as an individual deviation from biological and social norms (Scullion 2010) and as such can be remedied by medical treatment which has knowledge and power over how disability is both concurrently defined and treated.
- 3.22 Although the Welsh Government has explicitly adopted the social model of disability in cross-cutting policy documents such as the *Framework for Action on Independent Living* (2013), in many areas of non-devolved governance such as the welfare benefits system and anti-discrimination laws, disability is defined using many assumptions contained under the medical model (Woodhams and Corby 2003). The following sections give a brief overview of how disability is defined in welfare benefit supports and under the Equality Act 2010.

How Disability is defined under The Equality Act 2010

3.23 The Equality Act 2010 is a wide-reaching statutory document which 'legally protects people from discrimination in the workplace and in wider society' (UK Government 2013). The Equality Act 2010 was written to unify anti-discrimination legislation within a single law. In reference to disability, the Equality Act 2010 is a direct successor to the Disability Discrimination Act 1995 which previously defined disability in relation to anti-discrimination laws. Clear from the guidance provided by the Office for Disability Issues (ODI) (ODI 2010) is that the Equality Act 2010 applies to disabled people when accessing public services such as public healthcare.

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⁵ Sometimes also referred to as the 'medical assumption' (Woodhams and Corby 2003) or 'medical approach' (Bernell 2003).

- 3.24 The Equality Act 2010 defines a disabled person as follows:
 - 'A person has a disability for the purposes of the Act if he or she has a physical or mental impairment and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities' (ODI 2010: 6).
- 3.25 There are many aspects of this definition which require further explication.
 'Impairment' is defined by the Equality Act under its 'normal meaning' and a number of suggested impairments are listed in the Office for Disability Issues guidelines (2010). Conditions which can not be regarded as impairments include addiction, hay fever, exhibitionism, and tendency to set fires etc.
 'Substantial adverse effect' is defined as a 'limitation going beyond the normal differences in ability which may exist among people' (ibid.: 15) and 'long-term' is defined as a cumulative period lasting longer than 12 months. Lastly, the Equality Act does not stipulate what is to be regarded as a 'normal day-to-day activity', although it offers indicative guidelines that 'normal' should be considered as practical and social activities which are carried out by a large number of people.
- 3.26 It is therefore clear from the above discussion that, although the Equality Act 2010 distinguishes between an impairment and disability, it still posits that disability is inherent to the individual and a deviation from the 'normal' standards of ability. The definition contained within the Equality Act 2010 is therefore based on the medical model of disability and not the social model. There are some important exceptions to this, however, as in the case for the requirements to make 'reasonable adjustments' to workplaces and service provision in order to overcome disabling barriers which are more in keeping with the social model.

How Disability is defined in Welfare Benefit Payments

- 3.27 Disability Living Allowance (DLA) is being incrementally replaced by Personal Independence Payment (PIP) from April 2013 as stipulated by the Welfare Reform Act 2012. PIP is a benefit intended to help disabled people with mobility and participation within everyday life. To gain eligibility to receive PIP applicants must undergo an assessment of their ability to carry out practical and common tasks (such as preparing food and communicating verbally as two illustrative examples). A calculation is then made from this points-based system to determine the severity of disability and whether an applicant is eligible for the regular or 'enhanced' rate of PIP.
- 3.28 It is clear from the above discussion that the assessments for PIP are based on a medical model of disability which situates disability within the individual's own abilities when approximated against a 'normal' standard. Also relevant to the issue of healthcare access is the fact that applicants can not receive PIP if

they are admitted to hospital for a period longer than 28 days. One observer has called the changes to welfare benefits contained under the Welfare Reform Act 2012 as 'the most blatant corruption of the social model of disability' (Morris 2011) failing, as they do, to fully apprehend the barriers inherent in society.

3.29 The issue of how disability is defined under the welfare payments system can be shown to have direct implications for many healthcare access issues such as mental wellbeing, levels of social isolation and the financial situation of disabled people given consistent evidence which shows higher levels of poverty among disabled people, fewer employment opportunities and the extra-healthcare costs imposed by specific impairments.

Criticisms of the Social Model of Disability

- 3.30 Although the social model is the definition of disability adopted in this research, and by the Welsh Government more generally, it is important to acknowledge and detail some of the criticisms of the social model(s) as to highlight its limitations. Perhaps one of the main criticisms of the social model is that it 'does not accurately reflect what the experience of disability actually is' (Riddle 2013: 379). This criticism stems from the separation of 'impairment' and 'disability' which are seen by some to deny the concurrent way in which disability is experienced *both* by the individual and through society (Anastasiou and Kauffman 2013).
- 3.31 As a result, the social model often offers a better criticism of societal barriers and sometimes denies the individual healthcare interventions needed by people with particular impairments (Riddle 2013). Proponents of the social model often reply that impairment is not denied under the social model but is, in fact, a key part of the definition (Thomas 2002). Some have argued that rather than denying impairment, social models of disability, in fact, 'black box' impairment (in the form of unambiguously accepted it to be true) and end up mirroring many of the criticisms of medical models of disability (Hughes and Paterson 1997).
- 3.32 It is clear that the social model of disability arose partly as a political critique of the social barriers to participation and the societal stigma attached to disability. Some have contended, however, that without labels and a certain prioritisation of difference or special needs the individual needs of many disabled people would be ignored (in healthcare settings) (Anastasiou and Kauffman 2013). In particular, the argument has been put forward that the social model, due to its history in active lobbying, under-represents the needs of certain groups such as people with learning disabilities, for example (McClimens 2003).

3.33 Some have gone as far to contend that no single model can capture the multiple dimensions or experience of disability and, as such, different models are useful in different regards and at different times (Palmer and Harley 2012). There is also evidence from leading nursing journals which suggests that the social model of disability is not a prominent feature in nursing literature and theory and observes that, among healthcare professionals, the medical model still dominates in clinical practice (Scullion 2010). As such, for the purposes of a review such of this, multiple approaches to the issue of disability are incorporated and adopted.

Disabled People's Attitudes towards the Social Model of Disability

- 3.34 In 2009, the Office for Disability Issues conducted an analysis of data derived from the British Social Attitudes Survey concerning the popular attitudes towards disability in the UK (Staniland 2009). This research specifically examined the question of what and how disabled people feel about the social model of disability. They found that disabled people, when compared to non-disabled people, were more likely (46% compared to 36%) to say that it was a health condition alone which prevented people from living a full life.
- 3.35 Moreover, disabled people were less likely to say that it was a mix of health conditions and attitudes and barriers in society which prevented people living a full life. It was common, however, for both disabled and non-disabled people to say that societal factors played at least some part in preventing a full life. This research seems to suggest that a proportion of disabled people do not agree with some of the premises contained under the social model but that they, nevertheless, support many of the general principles implied by the model.
- 3.36 Beresford et al. (2010) have also conducted research, albeit with a much smaller sample, specifically examining people's views of the social model of disability in relation to mental health services. Their methodology comprised group discussions with 52 mental health patients, and 17 individual interviews. They found an agreement that the existing dominant medical model of mental illness was negative in effect. They also found that respondent's views surrounding the social model were complex: there was a general support for the social model particularly in terms of greater unity and shared understanding among disability groups; however, many had concerns about 'impairment' under the social model with many respondents viewing themselves as not having an impairment and stating that the term was unhelpful.

Emerging and Other Models of Disability

3.37 Often in direct criticism of the social model, new theories and approaches towards defining disability have begun to emerge which are useful and relevant to discuss (albeit briefly) in the context of this research. One such

emerging approach is theoretical in nature and is often referred to under different headings in the literature such as the 'social-relational model' (Palmer and Harley 2012) or the 'interactional approach' (Riddle 2013). These approaches share a common theme in that they seek to supersede the separation of impairment and disability by emphasising the relation between the personal experience of disability and the social conditions which inform it.

- 3.38 The social-relational model acknowledges more closely the personal and social effects of impairment but still maintains that disability is largely contingent upon the attitudes of society (Palmer and Harley 2012). The 'interactional approach' maintains more assertively that disability can result from factors intrinsic to the individual but seeks to integrate those factors with extrinsic factors arising from the wider social and environmental context (Riddle 2013).
- 3.39 Another approach towards defining disability which is worthy of note is that contained under the United Nations (UN) Convention on the Rights of People with Disabilities (CRPD). The CRPD defines disability under article 1 of its charter as the following:
 - 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (UN 2006)
- 3.40 It can be seen from the above definition that there is concerted effort to emphasise the *interaction* between individual impairments and social barriers created by society. A criticism may be that this definition does not stipulate, in any concrete way, how these two elements interact in practice. Some have also been critical of the above definition in that it seems to revert back to the medical premise of defining disability by restricting disability to people with an impairment (Leonardi et al. 2006).

Areas of Contention

- 3.41 The Equality Act 2010 outlines a number of conditions which can not be considered as an impairment (and therefore potentially lead to disability) and these are; addiction or dependency, seasonal allergic rhinitis, tendency to set fires, tendency to steal, tendency to physically or sexually abuse another person, exhibitionism and voyeurism.
- 3.42 One frequent issue of contention is obesity, which is generally accepted not to be an impairment in and of itself but which nevertheless has an important interaction with disability. As a report by Public Health England (2013) has highlighted, for example, obesity is often associated with concurrent impairments, and in many instances obesity can lead to health conditions (such as osteoarthritis) which can lead to disability. UK research has found

self-reported disability is indeed high among people with obesity but that this should be situated in a complex interaction between body-mass index measures, age, and comorbid conditions. For the purposes of this report, obesity has not been considered directly as an impairment potentially leading to disability.

The Extent and Prevalence of Disability in Wales

- 3.43 Given the difficulties and controversies surrounding different definitions of disability, any approach which seeks to measure the extent of disability in Wales must proceed with a large degree of caution. In particular, as the social model of disability implies that society creates disabling barriers measuring the number of disabled *people* may seem counter to the principles espoused by that model. In many instances, it may actually be beneficial to identify people as disabled in order that healthcare needs are met efficiently and effectively.
- 3.44 Nevertheless, available data from different sources often provides estimated figures for the number of people in Wales with a limiting long-term illness and such figures can perhaps provide some contextual support to this report by highlighting the breadth, magnitude, and complexity of the subject matter at hand. One of the major issues in the interpretation of such data, however, is that different estimations of the number of disabled people in Wales often use different definitions of disability and it is important to outline these nuances in the analysis.
- 3.45 Undoubtedly the largest attempt to measure the number of disabled people in Wales (and the UK as a whole) is the 2011 *National Census* (ONS 2013a). The 2011 *National Census* asked respondents if they had a 'limiting health problem or disability' and then gave two options in the form of 'yes, limited a lot' and 'limited a little' for respondents to indicate the severity of that limitation. It can be seen that such a measure is based predominantly on a medical model of disability and the split categorisation of severity may make the estimates contained within the National Census incomparable with similar statistics from other sources.
- 3.46 With this in mind, the figures from the 2011 census reveal that the combined total of people reporting that they had a less or more severe limiting health problem or disability was 22.7% of the population of Wales. The comparable figure for England is 17.6% indicating (on this measure at least) that the prevalence of disability is 5.1 percentage points higher in Wales than in England (ONS 2013). Analysis conducted by the Office for National Statistics (ONS 2013) also reveals that there is considerable geographical variation in the prevalence of people reporting they were limited 'a lot' in their day to day activities from a low of 9.2% in Cardiff to a high of 16.1% in Neath Port Talbot (shown in figure 1). Lastly, they report that there is a strong correlation

between area deprivation and limiting long-term conditions with the most deprived local authorities typically reporting the highest prevalence.

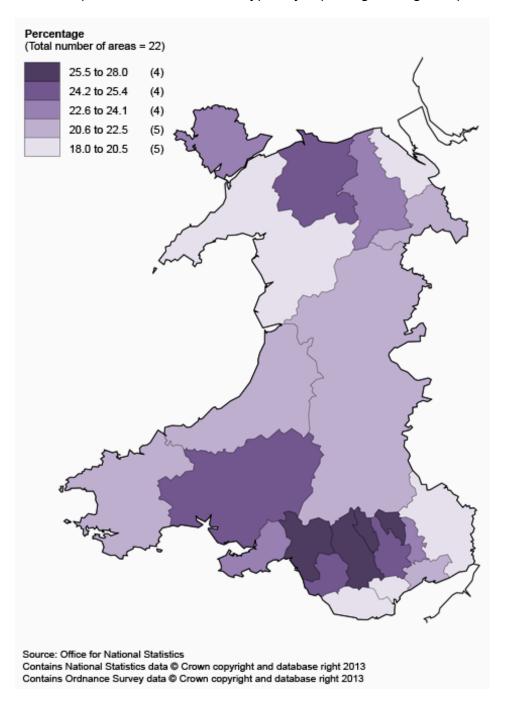


Figure 1: This map shows the percentage of the population in each Wales unitary authority who reported having a 'daily activity limitation' in 2011. Darker colours represent a higher percentage of the population and as can be seen from the map higher percentage areas are concentrated in the north and south east of Wales (Source – ONS 2013).

3.47 Another large-scale dataset which attempts to estimate the number of disabled people in Wales is the *Family Resources Survey* which in 2011 interviewed around 20,000 people in the UK (DWP 2013). The *Family*

Resources Survey stipulates that their adopted definition of disability covers 'people with a long-standing illness, disability, or impairment which causes substantial difficulty with day-to-day activities' (DWP 2013:79). Again, by emphasising how impairments limit a person's individual ability to conduct normal activities, this model of disability is more in keeping with the medical model of disability as stipulated under the Equality Act 2010.

- 3.48 The Family Resources Survey 2011/12 estimates that the prevalence of disability among the population of Wales is 24% (or 0.7 million people). This represents a 2% increase since 2008/09 and closely corresponds with the figures found in the 2011 National Census, outlined previously. This is both higher than the estimated prevalence for Great Britain as a whole (19%) and individual UK countries such as Scotland (20%) and Northern Ireland (17%). The survey also aggregated data by individual regions in England and found that disability was more prevalent in Wales than in any individual region in England.
- 3.49 The Welsh Government's Knowledge and Analytical Services has also used data from the *Annual Population Survey* (APS) to give estimates of the number of working-age disabled people in Wales (Welsh Government 2011). The purpose of the *Annual Population Survey* is to measure labour force statistics and therefore the model of disability used in this survey is based on the (now redundant) Disability Discrimination Act's definition of a 'work-limiting' illness. The statistics analysed by the Welsh Government reveal that the number of working aged⁶ people with a work-limiting illness was 23.5% of the whole population (again corresponding closely to the figures found by the 2011 *National Census* and *Family Resources Survey 2011/12*).
- 3.50 With the limitations of attempting to measure the number of disabled people in mind, the above figures seem to have a close correspondence with each other in suggesting that the number of people who self-report a limiting long-term illness or disability in Wales is around 23% of the population. Most sources also generally agree that this figure is typically higher than other individual UK countries and higher than the UK as a whole.

The Intersection between Poverty, Inequality and Disability

3.51 There is now a strong and well documented link between social position and general level of health. For example, the *Marmot Review* of health inequalities in England found that 'there is a social gradient in health – the lower a person's social position, the worse his or her health. Action should focus on reducing the gradient in health.' (Marmot 2010:9) Although the *Marmot Review* did not incorporate Wales, the findings can perhaps be taken as indicative of the challenges associated with the link between poverty and poor

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⁶ 'Working-age' is defined as 16-64 for males and 16-59 for females

- health. Often, tackling health inequalities is about tackling wider barriers to participation in society and this is a strong theme implied under the social model of disability.
- 3.52 There is now also a strong link between poverty (when measured traditionally by income or employment) and disability in Wales. The Equality and Human Rights Commission (2011) in their report titled *How Fair Is Britain* have argued that 'evidence shows a strong association with having never worked, or being in the more deprived or lower quintiles and having a limiting long-term illness (LLTI) or disability' (2010:258). Moreover, the *Living in Wales* survey has previously found that 'for all age groupings those in social housing were more likely to have a limiting long-term illness, disability or infirmity than owner occupiers and those privately renting' (Welsh Government 2008:11).
- 3.53 The Welsh Health Survey (Welsh Government 2012b) collects data on the general health of the population in Wales and the number of people with a limiting long-term illness. Again, such measures are very much based on medical principles under the medical model of disability but some of the data collected by the health survey can perhaps offer a picture of the link between poverty and disability. They find that 49% of those who had never worked or who were not in long-term employment reported a limiting long-term illness. This compares to 29% of those who hold a managerial or professional position.
- 3.54 They also find that for key conditions such as arthritis, for example, the number of those reporting being treated for arthritis is highest among the most deprived areas in Wales. In terms of general health, the amount of people reporting poor health in the most deprived areas was 30% whereas the proportion of people reporting poor health in the least deprived areas was 13%.
- 3.55 Estimates suggest that the number of working aged disabled people living in poverty in Wales is around 33% (or 130,000 people) (Allen 2011). Moreover, there is now conclusive evidence to suggest that disabled people face extra costs specific to impairments which greatly increases the level and qualitative depth of poverty faced. The Bevan Foundation (2012) has specifically analysed poverty in relation to visual impairment in Wales. They found that a third of people with visual impairments live in poverty and a third of this group is unemployed. They also found that the extra costs associated with those impairments can greatly increase this level of deprivation by a factor of around 23%.
- 3.56 Leonard Cheshire Disability (Greenhalgh et al. 2008) has produced a comprehensive report analysing the different facets of poverty experienced by disabled people in the UK. Some of the key findings from their research are presented as follows;

- **Savings**: There may be considerable barriers to disabled people saving money. Figures from their own research reveal that up to 49% of disabled people have no savings compared to 12% of people among the general population who have no savings.
- **Employment**: Around 50% of the disabled population are not in employment compared to 20% of the general population.
- Benefits and welfare: The benefits systems traps people in poverty and those furthest away from labour markets are particularly trapped in poverty (this may have implications for certain geographical populations in Wales).
- Housing and Accommodation: The quality and availability of housing for disabled people is lacking due to an under availability of affordable and accessible housing.
- **Education:** Young disabled people are twice as likely not to be in employment, education or training when compared to the general population.
- Quality of life and social exclusion: Figures from their own research reveal that close to 90% of disabled people feel that there is prejudice towards them and discrimination against them in society.
- 3.57 The Wales Institute of Social and Economic Research, Data and Methods (WISERD) (Davies et al. 2011) has also published updated figures in some of the above areas which specifically relate to Wales. These include;
 - **Education:** 'Disabled men are 3 times more likely to have no qualifications (35%) than non-disabled men (12%). 37% of disabled women have no qualifications compared to 13% of non-disabled women.' (pp2)
 - **Employment:** 'Three quarters (74%) of disabled people excluding those in education are not employed.' (pp2)
- 3.58 It is important to acknowledge that the link between poverty and disability is often a two-way causal link. In one sense, the existence of discrimination against disabled people in society creates relative deprivation, whereas in other senses relative deprivation itself can create long-term health conditions leading to disability. For example, the Mental Health Foundation (Goldie et al. 2013) has contended that 'there is a strong body of evidence that living in poverty brings with it poorer mental health, and that the stresses of living in poverty increases the risk of developing mental health problems' (pp3). One explanation for this is that the experience of poverty itself such as access to resources, social mobility and experience of the social-environment can lead to negative emotional and cognitive responses which lead to an increased probability of developing mental health conditions.

Research Concerning Inequality and Disability in Wales and Subsequent Research Gaps

- 3.59 There have been a number of large-scale pieces of research conducted on the subject of (or relating directly to) disability and inequality within Wales. Perhaps the most relevant and important two examples of this are a report authored by Winckler (2009) for the Equality and Human Rights Commission (EHRC) sub-titled *Equality Issues in Wales*, and a report by Davies et al. (2011) for WISERD titled *An anatomy of economic inequality in Wales*. A third example which is less explicit in its coverage of disability is a report by the Bevan Foundation titled *Poverty and Social Exclusion in Wales* (Bevan Foundation 2010).
- 3.60 In the review conducted by Winckler, she came to the important conclusion that there was a crucial lack of evidence and data specific to disability inequality in Wales. As she puts it 'despite the volume of literature identified, it cannot be said that there is anything approaching a body of Welsh literature on any of the equality strands nor on equality within any of the subjects' (2009: 198). One of the problems Winckler faced was that much research was typically situated at a UK level and did not explicitly include separate analyses for Wales. The second issue she found was that much of the relevant evidence was produced by third-sector organisations and was therefore much harder to locate. These findings are essentially mirrored by this current research which experienced many of the same problems in searching for evidence. However, other reviews such as the one conducted by Davies et al. (2011) have found enough suitable evidence to draw meaningful conclusions for Wales.

Disability and Demographic Factors

3.61 Demographic factors are crucially important to consider alongside distinct categories such as disability. There is a direct interaction with many individual demographic factors such as age and disability, for example. In general, Wales has a relatively older and ageing population when compared to the UK average. Moreover, although the majority of the population is urban, one of the major challenges for healthcare provision in Wales is providing accessible services to the much more sparsely and widely spread populations in midand north Wales (where transport links are considered to be poorer). Lastly, the population of Wales is increasingly diverse in terms of its ethnic composition and this often brings new challenges for healthcare provision.

Increasing Population

3.62 In the period from 2001 to 2011, the population of Wales grew by 5.6% or 153,300 people (ONS 2012b). The Welsh Government projects that the total population figure will continue to increase at a rate of 4% until 2022 - at which point the population will reach a total of 3.19 million people (from its current position at 3.06 million) (Welsh Government 2013c). The ONS highlight that,

although the population of Wales is indeed increasing, the rate of population growth is, in fact, relatively low when compared to other individual regions within England and England as a whole (ONS 2012). Moreover, the Welsh Government's own projections show that the working age population (16-64) (those who are traditionally considered as 'economically active') is actually predicted to decrease by 3% (or 60,000 people) between 2012 and 2027. A larger overall population implies increasing demand for health services and a lower working-age population implies a smaller pool of people producing economic wealth.

Age and Ageing Population

- 3.63 Eighteen per cent of the population of Wales are now over 65 (ONS 2012b). This is higher than other UK countries and the UK average as a whole. The Welsh Government has quoted figures which suggest that the proportion of over 65s in Wales is set to increase to 26% by 2033 (Baxter and Boyce 2011). The ONS has produced figures which suggest that 'of the four UK constituent countries, Wales was consistently the most aged between 1985 and 2010, with the highest median age and the highest proportion of people aged 65 and over in its population' (sic) (2012b:1). Such figures, taken together, indicate that Wales has a relatively older population and a population that is progressively ageing.
- 3.64 A relevant question is the level of increased demand such demographic changes will place on health services in Wales and the interaction between an ageing population and disability. As the ONS (2012b) highlight, in one sense an ageing population represents an improvement in mortality rates suggesting an improvement in the healthcare system in general. There is a surprising lack of robust and wide-reaching evidence, however, on the implications of an ageing population and disability in Wales. Individual pieces of research generally conclude that older age groups report poorer health, have a higher prevalence of chronic conditions, and a higher prevalence of conditions associated with age such as sensory loss and dementia (WLGA 2012, Bevan Foundation 2012).

The Urban Rural Divide

3.65 There are an estimated 900,000 people living in rural areas in Wales (Welsh Government 2011b). Although In many instances the evidence shows that people in rural areas have better general health, one of the major issues in terms of 'rurality' is gaining access to healthcare services and in particular specialist healthcare services which are often based in specific locations (NHS Wales 2009). Moreover, the fact that the rural population is typically older and ageing at a faster rate, points towards some of the specific challenges that Wales faces now and in the future in terms of demand for healthcare access (ibid.).

- 3.66 In 2008, the Rural Development Sub-committee (2008) conducted a scoping review of evidence concerning poverty and deprivation in Wales. In terms of healthcare access, they found that the main issues for rural populations were accessibility and gaining access to support services. They found that many people felt that they needed to travel unreasonably long distances to reach their nearest hospital. They also found that social isolation among rural populations was a significant problem due, in part, to a lack of support services such as those for the homeless or those experiencing a drug addiction.
- 3.67 Research has also estimated that as many as 25% of the rural population in Wales lives in poverty and that the experience of poverty in rural areas is on par with that experienced in urban areas (Milbourne and Hughes 2005).

4. General Evidence of Inequalities

4.1 The following sections present a number of 'general' issues which either show clear inequalities in access to healthcare or better health, or issues which form a background in which equality in healthcare access is realised. Such themes offer a more appropriate framing under the social model of disability as they seek to discuss the barriers and issues that disabled people, taken as a whole, face in relation to healthcare access.

Life expectancy and Excess Mortality

- 4.2 The EHRC's (2011) *Triennial Review of Evidence* find that there are currently no systematic national data sets for different leading causes of premature death disaggregated by impairment in Wales. The lack of data specific to Wales is also true for international research regarding premature deaths, excess mortality and variations in life expectancy. While the lack of data for Wales is evident, there is now a large body of international research which indicates that people with certain impairments have shorter life-expectancies than people in the general population (Barnes 2007 (offers a comprehensive review), Lei-Yee Fok et al. 2012, Tyrer and McGrother 2009, Patja et al. 2001, Bittles et al. 2002, Hollins et al. 1998).
- 4.3 Furthermore, while specific data for Wales may be lacking, data which is collected on life expectancy in general (and inequality surrounding this) can reveal some indirect, but nevertheless important, implications for disabled people in Wales in terms of health inequality. For the period 2005-09, Public Health Wales (2011) report that the average life expectancy at birth was 77.0 years for males and 81.4 years for females in Wales and that life expectancy (for most groups) is generally increasing. The report also finds that the 'inequality gap' in life expectancy is also increasing. On average, a male in the least deprived groups will live 9.2 years less than males in the most affluent group (the corresponding figure is 7.2 years for females).
- 4.4 This report also measured 'disability free life expectancy' and found even larger variations in inequality with a gap of 14.8 years for males and 12.5 years for females between the most and least deprived groups. This suggests that the most deprived groups in Wales have shorter total life-spans and a shorter life free of disability when compared to more affluent groups. These inequalities also extend to geographical variations between local authorities within Wales.
- 4.5 Such statistics also have implications for disability in Wales given the evidence which suggests that disabled people in Wales are typically among the poorest sections of society (due to fewer employment opportunities and increased costs of healthcare, for example) (EHRC 2011, Winckler 2009) and are therefore more likely to be among those with lower life-expectancies.

- Such figures also suggest that people are generally living longer with disability which can potentially lead to increased demand for health services.
- 4.6 In a comprehensive review of the international literature concerning life expectancy and disability, Barnes (2007) highlights many contextual issues which should inform any discussion on the subject including: the generally increasing life expectancies for people with impairments (mirroring the general population), expected comorbidities among people with impairments (leading to increased mortality), and the difficulties of measuring life expectancy among people with different medical conditions. With these issues in mind, Barnes still finds wide-reaching evidence that certain disabled people have lower life-expectancies than the general population. This is particularly true for immobility and learning disability.
- 4.7 In research in England which measured premature deaths among people with learning disabilities (Tyrer et al. 2009), it was found that 'standardised mortality ratios' for such groups were higher than the general population for many conditions including congenital abnormalities, nervous system/sense organ disease and mental disorders (indicating 'excess' deaths in these categories). This is a clear inequality, yet, Tyrer et al. are clear that their data cannot be used to assess how many such excess deaths can be classified as 'unexpected'. Separate research has contended, however, that such health disparities between people with a learning disability and the general population are largely avoidable given appropriate provision of care (Emerson et al. 2011).
- 4.8 Research (also from England) which analysed a large psychiatric care register in southeast London sought to analyse the life-expectancy at birth and all-cause mortality among people with personality disorder (Lee-Yee Fok et al. 2012). They found that patients with personality disorder can expect a shortened life-span of 17.7 years of life on average among men and 18.7 years among women when compared to the general population. This highlights, they contend, the particular vulnerability and specific healthcare needs of this group. The quoted mechanisms explaining this difference included increased prevalence of unnatural causes of death (suicide and homicide), associated poor (general) health, unhealthy lifestyles, physical consequences of psychotropic medication, problems accessing adequate health care, and greater unmet treatment needs among this group (indicating potential barriers in many cases).

Health Literacy

4.9 The definition of health literacy is a contentious issue which has evolved from a simple description of ability to understand and act on healthcare information towards an understanding of the cognitive capacity and social skills of people when obtaining, processing and understanding healthcare information

- (Edwards et al. 2012). Edwards et al. in a review of international research, found that poor health literacy is associated with adverse health outcomes in the areas of self-management, limited involvement in consultations and decision making, higher emergency department use and higher hospital admissions. Previous studies have also argued that poor health literacy is a strong contributor to health inequality (Kickbusch et al. 2006).
- 4.10 In 2010, Public Health Wales (Puntoni 2010) undertook a scoping review of health literacy in Wales using data from the National Survey of Adult Basic Skills in Wales (2004) to report that respondents who reported poor health or a long term disability, performed lower than average in literacy and numeracy assessments. As an example, 43% of people who reported 'fair', 'poor' or 'very poor' health were classified as 'entry level' in literacy assessments. Lower than average general literacy and numeracy ability may be correlated with greater (and more complex) healthcare literacy needs.
- 4.11 The scoping review by Public Health Wales also analysed data from a 2009 national survey of chronic conditions patient's experiences of care and found that the capacity to self-manage among respondents was strongly related to self-reported health status. Despite this, the survey revealed that 11% of respondents were unable to understand their own role in their own healthcare (i.e. successfully self-manage) and therefore were more likely to attend hospital. Data also drawn from the same survey indicates that 53% of respondents with the lowest confidence and skills to self-manage their condition did not feel they were provided with enough information to do this successfully. These results, taken together, indicate an information gap preventing patients from self-managing conditions in Wales and therefore from reporting better health.
- 4.12 Research conducted by a team of researchers (Edwards et al. 2012) from Cardiff University found many barriers to the development and use of health literacy among in-depth interviews with 18 respondents (all respondents had a potentially disabling impairment). The barriers they identified included 'personal' barriers such as lack of personal motivation, not accepting a diagnosis, and not being compliant with medical advice; 'emotional' barriers such as shock, fear, and anxiety surrounding diagnosis; and 'health professional' barriers such as not being given enough information, not being listened to and information being withheld by professionals wrongly assuming the participants' information needs.

Carers

4.13 It was estimated in 2011 that there were 370,000 unpaid carers in Wales, representing 96% of all care hours provided (Marie Curie 2012). It is now widely acknowledged that understanding the health needs of carers is crucial to understanding disabling barriers in society. Comprehensive evidence now

- suggests that carers frequently find themselves in concurrent poor health (CarersUK 2004) and poor financial situations (CarersUK 2007). One of the immediate barriers faced by carers is that many people do not recognise and identify themselves as carers (especially if they are an immediate family relation). This often prevents carers from seeking formal help, such as assessments for benefits, where it is estimated that £660million is left unclaimed each year in the UK (CarersUK 2004).
- 4.14 Evidence now suggests that carers report generally poorer health as a direct result of caring (CarersUK no date, PRTC 2011). Research which investigated the experiences of older carers in the UK found that seven in ten respondents reported that care-giving had a negative impact on their physical health and that over three quarters of carers aged 60-69 reported that caring had a negative impact on their mental health (PRTC 2011). Research suggests that emotional and mental health problems are the most likely health concern among carers, although physical injuries and stress (due to lifting and moving the person being cared for) and diminished immune systems (due to the persistent stress of providing 'round-the-clock' care) are also common problems (CarersUK 2004, CarersUK no date).
- 4.15 In 2004, CarersUK analysed 2001 UK census data to find that 21% of carers providing more than 50 hours of care per week report that they are in poor health compared to only 11% in the non-carer population. The research also disaggregated care-giving data by individual UK country and found that the percentage of carers not in good health was highest in Wales (14.7% compared to: 11.84% England, 12.29% Scotland and 8.86% Northern Ireland). They also found that the percentage of carers providing more than 50 hours of care per week who are in poor health is highest in Wales. Data from the 2011 census also maintains that levels of unpaid care were higher in Wales than in England (ONS 2013b). This leads CarersUK to the conclusion that carers in Wales care for the longer periods of time and have the heaviest caring responsibilities in the UK.
- 4.16 Data from the 2011 census also reveals that there is a geographical variation in the percentage of the population providing unpaid care across Wales from a low in Cardiff of 10.1% to a high in Neath Port Talbot of 14.6% (ONS 2013b). The ONS attribute this difference to discrepancies in age composition and the proportion of the population reporting activity limitations (i.e. Cardiff has a relatively younger population composition and Neath Port Talbot has a larger percentage reporting activity limitations).
- 4.17 Research conducted by Marie Curie (2012) who surveyed the experiences of carers caring for a person with a terminal illness in Wales found that in some cases respondents were not getting access to basic information about diagnosis and were not being directed to sources of information which could

be investigated independently (a particularly acute problem for dealing with death and after-death periods). They also find that opportunities are missed to identify end-of-life carers as carers and, to this end, suggest that when patients are placed on the Palliative Care Register, that this provides an ideal opportunity for carers to be offered a carer's assessment.

- 4.18 Conversely, separate research has suggested that General Practitioners (GPs) are best placed to identify carers as such given that this is the most likely source of contact with healthcare services (CarersUK 2004a). The information needs of carers have also been shown to be important in the case of those caring for people with Down's syndrome in terms of early intervention in medical problems that may not be easily detectible (McLaughlin and Jones 2011). Evidence also suggests that carers who are caring for people with a mental health condition will have fewer adverse health effects as a result of caring if they have access to the right information (CarersUK 2004b).
- 4.19 In 2003, Rethink surveyed 1,451 carers across the UK concerning their experiences of care-giving and barriers to receiving appropriate care. They found that 27% of carers said that they had been denied access to help in the preceding three years. For example, 30% reported a problem with finding a hospital bed. The research finds that people caring for an individual with a diagnosis of schizophrenia were more likely to be denied healthcare than people caring for someone not with schizophrenia.
- 4.20 Evidence reported by CarersUK (2004a) suggests that 32% of women and 18% of men providing more than 20 hours of care per week report high distress scores every year, up to 6 years after commencing care. The leading causes of such distress are social isolation, financial stress, and lack of appropriate support for carers (CarersUK 2004).
- 4.21 In 2009, a report was published titled *Full of Care* by the Powys Carers Service which aimed to analyse the experiences of young carers by conducting eight consultations at Young Carers Projects in Wales. They found that young carers in Wales regularly reported worry, anxiety and stress. For example, 86% of respondents said they had felt stressed within the last week, 64% felt stressed at school/college and 77% worried about other people more than themselves.
- 4.22 The research also found that although such young carers had a high understanding of medical conditions, many reported a lack of specific understanding and training in administering medication (but nevertheless had some degree of responsibility in this area). Lastly the respondents felt that the healthcare help that they did receive (although generally appreciated) only came during times of crisis and thus came too late.

Welfare Reform

- 4.23 The UK government is currently undertaking the largest welfare reform (Welfare Reform Act 2012) in the history of the UK. Following a spending review in 2010, it was estimated that cuts to the welfare benefits would total £18 billion per annum by 2014/15 across the UK (Audit Scotland 2013). Such changes have important implications for inequality and disability in Wales and although sometimes indirect important implications for access to healthcare services across the country.
- 4.24 The Welfare Reform Act 2012 has been met with widespread condemnation and opposition from disability groups in Wales and across the UK (Bevan Foundation 2013, Wood and Grant 2010, Unison 2013, Duffy 2013). Campbell et al. (2012) published a report in which they used freedom of information requests to analyse 523 organisational responses submitted to the UK government's consultation process concerning the introduction of PIP. They found that only 7% of organisations fully supported the proposed changes regarding PIP, whilst 74% of organisations were against the proposals but open to further discussion. The report also finds many inconsistencies and inadequacies in the manner in which the consultation process concerning PIP was conducted with many disability organisations feeling disenfranchised.
- 4.25 One of the immediate barriers that the Welfare Reform Act 2012 raises to achieving the social model of disability in Wales is 'an increasing focus on medical aspects of disability' (Wood and Grant 2010:13) contained within the reforms. In sum, receipt of benefits such as PIP, which will eventually replace DLA, will be based on increasingly stringent assessment measures in which the focus is placed on the individual's personal capacities and not socially created disabling barriers (Bevan Foundation 2013, Unison 2013). In line with this, the UK government has published separate impact assessments for each separate reform and not a cumulative impact assessment which some leading disability groups have called for (Unison 2013, Duffy 2013) and which would be more appropriate to the social model of disability.
- 4.26 Evidence suggests that many (if not all) of the changes being introduced under the current welfare reforms will have a disproportionately negative effect on populations in Wales when compared to other regions and countries in the UK. This is partly due to a number of contextual factors outlined below:
 - Wales has a higher percentage of disabled people when compared to other regions and nations in the UK (ONS 2012a).
 - Wales has a relatively older and ageing population meaning the demand for healthcare services is likely to increase in the future.
 - Proportionately less disabled people in Wales are in employment than in other UK regions (Bevan Foundation 2013).

- Wales has a higher proportion of its population living in relative poverty and a higher dependence on welfare benefits when compared to the rest of the UK (Welsh Government 2012c).
- A higher percentage of working age people (16-68) claiming benefits in Wales are disabled (38%) when compared with Great Britain as a whole (33%) (Welsh Government 2013e).
- 4.27 Due to the predicted disproportionate impacts that the welfare reforms will have on people in Wales, the Welsh Government ('Task and Finish Group on Welfare Reform') initiated a staged research process which aimed to analyse these impacts. In *stage one* of the research (Welsh Government 2012c), it was found that households in Wales stood to lose 4.1% (£1,100) of their yearly income on average. This is less in absolute terms than the UK as a whole (£1,170) but more in proportional terms (where the figure is 3.8% for the UK). They find that the changes to benefits would be even 'more regressive in Wales' when compared to the rest of the UK and areas such as the South Wales Valleys and inner city areas of Cardiff, Newport and Swansea would be disproportionately impacted.
- 4.28 Stage two of the research (Welsh Government 2013d) found that some 42,500 claimants would lose their entitlement to DLA in Wales at an equivalent of around £55-83 loss per person per week. Both stage two and stage three of the research commissioned by the Welsh Government failed to fully incorporate the impact of welfare reforms on disabled people in Wales but stage two of the research did indicate the possible negative health consequences produced by the changes. Such negative health outcomes would be caused by, the report suggests, direct loss of income, tougher conditions and sanctions, increased poverty levels, stricter medical assessments and migration of claimants into poorer quality housing (this is an indicative but not comprehensive list).
- 4.29 Stage three of the Welsh Government's research (Welsh Government 2013e) did mention the impact that the welfare reforms would have on disabled people in Wales and found that there would be a 'significant' impact on disabled people due to the relatively high dependence on disability benefits in the country. They also found that the changes would have many adverse effects on carers in Wales.

Extra-healthcare Costs

4.30 Evidence suggests that many disabled people in Wales live in poverty (Allen 2011). Such poverty is often caused by environmental or social factors such as uneven levels of access to employment (Bevan Foundation 2012, Schizophrenia Commission 2012). There is now also widespread and conclusive evidence to suggest that disabled people in Wales face a number

- of 'extra-healthcare' costs which can increase the magnitude of this poverty by a considerable margin. Such costs are broad in range but can include the extra fuel costs needed to fuel homes, extra costs for specialist foods, extra transport costs to access healthcare services through to assistive technology costs such as for wheelchairs and glasses.
- 4.31 Research conducted by Wood and Grant (2010) has found that 23.1% of UK households with a disabled member live below the poverty line, yet, when the extra costs of disability are factored in, this figure rises to 47.4%. Some estimates have even suggested that the corresponding figure specific to Wales may be as high as 56% (Allen 2011). Wood and Grant also conducted a survey of 845 disabled people in the UK and found an inconclusive relationship between the level of care need and the magnitude of extra costs. What they do suggest however, is that people with the very highest care needs tend to face higher costs and there is also evidence to suggest that those who rely on public transport or private accommodation also face relatively higher costs.
- 4.32 Research specific to Wales conducted by the Bevan Foundation (2012) has found that people with visual impairments face many extra-healthcare costs which increase already existing inequalities among this group. UK wide research conducted by Wind-Cowie and Salter (2013) which specifically analysed the extra-healthcare costs faced by cancer patients has found that such groups typically (83%) face extra monthly costs totalling £570. They claim this puts extra pressure on both people diagnosed with cancer and their families.

Telehealth and Social Isolation

- 4.33 There is now widespread evidence to suggest that social isolation is a key health concern facing disabled people in Wales (see specific evidence sections). Therefore, increasing the number, range and effectiveness of potential social contact points with healthcare professionals is a key priority for Wales under the social model of disability. Traditionally, telehealth services have been viewed as a means to approach uneven levels of geographical care (such as the rural urban divide), the care of older age groups and for the management of certain chronic conditions.
- 4.34 There is evidence from UK and international research which suggests that telehealth services can be an effective tool towards meeting the healthcare needs of the social groups listed above (Henderson et al. 2013, Dorstyn et al. 2011, Liss et al. 2002, Glueckauf 2002). There is a general lack of research and understanding, however, concerning the issue of how telehealth services can be used to reduce the problem of social isolation specifically among disabled people in Wales. During consultation exercises conducted for this research, a number of disability groups raised the issue of the provision of

- telehealth services as an important issue in relation to potentially addressing social isolation among disabled people in Wales.
- 4.35 Health services within Wales now offer a broad range of different telehealth services ranging from video conferencing facilities through to 'telerehab' services (RHIGT 2013). There are also specific areas of healthcare in Wales which have incorporated telehealth services successfully into healthcare practice such as the South West Wales Cancer Network (SWWCN 2009). In 2013, the Welsh Government announced that £9.5m of extra-funding would be provided to the 'Health Technology and Telehealth Fund' in an effort to encourage the development of new technologies in non-hospital settings (Welsh Government 2013f).
- 4.36 The Rural Health Implementation Group (2013) has produced a report which reviewed the use and progress of development of telehealth services within NHS services in Wales. They found that there is 'considerable scope for continued development of telemedicine services and telehealth more generally across Wales' (ibid: 5), suggesting that there are improvements in telehealth services to be made in Wales. The five key areas which they highlight as needing improvement are:
 - Supporting a shift towards more home-based or local care in the community – minimising the need to travel to hospital unless absolutely necessary.
 - Increased opportunity to work collaboratively between all health (between primary and community care with secondary care) and social care sectors.
 - Supporting improved communication between staff including videoconferencing and sharing of timely information to support decision making.
 - Empowering people to take increased responsibility for their own health.
 - Supporting efficient working practices to enable the right treatment at the right time in the right place.

(direct quotes taken from RHIG 2013)

Person-centred Planning, Personalisation and Direct Payments

4.37 One of the key critiques contained under the social model of disability is that disabled people themselves are not sufficiently involved in the knowledge creation and decision making processes surrounding how they receive medical care (Oliver 2004). Therefore, one of the key changes implied under the social model of disability is the realignment of services from a position

- where disabled people are the passive recipients of healthcare policy changes (expected to 'fit into' existing services) towards a position where disabled people are actively involved in constituting their own care.
- 4.38 Under the broad rubric of 'personalisation', various approaches have developed which aim to achieve the above stated goals including personcentred planning and direct payments. Such approaches have developed due to the frequently quoted observation that service users often feel they have little impact on the way services are planned and delivered (Dowling et al. 2006). Dowling et al. 2006 have outlined that person-centred planning is, in fact, a broad family of approaches aimed at enabling disabled people to plan their own individual care. Although the terminology may differ, the same principles of independence, choice, inclusion, equality and empowerment are often evident under such approaches.
- 4.39 Person-centred planning is also intended to alleviate another health access barrier which disabled people face and that is being reduced solely to their condition when contacting healthcare professionals and not being treated as an individual. Ekman et al. perhaps describe this most eloquently when they suggest that person centred care is...
 - "..the antithesis of reductionism. It asserts that patients are persons and should not be reduced to their disease alone, but rather that their subjectivity and integration with a given environment, their strengths, their future plans and their rights should also be taken into account (2011:249).
- 4.40 One of the key issues in terms of person-centred care or planning, however, is that, although the benefits are well theorised by advocates in the literature, there is perhaps little systematic or robust evidence to analyse the impact that such approaches have on the health or healthcare access of those intended to use such services (Wigham et al. 2008). One report has analysed the impact of person-centred planning in England, and found that it was associated with benefits in the areas of: community involvement, contact with friends, contact with family, and choice (Robertson et al. 2005). It is important to highlight that in some areas they also found that person-centred planning had no or little apparent impact such as with 'physical activity' and 'medication' and in some areas it had a negative impact such as in the case of 'physical health'.
- 4.41 The above quoted report by Robertson et al. also analysed access to personcentred planning for a number of disabled groups. They found that people with mental health, emotional or behavioural conditions were less likely to receive a personal plan and therefore less likely to receive the potential benefits. Research at a UK level has found that the barriers to achieving

quality care through person-centred services are predominantly bureaucratic relating to, for example, the management, training and retention of frontline staff (Innes et al. 2006). Such findings are also mirrored by research from Dowling et al. (2006) who find that two of the main barriers to achieving person-centred approaches are resource constraints and skills deficits among frontline workers.

- 4.42 One way in which person-centred planning has been implemented in Wales is through the direct payments scheme which offers direct monetary payments to disabled people and their carers as well as an increased responsibility for organising their assistive technology needs. Once more, the evidence surrounding the impact of direct payments is not conclusive although the potential benefits of direct payments are documented in some research (Wood 2010).
- 4.43 In comprehensive UK-wide research that compared the implementation of direct payment schemes across local authorities it was found that such payments were most commonly provided to people with either a physical disability or sensory loss and were least likely to be given to people with a mental health condition perhaps suggesting an inequality (Davey et al. 2007). Davey et al. also found considerable geographical variations in the rate of payment provided under the schemes with the rates paid by Wales being lower when compared to England, Scotland and the UK as a whole.
- 4.44 The group Social Interface has also published research which examined the implementation of direct payment schemes in Wales (Social Interface 2007). They found that the transition from child to adult services was one area of concern, as many young people whose parents received direct payments as a contribution towards care for the child would not be eligible for independent payments once they reached adult age. They also found that direct payments were not offered to many of the people who were eligible to receive them, often due to a lack of a proactive encouragement among practitioners.
- 4.45 A further issue which has relevancy to Wales is person-centred technology. Person-centred technology is technology which is designed to support the independence of people through the provision of assistive technology, mobility devices and telehealth services. The Welsh Government's Framework for Action on Independent Living (2013) has acknowledged the efficacy of supporting person-centred technology but has also outlined a number of barriers to achieving the potential benefits of such services. These barriers include technology which is designed by manufacturers based on an essentially medical model and not designed by service users themselves, and the better training of staff in the use and potential of person-centred technology.

- 4.46 One piece of research has critiqued the notion of 'personal budgets' by suggesting that many of the areas that disabled people value in terms of personalisation (such as 'retaining independence', having a job or maintaining family links) do not rely on people having a (monetary) personal budget (Wood 2010). Wood is clear, however, that this does not mean that personalisation approaches are not worthwhile in general but suggests that the two should not be confused with each other as providing personal budgets does not necessarily mean that personalisation is automatically achieved (implying that further healthcare interventions would not be needed).
- 4.47 As a supporter of personalisation approaches, Wood outlines a number of barriers to achieving such approaches and these are quoted from the report as follows:
 - a lack of funding,
 - poor integration of health and social care,
 - the limitations of the health, care and wider service markets, the lack of integration of health and care with housing,
 - the constraints of communal living for those in residential care.
 - the challenges for palliative care (e.g. the low take-up of advance care plans).

(quotes taken directly from (Wood 2011:14).

The Experience and Expectations of Disabled People

- The social model of disability calls for a critical realignment of knowledge-creation away from previously considered 'expert' sources onto a closer consideration of the views and opinions of disabled people themselves. One piece of UK level research which has attempted to do this is a report authored by Williams et al. (2008) which was written for the Office for Disability Issues and is titled *Experiences and Expectations of Disabled People*. The research used a mixed-methods approach including focus groups, 18 in-depth interviews with people who had experienced discrimination, and a quantitative survey of 1,860 disabled people in the UK. The report included a section on health and healthcare access and some of the main findings from this section are summarised below:
 - The majority of respondents (90%) described their well-being in positive terms.
 - The majority of respondents across multiple categories such as 'being treated with dignity and respect (94%) and 'friendly, helpful and understanding staff' (90%) felt satisfied with nearly every aspect of health services provided by the NHS. However, there was a small degree of dissatisfaction evident in terms of the choice of where and

- when appointments took place, the choice of who people saw, and the location of services provided.
- The issue of when appointments took place was a particular point of dissatisfaction among respondents (17%) (although no comparison with the general population is given) and results from the qualitative aspects of the research reveal that some of the reasons for this included delayed appointments due to a sign language interpreter not being available.
- 49% of respondents stated that they had experienced a barrier to accessing healthcare. The most common barriers included; 'difficulties with transport' (15%), 'distance to premises' (14%), 'need someone to accompany me on all of the journey' (12%), 'need to be accompanied at appointment' (10%), 'inconvenient appointment times' (8%), 'poor communication between health professionals' (7%).
- Women were more likely than men and younger people were more likely than respondents aged over 75 to report a barrier to healthcare.
- The majority of respondents were satisfied with the advice and information they were provided with. A small number were dissatisfied and the most frequent reasons given for this were that information was not detailed enough and that information was not provided regarding how respondents could help themselves (i.e. 'self-help').

Comorbidity and Disability

- 4.49 Under medical explanations, 'comorbidity' is the co-occurrence and interaction of two or more distinct diseases or conditions (Valderas et al. 2009). In the area of disability, comorbidity has traditionally been viewed in relation to underlying health conditions and concurrent mental health or behavioural conditions which interrelate with the underlying condition(s). It has previously been noted that defining comorbidity is often heavily based on medical assumptions and frequently does not take the patient's perspective into consideration (ibid.).
- 4.50 While this is true, there is now widespread evidence which suggests that across many different types of impairment, disabled people face disproportionately (and therefore inequitably) high levels of comorbidity (Naylor et al. 2012, du Feu and Fergusson 2003, Diabetes UK 2008, Fellinger et al. 2012, Aguglia et al. 2011).
- 4.51 Overall, research suggests that at least 30% of people with a long-term or chronic condition also experience a concurrent mental health condition (Cimpean and Drake 2011). This figure is higher than the general population. Mental health comorbidities are not the only concern, however, as certain long-term conditions such as cardiovascular disease and diabetes, for example, are risk factors for mild cognitive impairment (Naylor et al. 2012).

- 4.52 Naylor et al. (2012) have produced a report for The King's Fund sub-titled *The Cost of Co-Morbidities* which offers a comprehensive review of international data relating to co-morbidity in the case of mental health. They find that in England there is a limited integrated response towards approaching dual physical and mental health concerns, however, they do not draw conclusions for Wales. In their review of evidence they find that there is a relationship between co-morbidity and economic deprivation. Firstly, a greater proportion of people living in more deprived areas have multiple long-term conditions. And secondly, the effects of co-morbidity are 'stronger' when deprivation is present.
- 4.53 They also find that the implications for patients are 'poorer clinical outcomes and prognosis', 'adverse health behaviours and poorer self-care', 'lower quality of life' and 'increased service use' (ibid: 6-8). In particular, co-morbidity reduces a person's ability to self-manage their own condition and therefore increases the likelihood of unhealthy behaviour such as smoking. Although the research by Naylor et al. reviews international evidence, they only make recommendations and discuss the findings in specific relation to England.
- 4.54 Although comparable research specifically for Wales could not be located, during the consultation exercise conducted as part of this research a number of disability groups raised concerns that there was also no suitable strategic provision for co-morbidities within healthcare services in Wales.

5. Specific Evidence of Inequalities

5.1 The following sections of the report are organised into five distinct categories which are; 'Physical Disability, Musculoskeletal Conditions and Pain', 'Sensory Loss', 'Chronic and Long-term Conditions', 'Learning Disability' and 'Mental Health Conditions'. Such a classification is used as a way of presenting evidence pointing towards inequalities in a more concise way which often reflects the way the evidence is presented in the literature. Such a classification is not intended to be prescriptive. These sections therefore discuss in more detail some of the specific challenges experienced in relation to different specific groups and attempts to draw out the cross-cutting themes evident across these different sections.

Physical Disability, Musculoskeletal Conditions and Pain

Wheelchair and Physical Access

- In an inquiry concerning access to transport services for people with a physical impairment in Wales, conducted by the Welsh Government (2011c), evidence was presented by disability groups which suggested that poor access to public transport compounded already existing disadvantages to accessing healthcare services. Although there is now an established body of literature regarding access to transport services for disabled people in Wales (Wilson 2003), there is less evidence available which specifically examines physical access to healthcare service infrastructure (perhaps a contradiction given that the latter is a devolved area of governance whereas the former is not).
- 5.3 A report which examined wheelchair services for young people in Wales (Davies 2006) found that wheelchairs supplied by Artificial Limb and Appliance Service (ALAS) were often not suitable for rural locations and rough terrains. The *Health in Rural Wales* survey (Davies et al. 2008) highlights the complexity of rural healthcare access (in many instances people in rural locations have better general health than people in urban locations) and point out that it is a poorly researched area in the Wales context in general. They analysed the Welsh Index of Multiple Deprivation and found that there was wide ranging deprivation in terms of geographical access to both GP surgeries and NHS dentists. They did not, however, find enough meaningful evidence for conclusions to be drawn regarding access to healthcare services for physically disabled people in rural locations.
- 5.4 In large-scale UK-wide research conducted by the ODI (Williams et al. 2008) concerning the experiences and expectations of disabled people (total sample size = 1,860) it was found that 'location' was rated as one of the least satisfactory aspects of healthcare provision. In total, 12% of respondents expressed dissatisfaction with the location of healthcare facilities while 31%

- were 'quite satisfied'. When asked to indicate 'barriers to accessing health services' the three most common barriers (the most common response was 'no barriers' at 51%) were 'difficulties with transport' (15%), 'distance to premises' (14%) and 'need someone to accompany me' (12%).
- 5.5 The 2011 National Audit of Pain conducted by the Healthcare Quality Improvement Partnership (HQIP) included wheelchair access as part of their audit criteria for acute pain services and found that in Wales, 80% of service points reported 'good' access for wheelchair users. This figure compared unfavourably with England, however, where the corresponding figure was 93%.

Wheelchair Services

- There are currently three 'Artificial Limb and Appliance Centres' (ALAC) in Wales based at Cardiff, Swansea and Wrexham. The Welsh Government's inquiry (2010c) and follow-up inquiry (2012d) into wheelchair services in Wales found that people living closer to these centres had an improved chance of being assessed for a new or replacement wheelchair.
- 5.7 One of the main findings of the two inquiries was that there were long waiting times faced by people waiting to be assessed for a wheelchair in Wales. The first inquiry quoted research by (Davies 2006) that surveyed 52 parents of children with a physical impairment in Wales and found that 80% of families waited longer than the National Service Framework (NSF) guidelines of 8 weeks for an assessment for a wheelchair. They also found that over 60% of respondents waited longer than the NSF 8 week target for delivery of a wheelchair (ibid.). The first inquiry heard evidence that waiting times at the Wrexham Artificial Limb and Appliance Centre (ALAC) could be as long as 15 months for adults and 23 months for children (Welsh Government 2010c).
- 5.8 The consequences of long waiting times for wheelchair services in Wales are that many children outgrow the initial wheelchair for which they are/were being assessed (Davies 2006). Secondly, this often forces many families to purchase wheelchairs through their personal finances. Given that wideranging evidence conclusively agrees that specific impairments can cause increased financial burdens through increased costs (Wood and Grant 2010, Bevan Foundation 2012), this is a further access issue potentially contributing to this inequality.
- 5.9 The follow-up inquiry led by the Welsh Government (2012) noted that although waiting times had generally improved, there were still lengthy waiting times faced particularly by those living in north Wales. Through the findings of the first inquiry the Welsh Government committed to supply £2.2million in extra funding to wheelchair services in Wales. Although a positive step, previous research analysing the experience of wheelchair services in the UK

has found that, in general, wheelchair services are under-funded and that this under-funding has led to stricter eligibility criteria for receiving a wheelchair (Sharma and Morrison 2008). According to Sharma and Morrison, this inadequate provision leads to discrimination against physically disabled young people in particular.

5.10 The survey conducted by Davies (2006) which investigated wheelchair services for young people in Wales also found that 33% of respondents suggested that the wheelchair they were provided with did not fully meet their needs. Moreover, 60% of respondents state that their children's wheelchairs were not regularly reviewed and maintained. The exact same number (60%) reported that they had received no training regarding how to use the provided wheelchair. A third of children's needs are not being reassessed annually and many respondents said that assessments were only accessed by request.

Rehabilitation

- 5.11 A report analysing access to mental health services in the UK for physically disabled people has argued that it has previously not been recognised that people with a physical impairment experience unequal access to mental health services (Morris 2004). Morris used a mixed methods approach (literature review, 83 person survey, further in depth interview including respondents from Wales) and found that two-thirds of respondents with a physical impairment experienced problems with access to mental health services. 79% said there had been little or no recognition of their physical impairment needs, 66% identified negative attitudes of staff as a problem and 49% said buildings were inaccessible, unsuitable or unadapted (ibid.)
- 5.12 The Limbless Association (2013) recently surveyed 119 people with lower limb amputations in England with the aim of exploring their physical and care needs. Similar sample surveys for (or incorporating) Wales based populations could not be identified in the literature although the findings from the Limbless Association report may have some relevancy for Wales. They found that there was a high percentage of respondents who had difficulty (i.e. a 'severe' to 'moderate' difficulty) in gaining access to both counselling (49%) and physiotherapy (38%) services.
- 5.13 Davies (2006) who surveyed the experience of people with lower limb amputations in Wales found problems with the limb fitting process including many respondents who expressed that long waiting times during the fitting process were largely avoidable and due to problems with the providers. McFadden (2012) analysed prosthetic limb and amputation services in the UK and highlighted how the process of fitting a prosthetic limb is largely dependent on the amount of time that a Prosthetist can dedicate to individual patients. While this is true, they find a shortage of trained Prosthetist professionals in the UK with Wales having the highest patient to 'Prosthetists

- trained in rehabilitation medicine' ratio of any UK country (indicating less trained Prosthetists available in Wales).
- 5.14 The above quoted report from McFadden (2012), published by the charity 'Limbcare', used freedom of information requests to analyse nearly every aspect of prosthetic and amputation rehabilitation related services in the UK and drew comparisons between the four main UK countries. Some findings from this report are presented as follows:
 - Although the UK government has estimated figures of 5,000 for the number of new civilian amputations performed in the UK, McFadden estimates an exact figure of 5,652. This indicates not only a discrepancy in official records but also reports increasing number of diabetes and vascular related amputations.
 - 25% of new amputation presentations are not able to benefit from prosthetic devices. The reasons for this are not clear but the report quotes anecdotal evidence which suggests that budget reforms may be leading to older people in particular not being offered opportunities to learn to walk with prosthetics.
 - When aggregated by individual country, Wales has the lowest proportion of amputees not able to use prosthetics at 12%.
 - Wales has the 2nd worse 'consultant lead trained in rehabilitation medicine' per patient ratio of all the countries in the UK at 5213 per 1 consultant.
 - There are only an estimated 17.5 (this is an extrapolated figure based on incomplete responses to freedom of information requests) psychologists trained in rehabilitation medicine in the UK with 28% of Disablement Service Centres offering no psychological service and 44% only offering a part-time service. McFadden claims this indicates that the psychological impact of limb loss has almost been abandoned among the civilian population in UK health care provision.
- 5.15 The National Audit Office (2009) has presented large-scale research (from England) which suggests that 75% of patients with rheumatoid arthritis say that physiotherapy has either helped them 'a lot' or 'a little'. This conclusion is also strongly supported by clinical research (Briggs et al. 2013). Despite this, the National Rheumatoid Arthritis Society (NRAS 2011) surveyed 245 of its members across the UK and found clear evidence of delays in the time taken to refer patients with rheumatoid arthritis to physiotherapy services. 31% of respondents stated that they had never been offered a referral to a physiotherapist and 32.2% said they had waited over one year for a referral. The majority of respondents in this survey (58.6%) felt physiotherapy either moderately or strongly improved their mobility yet 21.9% of respondents said it was difficult to contact their physiotherapist.

- 5.16 The All Party Parliamentary Group for Muscular Dystrophy (APPGMD 2009) published a report in 2009 analysing access to specialist neuromuscular care sub-titled *The Walton Report*. This report claimed that the group was alarmed to find a decline in services for muscular dystrophy in Wales for the preceding ten years. Of particular concern was that Wales was the only UK country not to have access to a muscular dystrophy Care Coordinator which they claim is an essential service for the 3,000 people (and families) with muscular dystrophy.
- 5.17 In 2010 the Royal College of Physicians produced an audit of falls and bone health in older adults for England, Wales and Northern Ireland. The findings from the report are comprehensive (90% of relevant healthcare organisations were audited including 100% of acute trusts) and some of the key relevant findings are presented below:
 - Pre-operation care is not adequate: only 30% of hip fracture patients receive basic acute care.
 - Elderly patients are not being properly assessed in order to prevent further injuries when in hospital: only 37% of health services provide a fracture liaison service. 68% of non-hip fracture patients had not received a 'multi-factorial falls risk assessment'.
 - They found that access to exercise provision for more than 12 weeks is limited.
 - Access to home hazard assessments and intervention is particularly poor for non-hip fracture patients with only 19% having received such a service.
- 5.18 In 2012, the All Wales Osteoporosis Advisory Group conducted an audit of all acute care centres in Wales concerned with the management of fragility fracture patients (i.e. 17 hospitals 100% return rate). One of the findings of this report was that the majority 59% (10/17) of hospitals have no funded service for routine post-fracture assessment for future fracture risk for inpatients. Five of those hospitals which do not offer this service cited 'lack of funding' as the reason. Likewise, the majority of hospitals (76%) reported having no such services for outpatients with 7 hospitals citing 'lack of funding' as the reason. The audit concludes that there is a pressing need to improve fracture liaison services in Wales in line with other countries in the UK where enhanced services have already been introduced.

Specialist Spinal Cord Injury Services

5.19 There are a total of 11 specialist spinal cord injury (SCI) centres in the UK with one centre based in Wales at Cardiff (SIA 2009). The World Health Organisation (WHO 2013) stipulates that acute rehabilitation care should be available to promote functioning for SCI patients in a number of different environments including hospitals, the home and the community. They quote

- research which suggests that regaining upper limb function and regaining sexual function are high priorities for people with different types of SCI (ibid; Burns et al. 2010). International research has also drawn attention to the importance of increasing community engagement and removing social barriers as important aspects of care for people with SCI (Lysack et al. 2007).
- 5.20 There are currently an estimated 40,000 people living with a SCI in the UK (Smith and Caddick 2012). There are typically more men and more people in the 15-40 year old age group who have sustained a SCI (ibid.). Research has found that masculinity norms have some effect on men's health seeking behaviour (Burns et al. 2010). Burns et al. outline how men's efforts to 'cope with their injury independently' (pp163) may deny them access to appropriate forms of emotional and instrumental care, therefore potentially increasing rates of depression among people with a SCI. Research also suggests that a significant proportion of people with a SCI also experience symptoms of depression (Elliot and Kennedy 2004, Elliot and Frank 1996).
- 5.21 Research has been conducted by the Spinal Injuries Association (2009) who undertook an extensive review of specialist SCI centres in England and Wales including both an on-line user survey of SCI patients and a postal survey of service providers. In phase one of the research they found reported instances of delays in referrals and admission to SCI services, a lack of coordination for referrals and admission between different SCI centres across the UK and no standard process for ring-fencing beds for specific patient groups. They also found the availability and provision of psychiatric and counselling services was variable between different SCI Centres across the UK.
- 5.22 In phase two of research, including evidence drawn from a user-survey of 829 respondents, they found that the average time from diagnosis of a SCI to admission to a specialist SCI centre was 46 days. In total, 41% with new injuries were not admitted to specialist SCI Centres within 1 month of injury. The quoted reason for these delays in the Spinal Injuries Association report was 'restricted availability of appropriate beds'. In their concluding remarks they also argue that blockages in the number of SCI beds available result from delayed agreements and funding for complex care packages to reintegrate SCI patients into the community.
- 5.23 In a separate survey, also conducted by the Spinal Injuries Association (2012), which investigated the use and value of the social care system for a sample of 98 people with SCI in the UK it was found that the majority of respondents (63%) said that their care package did not meet their needs. 36% said that there had been attempts to reduce their care package against their will, with 28% appealing against the decision and many proving unsuccessful.

- 5.24 The comprehensive review by the Spinal Injuries Association (2009) quoted above found that 6% of patients discharged from SCI Centres were discharged to nursing homes. Research specifically analysing the experience of SCI patients in nursing homes has quoted a discharge figure of 20% although this research used a small sample of only 20 people (Smith and Caddick 2012).
- 5.25 Smith and Caddick (2012) conducted in-depth interviews with 20 SCI patients discharged into nursing homes (from SCI Centres) and found that many respondents were unhappy with the transition from SCI rehabilitation services to nursing homes. Many respondents felt they were 'pushed out' of rehabilitation services. The results indicated that nursing homes may not be the most suitable discharge destination for many SCI patients as respondents felt a lack of independence inside care homes, felt it was unsuitable to be living with older people with dementia, felt care homes were preventing them from engaging in activities that improved their well-being and felt that care homes further damaged their physical and psychological health. It is noted, however, that the sample size is low and findings cannot be generalised to the wider population of SCI patients.

Diagnostic, Referrals and Health Seeking Behaviour

- 5.26 It is widely acknowledged that there are many delays in the diagnosis process for different types of arthritis for a wide range of reasons including the unspecific nature of symptoms (House of commons 2010). Research has indicated that a low level of public awareness and resultant late presentation in England is a major reason for delays in diagnosis of rheumatoid arthritis (The King's Fund 2009). In relation, the National Audit Office (2009) has found that up to three quarters of people with rheumatoid arthritis delay contacting their GP for the first three months following first appearance of symptoms.
- 5.27 Evidence suggests that more women (34% compared to 23% men) more older people, the less affluent and those less well educated are more likely to report arthritis or joint pain (Arthritis Research UK 2008, ARC 2002). There is also evidence which suggests that, although the need for services is likely to be greatest among the most deprived groups, the referral rate for rheumatology and orthopaedic services is still higher for the most affluent and higher for suburban areas when compared to rural locations (ibid.).
- 5.28 One of the most widely acknowledged issues in terms of access to health care services for arthritis and other musculoskeletal conditions is late and delayed diagnosis (National Audit Office 2009a, National Audit Office 2009b, Arthritis Care 2011, Arthritis Care 2004, Zheltoukhova 2012). Diagnosis of different types of arthritis is generally considered to be problematic due, in part, to the unspecific nature of symptoms (House of commons 2010).

- 5.29 While there are medical explanations for the observed difficulties in diagnosis, there is clear evidence to suggest that people's health seeking behaviour and the medical knowledge of practitioners are also barriers to access. It is widely acknowledged in the literature that early diagnosis of arthritis is a key determinant of appropriate access to subsequent healthcare services (such as preventing irreversible damage) (National Audit Office 2009a, House of Commons 2010).
- 5.30 Evidence from an Arthritis Care (2012a) survey which interviewed 1,762 patients with osteoarthritis across the UK (including 255 from Wales) found that diagnosis was typically made 18 months after symptoms first appeared and that the majority of respondents had to make multiple visits to GPs before a diagnosis was made (20% 3 or 4 visits, 12% 5-10 visits, 7% 11+ visits). In 2009, the National Audit Office (2009a) conducted a survey of 30 patient groups and voluntary organisations representing rheumatoid arthritis patients in England and found that 65% of respondents reported that 3 months or more passed between a person first experiencing symptoms and receiving a correct diagnosis.
- 5.31 There are multiple sources of evidence which suggest that one of the main reasons for such delays in diagnosis is the health seeking behaviour of patients. The National Audit Office (2009b) conducted a survey of 1,400 people with confirmed rheumatoid arthritis in England and found that 32% of respondents admitted that they delayed visiting their GP for 6 months or more once their symptoms had first appeared. This is a pattern of behaviour which has also been found after diagnosis has been made with data specific to Wales showing that 4 out of 10 patients with osteoarthritis in Wales never visit their GP (Arthritis Care UK 2012b).
- 5.32 The exact reasons for such behaviour are unclear and need further investigation, although the evidence suggests that the complex way in which people with different forms of arthritis experience pain is an explanatory factor. Evidence specific to the Arthritis UK (2009b) survey of 255 people with osteoarthritis in Wales found that 79% 'have constant pain or are limited in their scope to perform everyday tasks'. Subsequently, over half of this sample report that they would need 'frequently unbearable pain levels' before presenting themselves to a doctor.
- 5.33 While the individual behaviour of patients creates a barrier to seeking healthcare, there is also evidence to suggest that supply of services for people with musculoskeletal conditions also creates significant barriers. A (UK) House of Commons (2010) review of services for people with rheumatoid arthritis found that GPs only receive two hours of teaching concerning musculoskeletal conditions during their training, with limited training on inflammatory arthritis included.

- 5.34 This finding is mirrored by academic research which has found that knowledge of rheumatoid arthritis is limited among GPs (Pollard et al. 2011). Separate research which surveyed 481 GPs in England found that 5% of respondents said they had 'little knowledge' of rheumatoid arthritis, 8% said they were 'not very confident' in diagnosing rheumatoid arthritis and 38% said that their pre-registration training did not cover the condition (Medix 2009).
- 5.35 There are multiple sources of evidence highlighting issues surrounding referral to secondary care for people with musculoskeletal conditions. Findings from a Welsh Government (Morris and Hill 2008) review of the implementation of arthritis and chronic musculoskeletal conditions in Wales has found that there are many inconsistencies in service delivery across the country including only 3 out of 22 LHBs having implemented a Joint Service Advisory Group. Moreover, only 6 (out of 22) LHBs have developed a care pathway and many LHBs do not have a 'patient-centered, integrated, multi-disciplinary service in place'.
- 5.36 The previously quoted audit of rheumatoid arthritis patient groups in England, conducted by the National Audit Office (2009b), also reported that 53% of respondents believed that the referral process remained inefficient. One third of patients in England wait 6 months or more for a referral to a specialist (National Audit Office 2009b) with patients blaming GP uncertainties about the condition (28%), receiving an initial misdiagnosis (16%) and mentioning that their symptoms were not taken seriously enough by GPs (16%). Research has also found that, once referred, secondary care professionals do not provide sufficient time to meet the need of patients with rheumatoid arthritis (Pollard et al. 2011).

Orthotic services

5.37 In a review of orthotic services in England and Wales, Arthritis Research UK (Ross 2012) find there are many inadequacies in the provision of suitable footwear leading to, for example, only one in ten respondents in their survey being satisfied with the current availability of shoes. Poor access to physically and socially appropriate footwear can be considered as a key barrier to healthcare under the social model of disability. The report by Arthritis Research UK finds that access to orthotic services is generally poor and beset by frequent delays. They also find that 89% of service users reported problems with the choice and style of footwear available leading them to buy shoes privately. Lastly, they report that both high street and therapeutic footwear designers and manufacturers do not fully embrace the therapeutic needs of patients and cite the high street optician providers as a model of potential good practice.

Chronic Pain

- 5.38 Pain is now considered to be one of the largest global health issues (Goldberg and McGee 2011). Due to the fact that pain has not traditionally been viewed as a 'disease', some have argued that this has led to its neglect as a condition in public health (ibid.). Goldberg and McGee review the data and conclude that chronic pain is 'strongly determined by the social and economic conditions in which people work and live'. This is supported by international academic research which has found that the spread, intensity and degree of physical disablement of pain are positively associated with levels of deprivation (Brekke et al. 2002).
- 5.39 The Welsh Government has acknowledged the link between inequality and pain in its published strategy titled *Designed for People with Chronic Conditions: Chronic non-Malignant Pain* (2008b). This document also establishes that chronic pain management services in Wales vary in their type and availability. Some LHBs do not provide any form of chronic pain management services, for example, while others only offer services that can be referred to via secondary care providers.
- 5.40 In 2011, HQIP conducted a National Pain Audit of all chronic pain services within NHS services in England and Wales. They found that, against best guidance, only 60% of services in Wales meet the higher standard of 'multidisciplinary' status (although this compared favourably against the figure of 40% for England). The definition of multidisciplinary is a service which offers the presence of all of a psychologist, a physiotherapist and a physician. In Wales, 60% of services reported the presence of a psychologist, 90% reported the presence of a consultant for medication management and 60% reported the presence of a physiotherapist indicating that services may be unequal based on geographical location.
- 5.41 A report title 'pain proposal' (Pfizer 2010)⁷ which gathered data on the management of chronic pain in UK health services found that 44% of patients waited over a year to receive a diagnosis or reason for their pain. Moreover, 45% of patients believe that their pain is not adequately managed. They also quote results from their own research which suggests that only 46% of physicians confidently know what to do if a patient complains of pain after treatment and also that 76% of physicians would like to receive more training regarding the management of chronic pain.
- 5.42 The same report from Pfizer quoted above also find that 55% of respondents think that other people doubt the existence of their pain. This is an important finding that has been confirmed by numerous pieces of qualitative academic research (Toye et al. 2013, Miles et al. 2005, Werner et al. 2004, Clarke 2007,

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⁷ Please note that this is quoted from research carried out by a pharmaceutical company, and for the reader to note the potential for bias within the reporting of findings.

Werner and Malterud 2003). In particular, the absence of objective criteria to validate pain can often lead to a 'crisis of legitimation' among patients (Miles et al. 2005). This has been reported as a particularly acute problem for women who often do not feel believed by doctors and health services about their experiences of pain and who have to 'exert themselves' to get correct attention from doctors (Werner et al. 2004, Werner and Malterud 2003).

- 5.43 While not being believed about pain symptoms may be an important issue specifically for women, interestingly, in a poll conducted by the Pain Society (2005) it was found that men were less likely to have visited a healthcare professional in the preceding 12 months (20% compared to 14% of women) regarding pain. Men were also less likely to have visited a hospital consultant regarding pain when compared to women. This suggests that there may be important barriers specific to both women and men in terms of norms of health seeking behaviour and wider public understanding of symptoms in relation to pain. Such issues require further investigative research (particularly in the context of Wales).
- Toye et al. (2013) have conducted a review of 77 pieces of qualitative research relating to the experience of chronic non-malignant musculoskeletal pain in an exercise they call a 'meta-ethnography'. They find that not having a diagnosis of the cause(s) of pain can often lead to feelings of worthlessness, fear, shame, guilt and can impact on a person's ability to fully participate in everyday life. This leads them to the conclusion that 'feeling valued' should be considered as central to a therapeutic model of healthcare.

Sensory Loss

- In 2009, it was estimated that there were 47,300 people with 'severe' sight impairment and/or blindness in Wales although as many as 115,000 people may have 'significant sight loss' (Access Economics 2009). It has been estimated that there are as many as 480,000 deaf and hard of hearing people in Wales (Welsh Government 2010b). There are also an estimated 18,850 people classified as deafblind (i.e. concurrent sight and hearing loss) in Wales (WLGA 2012). The prevalence of all forms of sensory loss is predicted to increase in the next 30-40 years in the UK with Wales most susceptible to this change due to its already older and ageing population. Sight loss alone is expected to double in Wales in the next 25 years (ibid.).
- 5.46 Published literature suggests that people in the UK value their eye sight highly and have a comparatively stronger fear of sight loss (The College of Optometrists 2013; RNIB 2007). Despite this, thousands of people across the UK are said to lose their eyesight unnecessarily each year (RNIB 2013). The following sections discuss in more detail the health access inequalities specifically relating to people with different forms of sensory loss in Wales.

Accessible Communication, Ease of Access and the All-Wales Standards for Accessible Communication

- 5.47 Accessible communication and ease of access to healthcare services are crucial issues for people with different forms of sensory loss in Wales towards realising equal engagement in society. The evidence shows that people with sensory loss are at higher risks of falls, higher risk of misunderstanding healthcare information and less mobile due, in part, to generally poorer health (WLGA 2012, Cupples et al. 2012, Pey et al. 2006). Such immediate safety and health concerns are compounded by the correlation between poor sensory health (e.g. Age-related macular degeneration) and increasing age with older age also associated with concurrent mobility problems.
- 5.48 In 2013, the Welsh Government published standards on accessible communication in healthcare settings for people with sensory loss (NHS Wales 2013). This document acknowledges the inequalities that exist in healthcare settings in Wales and sets new standards for methods of communication, staff training and accessibility of physical infrastructure. Although the standards are comprehensive in their coverage, some examples can be taken as illustrative of the inequalities which should be addressed. These include the need for sensitivity among staff members, consideration of environmental factors such as lighting, colour and design of buildings, the need for multiple methods for appointment booking and the need for specific equipment such as hearing loop induction systems within reception and consultation areas.
- 5.49 A report by the Accessible Healthcare for People with Sensory Loss Steering Group (Welsh Government 2010b) (including Welsh Government agencies and third sector organisations) identified three priority areas which needed to be improved including; communication (particularly regarding appointments), dignity and respect (customer care and staff training) and environment (ensuring accessible infrastructure).
- 5.50 A survey conducted by Action on Hearing Loss (2013) which interviewed 607 people (10% of this sample were from Wales) with different degrees of hearing loss regarding their experiences of accessing healthcare services found that the majority of respondents contacted GPs using a method which was not preferential. 72% of respondents said they contacted their GP by phone with only 44% of total respondents indicating that this was their preferred method.
- 5.51 A similar statistic is also measured by Action on Hearing Loss (2011) in their 'Annual Survey' of experiences of people with different degrees of hearing impairment regarding access to healthcare services. Of the 5,988 responses received in the 2011 UK-wide survey (3% of respondents were from Wales), 55% said they visited their GP in person to make an appointment while only

- 14% said that this was their preferred method. 15% of respondents expressed that they had experienced a problem related to hearing loss when contacting their GP. Moreover, a survey of 860 blind and partially sighted health care users across the UK by the RNIB found that 28% of respondents found it difficult to contact their GP.
- 5.52 The Deaf Action Research Group has published a report claiming that 90% of all GP surgeries in Wales do not provide deaf and hearing impaired people with suitable alternatives for making appointments (Crimond 2012). Moreover, the report also highlights that all out-of-hours GP services in Wales are only accessible by telephone.
- 5.53 The 2011 Annual Survey by Action on Hearing Loss also reports that 39% of people experienced a problem relating to hearing loss when visiting GP surgeries in the UK. For example, it was found that 51% of respondents self-reported that visual display screens were not available at GP surgeries. A separate survey by the same organisation found that only 44% of GP surgeries had visual display screens available (Action on Hearing Loss 2013). There is evidence from multiple sources that people with sensory loss are missing appointments due to not hearing being called inside surgeries and also missing appointments because letters are sent in formats which can not be read (ibid., Sibley and Alexandrou 2009).
- 5.54 There is also a great deal of evidence pointing to miscommunication between patients with sensory loss and healthcare professionals causing negative health outcomes. The Accessible Healthcare for People with Sensory Loss Steering Group (2010) has reported that 35% of deaf and hard of hearing people had been left unclear about their condition due to difficulties communicating with healthcare staff. Action on Hearing Loss (2013) has reported similar findings highlighting specific problems relating to GPs not facing patients, GPs not speaking clearly and GPs not checking if medical instructions were understood.
- 5.55 Sibley and Alexandrou (2009) have contended that too much emphasis is placed on verbal and not other forms of communication which can lead to patients not taking prescribed drugs in the correct dosage (where only written communication is available). There is also evidence to suggest that communication problems, including those outlined above, are causing people with sensory loss to avoid seeking medical help/advice when needed (RNIB 2009).
- 5.56 Deafblind UK (2007) surveyed 486 deafblind people to investigate their experiences of the NHS in the UK and found that only 16% of patients were offered longer appointments or alternative communication methods (such as deafblind manual or British Sign Language (BSL)). Moreover, 58% of

- respondents did not receive appointment letters in a format that they could access themselves (such as braille). Such issues are often the result of staff who do not fully understand the needs of deafblind patients (ibid.)
- 5.57 Such issues are not solely reserved to GP surgeries. The RNID (2004) has found that 66% of British Sign Language (BSL) users find it difficult to communicate with NHS staff in hospitals. It has also been reported that 70% of BSL users are not provided with an interpreter inside accident and emergency departments in Wales (Action on Hearing Loss 2012a). This concern has also been reported by Action on Hearing Loss who concluded that 'we are concerned that BSL users are not being provided with fully qualified interpreters in healthcare settings' (Action on Hearing Loss 2012b).
- 5.58 It has long been noted in the literature that there is an overall shortage of trained BSL interpreters in the UK. This under-provision can often lead to problems of miscommunication between untrained interpreters (often family members and friends), healthcare staff member and patients, particularly when very specific medical advice/instruction needs to be communicated (du Feu and Fergusson 2003).

Social Isolation, Loneliness and Depression

- 5.59 Mental healthcare for people with sensory loss in the UK has traditionally been considered as poor (du Feu and Fergusson 2003). There is also evidence to suggest that certain sensory loss groups experience higher rates of mental health conditions when compared to the general population (Fellinger et al. 2012; Bennion et al. 2012, WLGA 2012). As an example, 25% of people with sight loss in the UK report being dissatisfied with their life overall (RNIB 2012).
- 5.60 Social isolation is also a substantial public health concern for people with sensory loss in terms of exclusion from both social interaction and societal amenities (Stephens 2007; Action on Hearing Loss No Date). Such isolation must be understood in the context of evidence which shows that people with sight loss are more likely to be in poverty (and therefore further socially isolated) compared to people with able sight (Bevan Foundation 2012).
- 5.61 Primary research suggests that nearly 50% of people with sight loss report being 'moderately' or 'completely' cut-off from people and things around them (Pey et al. 2006). For example, over one-third of people with sight loss report that they have little or no choice in how they spend their spare time (RNIB 2013). Research also suggests that people with hearing loss, for example, are more likely to be withdrawn from social activities particularly those involving large groups (Action on Hearing Loss No Date). Hearing loss can also lead to a loss of intimacy between families and couples (ibid.).

- 5.62 A comprehensive review of qualitative research data concerning the experience of age-related macular degeneration found that it is an isolating condition in which many people experience no social contact during the day (Bennion et al. 2012). Partly as a result of the embarrassment caused by the condition, many people actively avoid social situations in a context where public understanding is poor and independence is difficult (ibid.). Research has also found a stronger association between social isolation and younger ages among blind and partially sighted groups (Pey et al. 2006).
- 5.63 These barriers to social participation are a public health concern under the social model of disability but it is not clear what effects such findings have on people's likeliness to directly access healthcare services. What can be said is that there is evidence which shows that 43% of people with sight loss report that they would desire to leave the house more often with many citing visual impairment, mobility issues and/or lack of confidence as the reasons preventing them from doing so (WLGA 2012). Moreover, research has shown that blind and partially sighted people state 'fear and lack of confidence' as one of the main reasons stopping them from going out on their own (Pey et al. 2006).
- 5.64 The RNIB in their *Sight Loss UK* (2013) report estimate that less than half (48%) of eye clinics in the UK offer some specialist support to patients including: Eye Clinic Liaison Officers, volunteers, patient support services and specialist ophthalmic nurses.

Stigma, Privacy and Loss of independence

- 5.65 There is a crucial interaction between accessibility (which this section has previously outlined as lacking in many areas in Wales) and issues of privacy and independence. For example, UK-wide research by Sibley and Alexandrou (2009), who surveyed 500 blind and partially sighted people, found that 72% of all respondents could not read the personal health information that was given to them by GPs. Because of this, many people are forced to ask third parties to read the information on their behalf thus compromising their individual privacy.
- 5.66 Not only is this a direct compromise of privacy, it also contributes to a loss of independence. Loss of independence and privacy can also be associated with the (often internal) stigmatisation of different forms of sensory loss. For example, Action on Hearing Loss (2011b) quote a poll of more than 2,000 people (conducted by Mori) which showed that 22% of respondents were worried that if they wore a hearing aid people would perceive them to be getting old.

Eye Tests, Knowledge of Eye Disease and Diagnostic Issues

- 5.67 Available figures indicate that in 2011/12 there was a 3% reduction of people in the 'income support', 'tax credits', or 'low income certificate' classifications who took free eye tests (RNIB 2013). The RNIB indicate that this could be due to changing classification systems but they also state that there is evidence to suggest that the cost of glasses is a prohibitive mechanism preventing people with a low income from taking eye tests. Data on all eye tests is lacking, however, as such information is not collected in a central system.
- 5.68 In 2007, RNIB (2007) surveyed 3,848 over-60s across the UK to examine people's awareness and uptake of the free eye tests available to them. They found that 47% of all respondents said they do not have an annual eye test (this figure decreases with age). The main reason respondents gave for not having their eyes tested was that they did not perceive themselves to have an eye problem.
- 5.69 Research conducted by The College of Optometrists (2013) who reported on a YouGov survey of 4,032 UK representative adults found that although the importance placed on eye tests was generally high (as high as the importance placed on regular dental checks), 5% of people over 40 years old had not been for an eye test in the last 10 years. This figure increased to 11% for people from black and minority ethnic groups.
- 5.70 Results from the RNIB (2007) research, quoted above, also reveal that 17.5% of those who had not had their eyes tested in the previous two years said the 'cost of glasses' was a prohibitive reason. When this data is disaggregated by economic deprivation and age, it shows that people from lower socioeconomic groups and younger age groups are more likely to give this answer.
- 5.71 Research from multiple sources conducted among African-Caribbean populations in the UK also shows that such groups report feeling pressured by the cost implications of visiting optometrists (Cross et al. 2009), the perceived cost of eye tests and the fear of being forced to buy expensive glasses (Awoben et al. 2009).
- 5.72 'Geography' has also been found by multiple sources to be a barrier for people to uptake eye tests. The RNIB (2007) find that 25% of people over 80 who had not had their eyes tested in the previous 2 years stated 'transport problems' as one of the reasons for not doing so. Research analysing the geographical relationship between area deprivation and prevalence of optometrists found that there is a 'clear mismatch' with more deprived areas having lower access to optometrists (Day et al. 2010). They also found an association between late presentation of eye disease and age, and an association between age and area deprivation (ibid).

- 5.73 Johnson et al. (2011), in a comprehensive review of research concerning eye health inequality, reach the conclusion that there has traditionally been a greater emphasis placed on the needs of people with sight loss, maintenance of quality of life and treatments and not necessarily on early detection and prevention of sight loss. Their review clearly shows that people from certain ethnic minority groups, people from more deprived areas and people of older age benefit less from current best practices and they put the case forward for targeted intervention for such groups.
- 5.74 Attempting to explain the uptake of eye tests among various different populations also brings up the question of people's knowledge of eye disease and eye related healthcare services. The College of Optometrists (2013) has found that popular awareness of some eye related conditions is poor with, for example, 29% of people stating they had never heard of age-related macular degeneration. They also report that, although people of Asian and African-Caribbean origin are more likely to develop certain eye conditions: such populations are mostly unaware (78%) that this is true.
- 5.75 Large-scale research concerning the suitability for a hearing screening programme for people aged 55-74 has argued that the diagnosis of hearing loss in the UK is ad-hoc with up to 45% of GPs failing to refer patients who report hearing loss (Davis et al. 2007). They also review the literature which shows that hearing loss is generally an under-detected condition and that a simple screening programme for people in the 55-74 age group category is an acceptable and cost-effective measure to implement.

Lack of investment in Speech and Language Therapy

5.76 The Healthcare Inspectorate Wales (2012) have also found that speech and language therapy is geographically variable across Wales.

Sensory Loss by Geography and Social Category

5.77 Level of deprivation has been found to be associated with the late presentation of Glaucoma (the second leading cause of blindness) (Fraser et al. 2001) and the severity of the disease upon presentation (Sukumar et al. 2009, Ng et al. 2010 quoted in Johnson et al. 2011). Johnson et al. (2011) also find that people of African-Caribbean descent are at greater risk of developing glaucoma compared to the white population. This risk is compounded by an association between African-Caribean populations and late presentation of glaucoma (ibid.). They also find that ethnicity is a key risk factor for diabetic retinopathy due to the fact of higher rates of diabetes among certain groups such as people of Asian descent.

Chronic and Long-term Conditions

5.78 The following sections present evidence of inequalities in access to healthcare services specifically relating to chronic and long-term conditions.

The Welsh Government's policy strategy document for chronic conditions titled *Designed to Improve Health and the Management of Chronic Conditions in Wales* (Welsh Government 2007) highlights some of the equality challenges that Wales faces in regards to chronic conditions such as an ageing population, the expected increase in chronic conditions and the geographically uneven nature of chronic conditions across Wales.

Delays, Awareness and Diagnostic Issues

Neurology and Rare Diseases

- 5.79 A national audit of health services (UK wide) for Parkinson's disease patients found that 39% had received no written information about the condition after diagnosis (Parkinson's UK 2012). Furthermore, one third of newly diagnosed (Parkinson's) patients wait longer than 6 weeks to see a specialist (ibid.). Research by the Parkinson's disease Society, who surveyed 13,000 Parkinson's patients and carers across the UK (including 393 from Wales), found that respondents from Wales were more likely to wait more than a year to see a specialist after their first appointment when compared to the rest of the UK.
- 5.80 The National Audit Office quote figures which suggest that 35% of people newly diagnosed with multiple sclerosis do not receive information about their condition (National Audit Office 2011). In general, there is a consensus that the diagnostic process for neurological conditions is variable and inconsistent across the UK (ibid.), although data specific to Wales is often lacking to confirm this finding.
- 5.81 A report published by Rare Disease UK (2010), who surveyed 82 patient and family members of people with rare diseases in Wales, found that 29% of respondents waited over 2 years for a diagnosis with a proportion waiting over 5 years. The effects of such late diagnoses were increased stress and uncertainty for patients and family members as well as, in some cases, a rapid progression of the condition left undiagnosed. They also found that 36% of respondents received a misdiagnosis at some stage and many had to make multiple visits to primary care before a positive diagnosis was received.

Specialist, Reablement, Rehabilitation and Palliative Care

5.82 Specialist, reablement⁸, rehabilitation and palliative care are often crucial aspects of healthcare for people with chronic and long-term conditions both in terms of improved health and improved quality of life. There is an increasing awareness of the difficulty of defining the scope of such services given a

⁸ Reablement refers to the provision of services which aid in the transition from hospital to rehabilitation care at home. Such services may include physical adaptions to the home but also help with enabling people to carry out practical activities.

- general shift towards the social model of disability (as in the Welsh context) (Barnes 2003; Bridges and James 2012).
- 5.83 Traditionally, under medical or impairment models of disability the role of rehabilitation services was, for example, to 'solve' medical symptoms or to rehabilitate patients for specific social functions (such as employment). Increasingly, it is recognised that removing the social barriers to participation should also be considered as a crucial function of such services and this is reflected by the increasing importance placed on such issues as home modification and financial support services, for example (Welsh Government 2013g, Bridges and James 2012).

Neurology

- 5.84 Regarding specialist care, a survey by the Parkinson's Disease Society (2008) of 393 Parkinson's patients and 137 carers of people with Parkinson's in Wales found the following:
 - Three out of ten people with Parkinson's have not been assessed or received physiotherapy in Wales;
 - Four out of ten have not been assessed for or received speech or language therapy;
 - Half have not been assessed for or received occupational therapy;
 - 22% have never talked to a Parkinson's Disease Nurse Specialist.
- 5.85 Likewise, the national audit of multiple sclerosis services (in England and Wales) conducted by the Royal College of Physicians (2011) surveyed 704 users of multiple sclerosis services as well as a broad spectrum of healthcare professionals and found that:
 - Only 43% of people stated that they were aware that they had access to neurological rehabilitation services;
 - Problems with pain, fatigue and cognition are poorly controlled and treated among multiple sclerosis patients;
 - Only 56% of people with multiple sclerosis mentioned that they had been given the required mobility equipment to meet their needs;
 - Only 22% of hospitals had specialist neurological rehabilitation services which follow clinical guidelines (NICE). The report terms this 'inadequate service provision across the NHS'.
- 5.86 The Cross Party Group on Muscular Dystrophy (2010) reviewed specialist neuromuscular care services in Wales and reported the following:
 - In 2009, Wales was the only country in the UK not to have a neuromuscular Care Advisor;

- 'Lack of access to organised and structured multi-disciplinary care' (pp13);
- There is a shortage of respite care, psychological support, lack of support throughout diagnosis and a shortage of ongoing neuromuscular physiotherapy in Wales;
- There is a low level of knowledge surrounding neuromuscular conditions among healthcare professionals.

Post-stroke care

- 5.87 A report by the Stroke Association (2012) which surveyed over 2,000 stroke survivors in the UK (including 206 people from Wales) found the following in relation to post-stroke care:
 - 44% of stroke survivors in Wales had not received a single joint assessment of needs -potentially leading many to miss out on available services such as physiotherapy, speech therapy and help with washing and dressing;
 - 64% of stroke survivors had not received an individual care plan a higher figure than for England (60%) and Northern Ireland (46%);
 - 54% of those who had received an annual health review in Wales had only received one such review. This is the highest figure in the UK.
 Best practice states that such reviews should be conducted at regular intervals and then annually to assess patient needs/support pathways available but this evidence would suggest this is not being done in the majority of cases.
- 5.88 The seemingly sporadic nature of care outlined in the above quoted report is also confirmed by the Wales Audit Office (2008) who reviewed the management of chronic conditions by NHS Wales and found that many patients are treated in an unplanned way, that community care services are fragmented and both poorly integrated and coordinated.
- 5.89 By 2007, it was widely acknowledged by the Welsh Government that stroke services in Wales severely lagged behind the standards of the rest of the UK (AWSSIC 2009). This led to the development of the All Wales Stroke Service Improvement Collaborative (AWSSIC) and the adoption of the 1000 Lives Plus national programme for evidence and patient-led stroke care services.
- 5.90 The Royal College of Physicians (2011b) latest audit of stroke services in the UK conducted in 2010 reviewed the progress that Wales had made in terms of improving its stroke care services relative to best practice clinical guidelines and compared to other countries in the UK. The evidence shows that there has been a general improvement in stroke healthcare services in Wales since 2006. The percentage compliance with the 9 monitored indicators of best practice has increased from 52% in 2006 to 73% in 2010. Wales has

- improved its performance in all indicators except for the indicator 'patients treated for 90% of stay in a stroke unit' in which there was a small decline.
- 5.91 While this is true, Wales is still the worst performing country in the UK (and below the national average) in terms of stroke service provision (as measured by the 9 best practice indicators). Clear from the audit by the Royal College of Physicians is that there are 5 key areas where Wales is behind the UK average including: 'patients treated for 90% of stay in a stroke unit'; screening for swallowing disorders within 24 hours; brain scans within 24 hours of stroke; assessment by an occupational therapist within 4 days and mood assessment at discharge (ibid.). The report notes that 'access to stroke unit care and occupational therapy are particular challenges in Wales' (pp51).
- 5.92 There is a recurrent worry in the literature that palliative care services in the UK are traditionally aligned with approaching cancer and end of life care and not necessarily easily transferable to other aspects of care for other chronic and long-term conditions such as post-stroke treatment (AWPCPG 2008; Burton and Payne 2012). This means there is a lack of research in the UK concerning how to deliver palliative care to people with chronic conditions such as people who have experienced a stroke (Mead et al. 2013). This is ultimately surprising given the widely acknowledged potential for strokes to cause severe symptoms (Stroke Association 2012).
- 5.93 The above quoted survey by the Stroke Association (2012) continues to point out that 85% of respondents felt that those who they came in to contact with (including healthcare professionals) did not understand the full impacts stroke had had on their everyday lives. This lack of understanding may explain some of the discrepancies in the lack of focus on stroke patients in palliative care services. Moreover, 43% of respondents stated they wanted more support from NHS with the biggest priority given to physiotherapy services. There was also a large value placed on home adaptations and care assistants.
- 5.94 An earlier large-scale survey of stroke patients in England found that one in four felt they did not receive enough help with emotional issues (Healthcare Commission 2005). Moreover, the 'UK Stroke Survivors Needs Survey' conducted by McKevitt et al. (2010) found that 38% of respondents (out of a survey of 799 people) felt they had emotional problems following a stroke with 73% of these respondents stating that they did not receive enough help with such problems.

Specialist Cancer Services

5.95 Cancer is no longer a disease that necessarily leads to death in a short time period. Better treatments and survival rates have meant that cancer is increasingly considered as a chronic condition (Mitchell et al. 2013). For most cancers in Wales, survival rates have improved since 1985 (CNSAG 2013).

For example, the ten year survival rate has doubled over the last 30 years to 46% (Macmillan 2012). However, Wales currently has the highest proportion of people living with cancer in the UK (ibid.), a trend which is partly due to Wales having a proportionately older population. With an ageing population, the number of people living with cancer in Wales is expected to increase over the coming decades (Macmillan 2009a).

- 5.96 Such figures which show a clear increase of people both with cancer and living longer with cancer highlight the many specific challenges Wales faces in adapting to these changes. Some observers have noted that the long-term implications of living with and after cancer are poorly understood and that greater emphasis needs to be placed on the needs of cancer survivors (Elliot et al. 2011).
- 5.97 This conclusion is also reached by a report by Macmillan (2011) relating to the Wales policy context where they contend that perceptions of cancer and the provision of care have not kept pace with the transformation of cancer in to a chronic condition. They also report evidence which suggests that the focus of healthcare professionals is predominantly on treating the medical and physical symptoms of cancer and not necessarily the long term (emotional or other) needs of patients.
- 5.98 There is evidence to suggest that cancer patients self-report clinically high levels of distress, anxiety and depression and that these problems are associated with younger age, female gender, ethnic minorities and having a lower income (Carlson et al. 2004). Recent research comparing rates of depression and anxiety among people with cancer and their spouses post-diagnosis found that anxiety levels are significantly heightened among people with cancer up to 10 years after diagnosis (Mitchell et al. 2013). They point out that the importance of anxiety has often been overlooked in healthcare provision.
- 5.99 Research by Macmillan (2009a) who surveyed 168 people with cancer in Wales found that 20% of respondents said that they wanted counselling services but that only 43% of these people were actually told where they could get such services. 45% stated they did not receive this service. A separate report by Macmillan (2009b) found that 40% of cancer patients had not sought help from healthcare professionals regarding emotional issues. A third report by Macmillan (2011) drew on a sample of 138 respondents from a YouGov online survey and found that 33% of cancer patients stated that they did not feel 'emotionally strong enough' to return to work.
- 5.100 Recent reports have outlined the financial pressures that cancer places on people including increased costs of receiving care, increased living cost (food and utilities, for example) and loss of employment (Wind-Cowie and Salter

- 2013; Macmillan 2012). There thus seems an obvious disjunction between the absence of emotional care availability and the financial burden that cancer places on people in Wales and, by extension, almost all other chronic and long-term conditions.
- 5.101 Following such reports and campaigns, the Welsh Government stated in its Cancer Delivery Plan (Welsh Government 2012e) that financial advice services should be offered to all people with cancer and this development led Wind-Cowie and Salter (2013) to argue that this should be adopted as best practice for the rest of the UK. While this is undoubtedly a positive development, evidence suggests that emotional care related services could actually be just as effective at dealing with the financial and related symptoms of cancer and that a lack of such services is costing people money and may actually be leading to increased poverty.
- 4.102 The interplay between the financial and emotional burden of cancer and already existing inequalities (such as income poverty and social isolation) is a complex issue that needs to be understood. Cancer impacts upon 91% of patients financially (Macmillan 2012a). Research has shown that in some cases the worry and emotional stress surrounding financial problems may actually be more difficult to deal with than the actual emotional issue of cancer itself. 'Financial worries' may, in fact, be the second biggest symptom of cancer behind 'pain' (Macmillan 2011).
- 5.103 Evidence from a YouGov survey of 173 respondents from Wales quoted in Macmillan (2011) found that only 6% of adults in Wales received advice about financial issues following treatment.
- 5.104 Of those who stated that they wanted financial advice in the Macmillan survey quoted above, 30% said that they had not received such advice indicating services are not available to people who require them despite the Welsh Government's commitments. Moreover, many other reports have found that once people with cancer leave clinical care many feel 'left alone' and become isolated, which is also reflected in the fact that many healthcare professionals in Wales acknowledge that post-clinical care is difficult to provide (Macmillan 2011; Macmillan 2009a). One Macmillan (2009a) report found that simple things such as patients having to contact healthcare professionals themselves instead of *being* contacted were of significance to people with cancer.
- 5.105 As an example, analysis conducted by Macmillan (2011) based on a YouGov survey of 173 adults in Wales found that; 50% of people with cancer said that no one talked through their needs after finishing clinical treatment and 61% said they did not receive support from healthcare professionals after treatment.

- 5.106 Emotional and financial healthcare needs are not the only needs of people with cancer currently not being met in Wales. In the Macmillan survey quoted above, 43% of respondents also stated that they needed 'practical' help including (but not limited to); shopping, household tasks, bathing/showering, dressing and travelling. 49% of such respondents were not told where they could find such practical help.
- 5.107 There is a growing evidence base which suggests that physical activity can be an effective post cancer treatment method (Macmillan 2012b). A Macmillan (2012b) review, which surveyed 400 healthcare professionals across the UK, found, however, that many professionals were not aware of this new evidence base and that one in ten doctors and nurses believed it was best for patients to 'rest up'. They also found that over half of the healthcare professionals they interviewed knew little or nothing about the benefits of physical activity as a strategy to alleviate long-term symptoms of cancer.

Stigma and Discrimination

- 5.108 There is a growing body of evidence which suggests that HIV patients in Wales face certain levels of discrimination when accessing healthcare services (Hawkins 2009, UKGMHN 2004, Welsh Government 2010c, Dodd et al. 2005). A 2009 report by Hawkins who surveyed 111 people with HIV in Wales, found that 26 respondents reported experiencing some form of discrimination within the healthcare system. The most common problems found occurred at dentist surgeries but some respondents also reported problems with surgical staff at hospitals including being put at the bottom of waiting lists (ibid.).
- 5.109 These findings prompted the Welsh Assembly Government to form an inquiry concerning discrimination against people with HIV in the healthcare system in 2010. This inquiry reported some qualitative evidence and individual case studies of discrimination against people with HIV in healthcare services in Wales. This highlights the lack of research in the area, although it must be noted that The Terrance Higgins Trust (2013) estimate that there are only 1,960 people living with HIV in Wales meaning any evidence base will be small and the only 'reliable' data may come from smaller samples and individual case studies.
- 5.110 There is now an emerging body of literature detailing the nature of the discrimination that people with HIV face when accessing healthcare services. The inquiry by the Welsh Assembly (2010) received reports that HIV patients were put to the bottom of waiting lists, put in side-rooms while being treated and referred to HIV specialists for minor ailments which could have been addressed by GPs. The impact of such differences in care should not be underestimated particularly in terms of the psychological affects on patients.

- 5.111 One estimate suggests that homophobic attitudes are prevalent among 20% of healthcare staff within the NHS⁹ (GLADD 2004 quoted in Dodd et al 2005; see also UKGMHN 2004 for further evidence). Interestingly, the People Living with HIV Stigma Index (2010), in a wide reaching qualitative UK survey, found very little evidence of discrimination against people with HIV in healthcare settings but found that the *overemphasis on discrimination* may actually lead patients to avoid seeking healthcare. This phenomenon is recognised in the literature as 'anticipated stigma' (Earnshaw and Quinn 2011).
- 5.112 Research by Earnshaw and Quinn (2011) has highlighted the potentially harmful role of stigma in healthcare settings among people living with chronic conditions but has also found a lack of research in the area. In some instances, people with chronic conditions feel they are 'being blamed' for their illness by healthcare workers and therefore internalise a certain degree of stigma (ibid.). Research analysing stigma experienced by lung cancer patients has found that the stigma created by anti-smoking campaigns can have a serious 'enacted' and 'felt' effect on people's lives, which may lead to a fear of disclosure eventually causing people to avoid seeking healthcare.

Isolation and Loneliness among Chronic and Long-term Conditions

5.114 The following sections present evidence of inequalities in access to

5.113 Macmillan (2013) has conducted research on the issue of social isolation among people with cancer and surveyed 1,700 living with cancer and over 150 healthcare professionals treating people with cancer in the UK. They find that many people diagnosed with cancer lack support from family and friends during treatment and recovery and that 53% of healthcare professionals said that some patients have skipped treatment due to having no support from family and friends. Such isolation can have associated negative health outcomes. For example, 33% of people said that isolation had caused stress and anxiety, 53% said they had skipped a meal and 28% reported depression.

healthcare services for people with learning disabilities in Wales. The Welsh Government has acknowledged that people with learning disabilities are often among the most vulnerable in society (Welsh Government 2011d). Themes of inequality in access to healthcare services for people with learning disabilities include not being treated as an individual person and the failure to identify

Learning Disability

medical conditions which are wrongly attributed to a person's learning disability.

disability.

⁹ It is important to acknowledge that not all cases of HIV result from homosexual relations. In 2012, 51% of newly diagnosed HIV infection resulted from sexual intercourse between men, with 45% resulting from heterosexual relations, 2% from drug use and less than 2% from other causes (Public health England 2013b)

Annual Health Checks

- 5.115 A 2010 systematic review of evidence (predominantly in the UK but also globally) concerning the effectiveness of health checks for people with learning disabilities found that people with learning disabilities generally have poorer health than the general population, a distinction which, they argue, is largely avoidable (Robertson et al. 2010). Such conclusions have also been the finding of recent reviews of academic and epidemiological literature in the field (Schrojenstein Lantman-de Valk and Walsh 2008; Emerson and Baines 2010).
- 5.116 Pertinent issues explaining such disparities included (but are not confined to): increased exposure to social inequality (poverty, unemployment etc.); increased proneness to specific genetic diseases (e.g. congenital heart disease among people with Down's syndrome); communication difficulties in health literacy; and on the supply side of services: scarcity of services; physical and informational barriers; diagnostic overshadowing and 'disablist attitudes among healthcare staff' (Emerson and Baines 2010:9).
- 5.117 A report by Robertson et al. (2010) concludes that evidence shows regular health checks for people with learning disabilities are an effective measure to identify previously unrecognised health needs/conditions. Empirical research based in Wales has also found that routine diagnostic screenings can improve identification of healthcare needs among people with communication difficulties (Baxter et al. 2006). In 2006, Wales was the first UK country to offer free annual health checks for people with learning disabilities through primary care services.
- 5.118 Out of a survey of 181 people with learning disabilities who used the annual health check scheme in Wales, 93 (51%) were identified as having new health needs while 8% were identified as having serious new health concerns (ibid.) attesting to the potential usefulness of the scheme.
- 5.119 The report by the Welsh Centre for Learning Disabilities titled *Equal Treatment: Closing the Gap* uses these figures (and other data) to argue that health disparities exist between people with learning disabilities and other societal groups but that annual health checks are a justifiable tool to identify and potentially deal with such disparities (Kerr et al. 2005). A 2008 inquiry concerning healthcare for people with learning disabilities uses such figures to contend that there are avoidable deaths occurring among such groups (Michael 2008).
- 5.120 Despite the overall consensus that annual health checks can be effective, problems in access to such services still exist. For example, in a project monitoring the success of the free annual health check program in Wales, it was found that 4,493 health checks were undertaken in total in 2008/09

- representing 43% of people aged 18+ registered on learning disability registers in Wales (Perry et al. 2010).
- 5.121 This means that the majority of adults with learning difficulties still do not receive/uptake the free annual health checks in Wales. The report notes the general year-on-year improvement in uptake rates from 31% in 2006/07 to 43% in 2008/2009. There are also significant variations in uptake of health checks by Local Health Boards and by local area with areas such as Conwy experiencing an uptake rate of 88% among 16+ year olds compared to only 10% in Newport. Moreover, those living in south Wales are 3 times less likely to receive an annual health check compared to those in either mid, west or north Wales (Good 2009). The reasons for such regional variations are unclear and need further research.
- 5.122 The Healthcare Inspectorate Wales has found that poor uptake rates may be explained by the fact that health check letters are only sent to those included on Local Authority registers, which excludes 47,000 people with learning disabilities not included on such registers (HCl 2007). For example, in Cardiff in 2008 there were 967 people aged 18 and over on the Learning Disability Register although the total population of people with learning disabilities was estimated to be 1200 1400 (Cardiff Health Alliance 2011). The report by the Healthcare Inspectorate Wales also finds that health checks vary in their quality and consistency across Wales.
- 5.123 Robertson et al. (2010) note that a barrier to implementing effective health checks is GPs who are reluctant to conduct annual health checks for people with learning disabilities, a finding which is also supported by other research. (Perry et al. 2010). This is further supported by evidence from North Wales where in Flintshire some GPs have chosen to opt out of the health check scheme for people with learning disabilities (HCI 2007).
- 5.124 A report which interviewed 126 GPs in Wales revealed that GPs believed it was their responsibility to offer general medical care to people with learning disabilities but also found that views of annual health checks were generally negative (Kerr et al 1996). The data from this later survey is, however, somewhat dated and in general there is a lack of information regarding exactly why some GPs may be reluctant to conduct annual health checks, particularly in the post 2006 context (when the annual healthcheck scheme for people with learning disabilities was implemented).
- 5.125 In the survey of 181 users of the annual health check scheme, mentioned previously, the authors also find that only 61% of people followed the agreed schedule of health checks (Kerr et al. 2005). People who fail to turn up for scheduled health checks therefore account for a large proportion of the non-uptake of health check services. The authors of this report note that of

people who failed to attend scheduled health check meetings – many lived independently, and that a lack of support and information may mean they fail to attend scheduled meetings.

Health Promotion Uptake

- 5.126 Data from quantitative research conducted in Wales which compared uptake of health screening and promotion services between people with learning disabilities and a control group found large differences between the two (Kerr et al. 2005). Only 12.7% of people with learning disabilities received a cervical screening compared to 84% in the control group. 42% of people with learning difficulties received blood pressure measurements compared to 46% in the general population. Lastly, 26% of people with learning disabilities received a mammography (of those who were eligible) compared to 71% for the population as a whole. The weakness of such data is that it uses a relatively small sample size among people with a learning disability.
- 5.127 In a UK-wide review of literature concerning uptake of screening and promotion services, Emerson and Baines (2010) find that there are considerable variations between people with learning disabilities and other social groups in the uptake of assessments for vision and hearing impairments and also routine dental care. A report into the deaths of 238 patients with learning disabilities in South West England, including areas bordering Wales, found that people with learning disabilities had greater difficulty in accessing bowel cancer screening (Heslop et al. 2012).
- 5.128 Furthermore, a review of UK wide evidence concerning access to healthcare for people with learning disabilities found that such groups have similar rates of admission compared to the general population but shorter overall stays (Michael 2008). The report by Michael (2008) also finds that people with learning disabilities are less likely to be given palliative care and less likely to have BMI measurements taken.

Diagnosis and Diagnostic Overshadowing

- 5.129 Evidence from North Wales suggests that older adults in particular have difficulty receiving a diagnosis for Asperger's Syndrome (Jackson et al. 2011). This is partly attributed to a historical bias in which knowledge of Asperger's Syndrome has only become prominent in the last 25 years. Evidence from the same report also suggests that people with Asperger's Syndrome face difficulty in receiving an early diagnosis of the condition.
- 5.130 'Diagnostic overshadowing' is widely acknowledged as one of the most important healthcare access issues in relation to people with learning disabilities (Robertson et al 2010, Mencap 2007). Diagnostic overshadowing is when symptoms of physical ill-health are wrongly attributed to a person's learning (or other) disability and not the real condition causing the symptoms.

- In a report by Mencap (2012) titled *Death by Indifference: 74 Deaths and Counting* they document 74 cases (including cases from Wales) where people with learning disabilities have died due to, they claim, failings within the NHS specifically relating to issues such as diagnostic overshadowing. In total, 30% of the cases they document involved an element of diagnostic overshadowing.
- 5.131 Research which analysed the deaths among a sample population of people with learning disabilities in London, found that heightened rates of respiratory disease as the main cause of death suggest less than optimal medical care was provided to such groups (Hollins et al. 1998). While they attribute this partly to the health seeking behaviour of people with learning disabilities, they also suggest that diagnostic overshadowing is one of the main explanatory factors. More recent research specific to Wales is lacking in this area, however.
- 5.132 Research conducted in 2004 among a group of 223 clinical psychologists and psychiatrists found that diagnostic overshadowing does appear to be evident in hypothetical diagnostic situations with clinicians less likely to diagnose schizophrenia, consider psychiatric admission or use medication for people with learning disabilities (Mason and Scior 2004). As they highlight, however, research from real life clinical practice is lacking. They ultimately conclude it is reasonable to assume that diagnostic overshadowing does exist in practice.
- 5.133 Early diagnosis for people with autism spectrum disorders is considered an essential step to identify health needs, provide appropriate care and tackle social participation barriers. The Welsh Government has a Strategic Action Plan for Autism Spectrum Disorders published in 2008 (Welsh Government 2008c). This document highlights that there is no consistent diagnostic tool for such disorders within Wales (as in other areas) and that this discrepancy can often be a difficulty for people with Autism Spectrum Disorders and their families.

Carers and Communication

- 5.134 Communication is an essential issue for people with learning disabilities (as referred to below) in terms of accessing healthcare. Carers, whether family members or paid employees, are often a crucial intermediary for communicating the health information needs of people with learning disabilities. This intermediary role creates a unique set of issues concerning the communication of healthcare information in terms of accuracy and privacy.
- 5.135 In a 2007 report concerning specialist learning disability services across Wales, the Healthcare Inspectorate Wales found that access to easy read information and communication aids was limited in hospitals throughout Wales (HCI 2007). They also found that there is limited training available to

acute hospital staff - a problem experienced most acutely in Accident and Emergency departments.

Experience of Health Care Access

5.136 Data based on a sample of 63 people with learning disabilities in Wales found that many have great difficulty accessing out-of-hours services, particularly with the long calls needed to talk to a doctor and for those living in rural areas (Kerr et al. 2005). Some people from the same sample also expressed anxieties about calling doctor's surgeries to make appointments, although this was lessened in people who were dealt with quickly and able to make a quick appointment.

Mental Health Conditions

5.137 Mental health conditions are now said to be the single largest source of disability in the UK (Public Health Wales 2014). The vast majority of people who experience a mental health condition experience either depression and/or anxiety, with only a relatively small number experiencing what is classified are sometimes classified as 'severe' mental health condition such as bi-polar disorder or schizophrenia (which is not to suggest that forms of depression or anxiety cannot be severe). This section outlines some of the main themes and inequalities in the provision of care for mental health conditions in Wales. An immediate equality issue is that there is a gender imbalance in the reporting of mental health conditions in Wales with 14% of women in Wales reporting being treated for mental health conditions compared to only 8% of men (ibid.). In general, there is a great deal of evidence to suggest a general under-provision of treatment for mental health conditions within the UK.

Depression and Anxiety

- 5.138 As the National Institute for Health and Care Excellence (NICE) clinical guidelines for treating depression stipulate, defining depression is a problematic and complicated task. Often, the lines between 'normal' behavioural or mood changes and depression are extremely blurred. Generally, however, as the severity of depression increases, so do the number of socio-physical symptoms (such as social withdrawal, increased experience of pain, increased difficulty sleeping and decreased ability to work) (although it should be noted that many people with depression show no physical symptoms).
- 5.139 The Equalities Act (2010) is unequivocal in asserting that depression and anxiety disorders are an impairment which can be classified as a disability if they have substantial long-term (12 months or more) adverse effects on a person's ability to carry out normal day-to-day activities (Office For Disability Issues 2010). Under a social model of disability, there are also seemingly

- many factors preventing people with different forms of depression and anxiety from fully participating in society.
- 5.140 Due to such contentions surrounding how to define and classify depression, figures on the number of people with depression *as a disability* are crucially lacking. Thus, this section of the report uses data and evidence which primarily refers to depression *per se*, which does not necessarily imply any form of disability. This, in fact, is a problem for most mental health conditions and also a problem of defining disability itself, but it becomes most prominent in the case of depression predominantly due to the prevalence of depression in Wales and the whole of the UK.
- 5.141 Mental health conditions are now said to be the single largest group of diseases in the UK (Royal College of Psychiatrists 2010). In Wales, it is now estimated that mental health conditions account for 20% of the total prevalence of disease in the country (Friedli and Parsonage 2009). However, mental health expenditure still only accounts for 12.2% of public expenditure on health and social care in Wales (ibid).
- 5.142 There is a broad consensus that depression (and mental health conditions more generally) are undertreated in the UK (MHPG 2012). A report titled Sinking and Swimming: Documenting Britain's Unmet Needs (Watts et al. 2009) claims that fewer than half of people with depression in the UK receive any form of treatment. They also quote NHS statistics which suggest that only 8% of people with depression have seen a psychiatrist and only 3% have seen a psychologist. A report by the Mental Health Policy Group (MHPG 2012) at the London School of Economics quotes figures which suggest that only 24% of people with depression and anxiety disorders receive any form of treatment.
- 5.143 The double irony of the under-provision of treatment for depression is that not only are many conditions associated with depression potentially treatable, but that this treatment could actually save the NHS money in the long-term (MHPG 2012). This is due to the fact that initial investment in treating depression (predominantly via psychological therapy) would actually result in a reduction of comorbidity and societal problems associated with depression (which impose a further financial burden on the NHS and the individual). The same conclusions have been reached by the Wales Audit Office in relation to early intervention in psychosis treatment in Wales, which they claim can deliver net savings to the NHS in Wales (WAO 2011a).
- 5.144 Related to this, *The Depression Report* (MHPG 2006) written by the Mental Health Policy Group also claims that (NICE) guidelines on treating depression cannot be met simply because there are not enough therapists and that waiting times to see those therapists are too long. The Welsh Government

- has committed to a 12 month target for referrals to specialist mental healthcare teams but a report by the Wales Audit Office (2011a) found that these targets were not being met in many parts of Wales and that waiting times longer than 12 months still persisted.
- 5.145 Research conducted by Green and Benzeval (2013) has found that socioeconomic inequalities in levels of anxiety and depression among older age groups can be attributed to the perpetuation of inequalities in symptom levels which were present at younger ages. This means that interventions aimed at younger age groups can potentially reduce future rates of socioeconomic inequality in depression and anxiety. It also means that socioeconomic inequalities during the life course of depression and anxiety, such as adverse life events, poorer coping styles and weaker social support, contribute towards perpetuating such conditions.
- 5.146 In 2011 the Wales Audit Office published a series of reports for the Welsh Government which aimed to comprehensively review the current state of mental health services in Wales by surveying the practices of Local Health Boards and general practices (WAO 2011a). The findings from this report are too wide and detailed to be discussed in full detail in this exercise but some of the key and relevant findings have been selected and presented below:
 - In regards to staff training and coverage of services it was found that:
 eight out of 22 LHBs had not provided training for GPs or nurses
 regarding mental health conditions; around a third of LHBs reported
 that GPs had received no training on mental health conditions in the
 last 3 years; only 10 out of 22 council areas followed agreed protocols
 for assessing and managing mental health among adults; and the
 number of 'Section 12' GPs (those with specialist skills in mental
 health) varied dramatically by LHB with some areas such as
 Pembrokeshire, Flintshire and Powys having no Section 12 GPs.
 - The Welsh Government's policy has been to reduce the need to treat mental illnesses (within hospitals) through approaching mental illness proactively within a community and 'independent living' settings. The report details how certain progress has been made in this regard with the number of mental health beds reduced by 23% since 2005 and community staffing numbers rose by 14%. However, the report also notes that progress in this area has been mixed with some local areas actually seeing a decline in community staffing numbers. The report questions why staffing levels do not necessarily correlate with increased needs based on the Mental Illness Needs Index, which indicates that further evaluation/research is needed in this area.

- Assertive Outreach Services have been a key part of Wales's mental health policy since 2009. The report finds that such services have generally improved but that staffing levels among such services and the availability of such services remains inconsistent between different Local Health Board areas.
- As of 2009, only four areas in Wales (Gwent, Carmarthenshire, Ceredigion and Pembrokeshire) had early recognition and intervention services specifically for the treatment of psychosis, indicating that there is not only a geographical variation but also an inequality in how psychosis is treated in relation to other mental health conditions.
- 5.147 In general, the findings from the above report indicate that much progress was made in the provision of mental health care in Wales in the period 2005-2009 but that this success has been variable by geographical area. The reasons why the provision of mental healthcare (in so many recurring areas) is so geographically uneven across Wales needs further investigation. A separate report, also by the Welsh Audit Office, which sought to review Mental Health Services in North Wales found similar patterns to those found nationally such as variations in the level of care provision when disaggregated by geographical area (WAO 2011b). They partly attribute this to variations in expenditure and effectiveness of planning between multi-level agencies.
- 5.148 The Mental Health (Wales) Measure 2010 places new legal duties on local health boards and local authorities about the assessment and treatment of mental health problems.
- 5.149 The Measure became law in December 2010 and has four main parts:
- part 1 of the Measure will ensure more mental health services are available within primary care
- part 2 makes sure all patients in secondary services have a Care and Treatment plan
- part 3 enables all adults discharged from secondary services to refer themselves back to those services
- part 4 supports every in-patient to have help from an independent mental health advocate if wanted.

Postnatal Depression

5.150 It is a common misconception that postnatal depression is a temporary condition experienced by mothers in only a short period following the birth of their child. Research suggests, however, that not only can postnatal depression last longer than 1 year (i.e. 25% of those with postnatal depression still have the condition 1 year after the child's birth) but men can

- also experience the condition (4children 2011). As such, under the impairment model of disability stipulated by the Equality Act (2010), postnatal depression can potentially be considered as a disability. Under the social model of disability, adopted by the Welsh Government, there are seemingly many barriers to participation experienced by people with postnatal depression.
- 5.151 An estimated 70,000 women experience postnatal depression per year in the UK (ibid.). In 2011, the organisation 4Children surveyed 2,000 new mothers in England and Wales to investigate the prevalence and experience of postnatal depression. They found that 49% of people who experienced postnatal depression did not seek medical help (a process which they term 'suffering in silence'). 27% of people who eventually sought medical help only did so after 6 months and 60% of respondents were unaware what exactly constituted postnatal depression. They attribute this pattern to a lack of awareness of (and social stigma surrounding) postnatal depression in Britain where 60% of their respondents felt their condition was not serious enough to seek medical help.
- 5.152 In this regard, they also contacted all primary care trusts in England and Wales and found that only 9% were able to provide reliable data on the number of women diagnosed and treated for postnatal depression. This leads them to the conclusion that postnatal depression is not treated as a priority issue by the NHS at a national level.
- 5.153 The consequences of the neglect in treating postnatal depression are compounded by further health inequalities later in life for mothers, children and relationships between parents. The relationship between mother and child in particular can affect a child's health later in life. The report by 4Children includes a review of the literature which suggests that postnatal depression can impact on many aspects of a child's early development including cognitive and language skills. Such impacts can have lasting affects on a child's development producing depressive traits in children themselves and issues with cognitive ability in certain subjects such as mathematics.
- 5.154 Wales specific data and research in the area of postnatal depression is lacking. One research paper published in 2006 examined the experience of postnatal depression among women in Wales but only used a small sample (Hanley and Long 2006). They concluded that there was a great deal of ignorance and lack of knowledge surrounding postnatal depression before and during pregnancy among women which affected their potential to seek medical help.

Schizophrenia

5.155 The Royal College of Psychiatrists (2012) has conducted an audit review to examine the implementation of NICE guidelines for the treatment and care of

adults with a diagnosis of schizophrenia in England and Wales. In total, 90% (60 out of 64) of NHS Mental Health Trusts submitted data for the review. The findings from the audit have been summarised into key relevant themes as follows:

- Service users felt information about their medication was often not available in an adequately understandable form. For example, only 62% of respondents stated that information could be understood;
- 20% of patients had not responded to medical treatment, however 43% of this group had not received a recommended treatment (clozapine) and there was no documented reason for this;
- 34% of patients in England and Wales had not been offered psychological therapy;
- Although people with schizophrenia have increased risk of developing concurrent physical impairments only 29% of people received a comprehensive assessment of cardiometabolic risk factors. In particular, nearly a half of respondents had not been weighed in the preceding 12 months.
- 5.156 The Schizophrenia Commission (2012) has published research which argues that a barrier to treating schizophrenia is that there is a stigma around seeking help for fear of being labelled 'mad'. In this regard, there is also a general suspicion about what will happen at mental health services after seeking help and advice. They also report many other findings such as that too many people with schizophrenia stay too long in specialist wards when they could rather be reintegrated into the community. They also find in their survey that up to 87% of respondents report experiences of stigma and discrimination and family members of people with schizophrenia feel they cannot speak openly about the condition.

Mental Health in Prisons

5.157 Public Health Wales (2014) has estimated that only 8% of the 3,300 held in prisons in Wales at any given time do not have a mental health condition¹⁰. The Joint Commissioning Panel for Mental Health (2013) has reviewed the evidence which shows that prisoners experience a several fold increase in common mental health conditions, suicide, psychosis and personality disorder. Forrester et al. (2013) have conducted a review of variations in prison mental health services in England and Wales. They find that the provision of mental health care within prisons had improved in the preceding 10-12 years but that such services were still critically under-funded.

¹⁰ This figure is calculated from the 'Prison Health Needs Assessment' conducted by Public Health Wales in 2013. The methods used to calculate this figure include estimates of the prevalence of mental health diagnoses based on a literature review, the number of prisoners recorded on internal systems who experience mental health symptoms and lastly numbers of prisoners with a history of contact with mental health services (Public Health Wales 2013).

- 5.158 In particular, mental health services within prisons do not correspond in terms of equivalence to those available outside. For example, they find that mental health nurses within prisons had typical caseloads of 500 people and doctors had typical case loads of over 3700 people. They point out that the American Psychiatric Association recommend a caseload of no more than 150 patients on psychotropic medication or for each individual psychiatrist at any one time.
- 5.159 A second key finding from the study by Forrester et al. is that there is a significant geographical variation in the level of mental health services available within prisons. Some prisons have poorer access to trained staff compared to others, while some prisons have no access to supporting cells in healthcare units or basic clinical substance misuse services.

Suicide and Crisis Resolution/Intensive Home Treatment

- 5.160 Figures from the 2011 national census reveal that there were 341 suicides among people aged 15 and older in Wales in 2011 (ONS 2013c). Wales has had consistently higher suicide rates in comparison to England since 1990. This data should be situated in the context of a general decline in suicide rates in the UK as a whole since 1950 (Biddle et al. 2008). When disaggregated by age and gender the data shows that suicide rates among middle aged men (45-59) have increased while suicide rates for all other groups have generally declined.
- 5.161 Wales has a national strategy document for the period 2009-14 to tackle suicide sub-titled *Talk To Me* (2009). This policy document established a target of reducing the European age standardised rate¹¹ of suicide in Wales by 10% by 2012. The above figures from the national census indicate that this target was not met.
- 5.162 It has been noted in most (inter-)national settings that suicide rates are generally higher for men than they are for women (Hawton 2000, Shiner et al. 2009). However, data suggests that women in the UK are at least 1.5 times more likely to report depression and anxiety when compared to men (NMHDU 2010). In Wales, there is a clear and consistent gender imbalance in the rate of suicide between men and women. In 2010, for example, 235 males committed suicide in comparison to 66 women (Appleby et al. 2013). This gender imbalance ultimately shifts how access to healthcare is defined in relation to suicide and mental health conditions.
- 5.163 It has been found that there is a stronger association between depression and suicide in females whereas there is stronger association between breakdown of relationships, changes in economic conditions and breakdown of employment and suicide in males (Shiner et al. 2009). Such evidence may

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¹¹ European Age Standardised rate refers to the weighting of mortality data to an artificial European Standard Population which accounts for differences in age and sex of the population over time.

- suggest that particular interventions and broader definitions are needed to tackle the relatively high rates of suicide among men.
- 5.164 There are strong associations with suicide and mental health conditions more generally.
- 5.165 A report by the charity Mind (2009), who surveyed 2,055 males across the UK, found that a third felt embarrassed about seeking help for mental health conditions. The report attributes this to the socialisation of masculinity among males where help-seeking and being emotionally expressive is seen as a taboo. A report by the Equalities and Human Rights Commission in Wales (2008) suggests that there are many negative social attitudes towards people with mental health problems in Wales. Taken together, this suggests there is a certain degree of societal stigmatisation which may ultimately prevent men in Wales seeking adequate healthcare to prevent suicides.
- 5.166 A report by the National Confidential Inquiry (Applebly et al. 2013) found that between 2001 and 2011, 23% of all suicides in Wales were identified as 'patient suicides' (i.e. a person who had made contact with mental health services within 12 months prior to death). This suggests that 77% of all people who committed suicide in this period were not seeking immediate healthcare assistance. This may coincide with the high rates of suicide among men and their reluctance to seek help for mental health conditions. Exact research in this area is lacking, however, and this association remains an assumption.
- 5.167 Evidence from the same report quoted above also outlines that, of those who were classified as 'patients', 20% (160) committed suicide within 3 months of discharge from in-patient care. Moreover, 28% (198) of those same patients missed their last appointment before committing suicide. This data suggest there is the potential to improve access to healthcare and prevent suicides by ensuring appointments are met and that the progress of patients is monitored more closely after discharge.
- 5.168 A five year report which examined 6000 suicides in the UK among people with mental health conditions found that up to 20% of such deaths could have been prevented (Equality and Human Rights Commission 2010). The Equality and Human Rights Commission also argue, however, that 'mental health conditions would remain a risk factor for suicide even in an equitable society' (pp16).
- 5.169 A longitudinal study concerning the relationship between service delivery and suicide in England and Wales found that as the range of services offered increases, the suicide rate decreases (Gunnell et al. 2012). The biggest fall in suicide rates was found with the provision of 24 hour crisis care.

- 5.170 Crisis resolution and intensive home treatment services have been a priority for the Welsh Government since 2005 when targets were established under the Service and Financial Framework to provide crisis mental healthcare services across the entire country. There is evidence in the literature to suggest that crisis resolution services offer many positive healthcare advantages to people with mental health conditions such as reducing admissions and length of stay (Smyth and Hoult 2000), increased patient satisfaction (Johnson et al. 2005) and reduction of family burden (Joy et al. 2004). A report specifically examining crisis resolution services in Wales found that there was a consensus that such services offered high quality and valued healthcare access points which met the continuing needs of people with mental health conditions (Hannigan 2010).
- 5.171 Despite the potential for crisis resolution services to offer benefits to people with mental health conditions (including depression leading to suicide), there is also evidence to suggest that some services are lacking in this area. As of 2008, the coverage of crisis resolution centres was not universal across Wales (Jones and Robinson 2008). A national survey of crisis resolution services in Wales also found that 10 crisis resolution 'teams' offered a service from 9am to 9pm whereas only 3 offered a 24 hour service (Jones and Robinson 2008). This correlates with an earlier review of mental health service in Wales which reports that many people had difficulty accessing crisis resolution care (Hannigan 2010).
- 5.172 The National Audit Office (2009) in their review of mental health services in Wales also investigated crisis resolution services in Wales. They found that of those teams offering core hour services (as discussed above) six teams were not, in fact, providing full services between 9am to 9pm 7 days a week. Moreover, they found key variations in the staffing composition of crisis resolution teams and questioned whether crisis resolution accommodation offered a viable alternative to hospital admission.

Mental Health Act

5.173 The Mental Health Act (1983) provides provision for compu Isory hospitalisation for people assessed to be experiencing a severe mental health condition (provided other conditions are met) (NHS Wales 2014). In 2012, the 'Mental Health (Wales) Measure 2010' came into force which aimed, among other things, to create a statutory responsibility for care treatment planning and care coordination (ibid.). The Care Quality Commission (2014) has produced a report reviewing the provision of services under the Mental Health Act in England and Wales. Some of the key findings from this review are included below:

- The number of people detained under the Mental Health Act was 50,000 in 2012/13 representing a small and steady increase from the previous years;
- 27% of care plans showed no evidence of patients being involved in their production and 22% showed no evidence of patient's views being taken into account:
- There is inadequate discharge planning in around a third of care plans for people on mental health wards which can lead to prolonged detainment:
- There is a certain degree of evidence of unnecessary restraints placed on patients and an increased need for prolonged detention.
- 5.174 An issue with the above referenced report is that it is not clear to what degree such issues specifically relate to Wales and data is not disaggregated by individual country. What these findings seem to suggest, however, is that there are particular issues exclusive to people with mental health conditions in the provision of their own care specifically relating to key areas under the Mental Health (Wales) Measure 2010¹².

Forms of Dementia Including Alzheimer's disease

- 5.175 In 2012, it was estimated that there were a total of 44,598 people with dementia in Wales (Alzheimer's Society 2013a). The Welsh government's National Dementia Vision for Wales highlights that the number of people with dementia in Wales is expected to increase by between 31% and 44% by 2021 (Welsh Government 2011e), mainly as a result of the ageing population in Wales (Knapp et al. 2007).
- 5.176 Both under- and late diagnosis are widely recognised problems in the provision of healthcare for people with different forms of dementia in the UK (National Audit Office 2007). In Wales, despite cross-cutting policy documents emphasising the importance of early diagnosis (Welsh Government 2011e), the rate of diagnosis (at 38.5%) still lags behind both England (44.2%) and Northern Ireland (63%) (Alzheimer's Society 2013b).
- 5.177 UK wide research in 2007 found that the attitudes of GPs could potentially hamper the early diagnosis of dementia (National Audit Office 2007). The confidence of GPs to diagnose dementia had actually fallen since 2004. Among GPs who completed a knowledge survey (of dementia) as part of the research, the average score was only 47%. They also report that diagnosis of dementia is poorly communicated to patients and carers.

¹² More information about the Mental Health Measure (2010) can be found here; http://www.legislation.gov.uk/mwa/2010/7/contents/enacted

- 5.178 A 2013 report by the Alzheimer's Society which surveyed more than 500 people with different forms of dementia in England, Northern Ireland and Wales found that social isolation was a major issue among such groups (Alzheimer's Society 2013c). For example, 39% of those surveyed said they felt lonely after diagnosis rising to 62% among those who lived alone. The report outlines that, although loneliness and isolation are major problems within themselves, they can also lead to further mental health conditions for people with dementia such as depression and anxiety (Cacioppo and Hawkley 2008) and cognitive decline (James et al. 2011).
- 5.179 A 2012-13 report by the Royal College of Psychiatrists titled National Audit of Dementia Care in General Hospitals, who surveyed 210 hospitals in England and Wales offering dementia (and related) care services, found a number of gaps in care including 39% of hospitals which did not have a protocol in place for interventions concerning behavioural and psychological symptoms of dementia (Royal College of Psychiatrists 2013). They also find that 46% of hospitals do not have clear discharge policies in place for people with dementia leading to a lack of appropriate discharge discussions with patients and carers.
- 5.180 Carers and the national care home system are essential services for people with dementia and it is generally noted that most people (60%) in care homes experience from some form of memory impairment (National Audit Office 2007). A 2013 report by the Alzheimer's Society which surveyed over 2,000 people with dementia, care staff and family members of people with dementia found that only 42% of respondents believed that the quality of life among people with dementia in care homes was 'good' (Alzheimer's Society 2013d). Less than half of respondents (44%) felt that activities offered in care homes were sufficient and 64% did not feel that care homes did enough to prevent abuse.
- 5.181 In 2007 the National Audit Office, at the instruction of the House of Commons, conducted a nationwide review of dementia healthcare services in the UK and found wide-reaching inequalities in access to healthcare among people with dementia. These include (but are not limited to): a quarter of Community Mental Health Teams (the recommended care path for people with dementia) had no access to a social worker and 29% had no access to a psychologist; there is a lack of dementia specific training for care workers and nurses are also undertrained in this area; and there is a shortage of care for people with 'young-onset' dementia and for people from ethnic minorities (NAO 2007).

Inequalities in Mental Health Access across Social, Economic and Geographic Classifications

- 5.182 It has been noted previously in this section that there are noticeable inequalities in the provision of mental health services geographically across Wales. The reasons for these discrepancies need further investigation. This finding indicates a clear inequality given that there is research to suggest that psychiatric morbidity is significantly different across Wales based on area deprivation (with more deprived areas showing higher levels of psychiatric need) (Skapinakis et al. 2005).
- 5.183 Research has also found significant evidence of spatial clusters of suicide in Wales, specifically in the County Borough of Bridgend (Jones et al. 2013). Research concerning the broader relationship between suicide and geographical area in Wales is lacking however.
- 5.184 The research suggests that mental health problems disproportionately affect people from black and ethnic minority groups in the UK (Royal College of Psychiatrists 2010). Psychosis is nine times more prevalent among African-Caribbean and six times more prevalent among African populations than it is among the white population in the UK (NMHPG 2006).
- 5.185 Certain forms of depression disproportionately affect women, this is partly because women are more vulnerable to associated risk factors of depression such as poverty (twice as many women than men are economically inactive, for example), violence and (domestic) abuse, child sex abuse and social isolation (NMHPG 2006).
- 5.186 Men are consistently more likely to commit suicide in Wales in comparison to females yet they also are less likely to report depression related conditions. Related research suggests that this is partly due to societal stigmatisation of mental health and the socialisation of masculine norms which may prevent males from seeking mental healthcare advice and services.
- 5.187 There is consistent and strong evidence to suggest a relationship between income inequality and mental health problems in the UK (Naylor et al. 2012, Mangalore et al. 2007, NMHPG 2006, Royal College of Psychiatrists 2010, Skapinakis et al. 2011). For example, men from households in the lowest 20% income bracket are three times more likely to experience common mental conditions than men from the top 20% (Royal College of Psychiatrists 2010). Panic syndromes are consistently associated with economic inactivity in the UK (Skapinakis et al. 2011). Psychosis is highly associated with income inequality in the UK (Mangalore et al. 2007) and multi-morbidity (with mental health) is increased when deprivation is evident (Naylor et al. 2012).

6. A Road-Map for the Social Model of Disability and Subsequent Research Gaps

- During this research, it became evident that there was a severe lack of published evidence in terms of access to healthcare services for disabled people in Wales. A tension evident in this report is the question of how the social model of disability would (and should) be applied to the question of healthcare access.
- 6.2 Arguably, the social model of disability implies a fundamental reappraisal of the notion of 'access'. Traditionally, access has been conceived of in relation to primary and specialist healthcare services but the social model of disability implies that access be thought of in much broader terms such as the interaction between environmental factors (e.g. employment, rurality, design of buildings etc.) and traditionally conceived access to healthcare service points (i.e. primary and specialist care).
- 6.3 In all, there was found to be no strategic road-map to explicate how the notion of access would be readapted in light of the social model of disability.
- 6.4 Some of the key areas in which evidence is lacking are outlined as follows:
 - Physical access to healthcare buildings including location and public transport services;
 - The implications of gender imbalances in health seeking behaviour and wider access to mental health services;
 - The interaction of environmental factors (i.e. the design of healthcare buildings) and healthcare services;
 - The interaction between deprivation/inequality and disability;
 - The interaction between rurality and disability;
 - Unequal differences in life-expectancy specific to Wales;
 - The efficacy of telehealth and personalisation services in specific relation to disability in Wales;
 - The full extent of diagnostic overshadowing in Wales;
 - Reasons explaining the uneven geographical access to mental healthcare services across Wales.

7. Limitations of This Report

- 7.1 This review endeavoured to be as representative and comprehensive as possible within the given scope of the research but inevitably faces some limitations. The first of these relates to the time and resource constraints of the research. The research was conducted by one individual researcher over a four month period. Undoubtedly, to offer a *comprehensive* or fully *systematic* review would require a much longer timeframe and the benefit of multiple researchers to consider the often conflicting perspectives in the area of disability and inequality.
- 7.2 Due partly to the time and resource constraints outlined above, one limitation of the research is that very little primary research has been conducted directly contributing to the evidence base collated in the report. Most obviously, this would include a closer consideration of the views of healthcare professionals and practitioners as well as disabled people themselves: a key implication under the social model of disability. The primary research that was conducted for this research such as attendance at key meetings, informal discussions with disability groups, and the consultation exercise was aimed at gathering as many of the views of disability groups in the limited time available
- 7.3 Due to the breadth of disability issues in Wales, inevitably this research may not be fully representative of different forms of disability which may be under-represented in the literature. Thus, finding evidence for rarer medical conditions often proved difficult and inevitably the issues which are relevant to conditions which are more represented in the literature take precedence over the former.
- 7.4 A general challenge was finding evidence specific to Wales. This, on some occasions, means that the report refers to evidence solely based on data from England or England and Wales, which raises questions over the applicability of such data to Wales. Secondly, a great deal of evidence was found which referred directly to Wales but which was often presented in an unpublished or anecdotal manner and has therefore (although potentially relevant) been excluded.

8. Conclusion

- 8.1 This report has found wide ranging evidence to suggest that there are a number of considerable healthcare access inequalities experienced by disabled people in Wales. Many of these inequalities intersect with (and are compounded by) other social categories such as level of economic deprivation, ethnicity and age. This report also finds significant geographical variations in access to healthcare services for disabled people across Wales, particularly regarding mental healthcare provision and access to rehabilitation services for people with chronic and long-term conditions.
- 8.2 Many of these inequalities relate to a simple lack of provision or funding for appropriate services such as in the case of two examples given above. Other instances, such as the accessibility of healthcare for people with different forms of sensory loss, relate more to adopting methods of best practice and fully appreciating the access needs of different people. A third major cause of the access issues outlined in this report is people's individual health seeking behaviour and wider perceptions of access to healthcare. This is a particularly prominent issue for the experience of pain, the experience of mental health conditions among men and for increased social isolation and loneliness.
- 8.3 In general, this report found many difficulties in adopting the social model of disability for the question of access to the healthcare services. This is because healthcare services are often designed in a specialised way and much of the evidence is presented based on specific impairments or groups of impairments. If the social model of disability is to be applied to the issue of healthcare access for disabled people in Wales, then a framework needs to be developed to explicate how this would work in practice.

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Appendices

Appendix A

The following appendix contains notes taken from the main points raised during the discussion at the consultation workshop.

- It was pointed out that the acknowledgement and tailoring of the evidence to the social model was commendable, but also that the use of both the medical model and the social model was possible; they are not completely incompatible. It is important to use them in the way they were intended, being aware of their benefits and drawbacks. It is important to define the social model appropriately in order for it to be used effectively within policy and applied within health and social care.
- It is important not to treat disabled people solely as a condition, but as a whole person within a context. Disabled people need to be treated on an equal basis and as an expert in their own condition. An equal relationship needs to be established between the individual and the healthcare professional.
- Questions followed and included; How are services supportive of impairment? How does impairment prevent access in terms of comorbidity? What is this process informing?
- It was felt that there needed to be a distinction between some of the detailed recommendations detailed, but that these should be informed by 'big picture' or strategic recommendations, including; The inclusion aim, tackling fundamental access issues; Equal interaction between professionals and individuals; Local services and the problems inherent within. This should inform a suite of tools that can be used for evaluation purposes.
- Disability awareness is not part of service design, is not built into the system adequately. The communication of such issues is a fundamental cross cutting theme that should be addressed.
- There is a need for some kind of strategic framework that talks about the bigger picture for Wales that informs the generation of recommendations. These need to be consistent with, and draw upon, existing overarching policy and strategy frameworks for health and social care.
- It was noted that the consideration of crucial transitions of a disability or impairment and how these transitions would work and be managed is necessary. Such examples included: Transition from diagnosis to assessment/end result and an understanding of the needs of the individual from the healthcare professional; management of condition; relationship between health and social care

- Comorbidity at present there is no provision to cope with this example
 was given of someone who had arthritis and then had to undergo
 amputation, and the mental health problems that resulted from trying to
 manage these two conditions.
- There should be consultation with disabled people to determine how the social model could work in practice.
- The importance of understanding the interrelationship between UK and Wales regarding austerity and the impact on health e.g. the lack of funds allocated to public health initiatives and the consequent rise in lifestyle-related chronic conditions. Who is looking at the long term impacts on health in two, five, or ten years time?
- Welfare and social isolation and the impacts of austerity what changes will people be forced to make due to deteriorating health that will leave them socially isolated? How will welfare cuts contribute to this? We need to be thinking about long term impacts of welfare reform.
- The leadership role of Public Health Wales in developing the social model of disability – how should they be involved?
- GP training we need to take a look at what GPs are currently trained in and where the shortcomings are. This is of particular concern with regard to training GPs to know when to refer disabled people urgently, and when to know if low level care is required?
- What is missing from the report as it stands is the issue of rehabilitation for drugs and alcohol. Currently services for mental health and rehabilitation are not integrated as they should be. The subsequent impacts of these issues on the family of the individual should also be taken into account.
- The role of telehealth is crucial in tackling the problem of social isolation/reduction of anxiety about conditions – it can provide quick reassurance. Relatedly, telehealth may also be beneficial in accessing those with severe learning difficulties, as healthcare professionals could assess and monitor the health of these individuals and prevent escalation of conditions.
- An awareness of different networks and the way in which we transmit messages should be thought about so that they permeate education, the workplace and community groups. We need to be aware of networks and how they work to be able to educate and inform the population about some of the issues raised here i.e. relating to public health and awareness of issues relating to disability.
- There were some questions relating to the age groups covered in the report.

- Some issues of sparse provision for specialist services in Wales e.g. a paediatric rheumatologist, is not good at present. Often, affected individuals/families have to make long journeys to other parts of the UK for consultation and treatment. This could be solved in part by telehealth, but also through better dispersal of specialist services throughout the UK.

Appendix B

The following is a response from Action on Hearing Loss regarding the recommendations of the report. It was agreed that this recommendation should be included.

Action on Hearing Loss ... [suggest]... that the section on sensory impairment needs to echo the recently published Welsh Government All Wales Standards for Accessible Communication and Information for People with Sensory Loss.

These have been formulated in conjunction with people with sensory loss and reflect the main inequalities in accessing healthcare services for this group. I would suggest that the one of your key recommendations is that the "All Wales Standards for Accessible Communication and Information for People with Sensory Loss are implemented in full".

Appendix C

The following is a written response received regarding the recommendations of the report and consultation workshop from the Bwrdd lechyd Prifysgol Betsi Cadwaladr University Health Board.

- discussion about the lack of understanding around the social model in health, probably due to the traditional medical model that has been practiced historically. I do believe however that there are opportunities currently, as we shift the strategic focus to the provision of care closer to peoples homes and drive forward initiatives to empower people in managing their long term chronic conditions through expert patient initiatives etc. Locality working provides the opportunity for partners, health and social care, GP and third sector to work together with the patient as the focus and therefore adopt a more social model focus.
- Pan Impairment Whilst it is necessary to consider the provision of appropriate care, I believe there is a step before which should adopt a more preventative focus i.e. what are we doing to enable disabled people to stay healthy? What information does public health hold pan impairment and can this be mapped against other protected characteristics?
- Physical Impairment There are opportunities here to scope and explore care pathways and care bundles to ensure that they have been equality impact assessed, are inclusive and flexible enough to meet the needs of everyone.
- Sensory Impairment -I suggest a priority here is about identifying and sharing information about sensory loss. Whilst I understand NWIS have been advising in respect of the GP electronic referral system in this regard there needs to be some work to strengthen the IT architecture and mandate the collection, flagging and transfer of this information from primary to secondary care.
- Learning disability There is the opportunity to promote the WG care bundles recently launched to improve the experiences of patients with learning disabilities. The passport system is an excellent tool to empower patients, share important information and therefore reduce risk. Support for carers is key.
- Cross cutting links This is interesting and from an equality perspective very important, it would be useful to make the links with disability and other protected characteristic illustrating where individuals can become '

- doubly disadvantaged', i.e. patients with LD also have a significantly higher percentage of sensory loss.
- **Improved discharge, policy and planning -** The recommendations to improve discharge planning for patients with dementia is important, this applies to other groups i.e. learning disability.

Appendix D

The following written response to the recommendations was received by the Welsh Ambulance Service NHS Trust.

- Pan impairment In response to feedback from a number of disability groups (and asylum seeker forums) across Wales, it became apparent that one of the issues which was a common thread was difficulties with communication in an emergency. As it's not possible to get an interpreter (including BSL) to the scene of an emergency due to the time constraints, we looked at designing a communication aid which would address a multitude of communication needs. Therefore, it was decided that we'd use a pictorial communication aid, which could be used for people who are Deaf, have a learning disability, have an illness or condition which makes speech difficult and for people who don't speak English. Therefore, the Pre Hospital Communication Guide was developed (based on an original guide from London Ambulance Service) and was launched by the Health Minister in December 2013, along with the All Wales Standards for Accessible Communication and Information for People with Sensory Loss With regards to health literacy, we've designed a learning programme for those with learning disabilities, which I've covered in greater detail in the Learning Disabilities section below. Where you've mentioned the needs of carers, such as providing them with information, how they are identified and applying for appropriate assessments, all of these issues are addressed in the Carers Strategy (Wales) Measure 2010 which requires the NHS and local authorities to publish a 3 year strategy, which includes how each organisation will ensure: recognition of carers, engagement with carers, provision of information and signposting and being advised how to access assessments.
- Physical Impairments With regards to falls, although this is only relevant for patients who have not suffered a fracture ... the Welsh Ambulance Service has a falls pathway for patients who have fallen and don't need to be admitted to hospital (such as no fractures, no head injury, no health condition that requires treatment). The patient is able to stay at home but the paramedic instigates a referral to the community falls team so that they can visit the patient and carry out the appropriate assessments
- Sensory impairments A lot of the recommendations in the All Wales Standards for Accessible Communication and Information for People with Sensory Loss (launched by the Health Minister in December 2013 as mentioned above) would address a number of the issues in this section. Also, as many people who are deaf told us that they weren't able to ring 999 and would ask a family member to do it for them, we signed up to the

emergencySMS and, once they've done so, they can text 999 in the case of an emergency. Following public feedback on the difficulties with communication, we also designed a medical information card which is a wallet sized card designed for people who are deaf. The card allows the person to complete details about their medical history, next of kin and their preferred method of communication (e.g. BSL) which can be handed to the paramedic or other healthcare provider and help the patient relay important information about themselves. Over 15,000 cards have been distributed across Wales and some of the Health Boards include them in their 'first fit' packs when a patient has a hearing aid fitted for the first time. The Pre Hospital Communication Guide (as detailed above) also helps with communication with people who are deaf and includes additional advice for staff and the BSL alphabet.

- Screening and health checks With regards to reviewing the uptake of cancer screening programs, there has been a great deal of work carried out by Public Health Wales Screening Services, particularly to encourage transgender people to attend screening as there is low uptake amongst this community. Also, from our engagement with BME communities, there has been a reluctance to attend screening, often as issues and health problems are kept within the family and there may be cultural and religious reasons for reluctance in attending more 'invasive' screening that requires the patient to remove clothing. Therefore, we've held a number of public 'health and lifestyle' events for BME communities and have invited screening services to come along. Where you've mentioned the effectiveness of including assessment for diabetes as part of the annual health check for over 50's, as the health check is an online self assessment, I don't know how assessment for diabetes would work. Yes, there are some lifestyle questions which may indicate the need to see the GP to have blood sugars checked but as it isn't a face to face assessment, you're relying on the person taking the time to make that appointment with the GP after they've completed the online self assessment.
- Neurology and Rare Diseases The first point recommends that newly diagnosed patients are given written information on Parkinson's and MS but they should also be provided with details of additional support that's available (should they need it) such as support groups.
- **Post Stroke Care** The last point mentions the emotional needs of post stroke patients this is where they could be offered additional support such as counselling and support groups.
- Specialist Cancer Services 2nd point Cancer patients should be regularly screened for anxiety and depression and information on

counselling services should be made available. This will include counselling provided by the voluntary sector. 5th point – post cancer care should be improved to ensure social isolation doesn't increase. Again, this could be addressed by services provided by the voluntary sector. This helps the patient to receive counselling and support in familiar surroundings but also enables the counsellor to pick up on and address issues with social isolation.

- Learning Impairments In the summary evidence in this section, you mention that routine dental care is lower amongst people with learning disabilities, however, some dental practices may not have the knowledge and experience to treat patients with learning disabilities. An example of problems like this is highlighted by Mencap Cymru, where no special provision is made by the dental practice to consider anxiety, fear, how the patient demonstrates pain (an element of diagnostic overshadowing seemed to occur where the patient's dental pain wasn't taken seriously). Consideration would need to be given on what specific training dentists, dental therapists, hygienists and dental nurses receive in treating people with learning disabilities. Again, in response to feedback, we designed an (award winning) learning programme to help show people with learning disabilities how to ring 999 and how to navigate a complex healthcare system. The learning programme uses games and guizzes to help reinforce learning and help the individual learn about the different healthcare services that are available and when they should be used. The programme has been designed for different learning styles and capability and includes a facilitator/parent pack that can be used for group work and to support individuals work through the programme at their own pace
- **Mental Health Impairments -**The Mental Health (Wales) Measure 2010 would be relevant to some of these recommendations and initiatives such as 'Talk to me'

Appendix E

The following is a written response to the recommendations received by South West Wales Neurological Alliance.

- Chronic pain conditions, there needs to be more access to pain clinics, and pain management courses, as there is a huge waiting time for this and some areas don't have pain clinics therefore are not being offered referral to these and are at home suffering with the pain, especially in pain conditions that the GP does not know enough about and fully understanding the needs for a patient with chronic pain conditions and how to manage this, whilst hold down a job, or supporting their family.
- Neurological, there needs to be more emphasis on patients that have rare or not so commonly known neurological conditions and don't have access to a neurological specialist nurse. The top 5 neurological conditions have specialist nurses, (i.e. Parkinson's, Epilepsy, Stroke, MS, MND,) however there are over 140 neurological conditions that are not being given a platform or support from their GP or referral therefore these patients are not following a patient pathway, and left on their own, especially again when a GP does not know enough of the condition to support it or to refer them to community services.
- There is not enough emphasis on rare and not so commonly known neurological conditions and especially when there is no support network or support group in Wales for them to attend to talk to other people with the same condition.
- Education, awareness, and research as does the need to carry out signposting to services needs to be high on the priority, to make all patients with long term conditions have a better quality of life.