ADSS Cymru
Yn arwain Gwasanaethau Cymdeithasol yng Nghymru
Leading Social Services in Wales

ASSOCIATION OF DIRECTORS OF SOCIAL SERVICES CYMRU

Delivering Transformation Grant Programme 2021-22

Social care and support for people in Minority Ethnic Communities

Selective Literature Review

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Contents

1. Introduction

1.1 The Welsh Government asked ADSS Cymru to lead a programme of work to examine the use of social care and support by people from the minority ethnic communities. The programme is funded by the Welsh Government's Delivering Transformation Grant programme for 2021-22.

1.2 The purpose of the programme is to help understand the challenges and barriers encountered by people in minority ethnic communities when they need formal care and support, the decisions they make, and what influences their decisions.

1.3 The work will build a clear picture of the issues involved. This will provide the basis for more action to improve their access to, and use of, social care and support. It will study areas of Wales which have significant number of families from minority ethnic communities, engaging with statutory public service organisations and third sector organisations. More specifically, it will aim to:

(i) Understand the extent to which people from minority ethnic communities access care and support when they have an identifiable or assessed need.

(ii) Examine the issues, including barriers and challenges, involved to people accessing care and support.

(iii) Identify the impact of Covid-19 on levels of confidence and engagement with social services.

(iv) Explore the informal support network provided by family, and friendship carers, and how this network and the carers themselves are supported.

1.4 While the project will cover the well-established minority ethnic communities in areas of Wales, we are mindful of the value in this review in capturing the views of people from all areas, including the more rural areas. It will cover all areas of service provision which might be provided in response to a formal assessment of someone's needs.

1.5 The project aligns well with several elements of ADSS Cymru's strategic priorities 2021-24:

- **Priority 1:** The social care workforce is properly supported, resourced, and valued with the skills and resilience to deliver the high-quality, responsive services that people need.
- **Priority 2:** We want to ensure that people and communities are at the heart of the remodelling of social care and health services.
- **Priority 3:** We want to ensure that people have real choice and control in how their care is delivered.
- **Priority 4:** Sustainability is central to the rebalancing of care and support, with local authorities having confidence that services can meet the needs of people now and in the future.

1.6 Engagement with organisations in the public and independent sectors, including private providers and third sector organisations is at the heart of our approach. A wide range of engagement action will take place as part of the project.

1.7 As the first step, a selective review of available literature on themes relevant to the scope of the project has been undertaken. This provides the policy context and background to the work, and informs the programme of engagement. It also reflects the logic of looking at issues encountered in and among communities elsewhere in the UK.

1.8 This report summarises the findings of available literature, drawing out key issues and themes. **Chapter 2** provides the background and policy context. **Chapter 3** reports on literature on the broad subject of barriers to accessing social care, largely focusing on older people. **Chapters 4, 5 and 6** reflect the available literature on carers, gypsies and travellers, and people with learning disabilities respectively. Literature on the use of family and parenting support programmes (such as Family First and SureStart) by people from minority ethnic communities was also explored but without success. Too few sources of limited relevance were found to be able to draw conclusions hence its exclusion from this report. In **Chapter 7**, we summarise the key themes from our analysis of the research findings and from our assessment of issues relevant to the ultimate goals of the project.

1.9 A list of the main search terms used for the review is provided in Appendix 1.

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2. Background

2.1 This section provides the broad context for the following, more detailed, sections which explore the reasons why older people from ethnic minority groups might not seek to access social care, and the reasons behind it.

Policy context

2.2 Several elements of Welsh Government policy are relevant to the subject of this report. They include, "A Healthier Wales"[1], the Government's response to the Parliamentary Review of Health and Social Care[2], and Prosperity for All[3] in which social care is one of its five priorities. The Strategic Equality Plan 2020-2024[4] and the most recent development, the Race Equality Action Plan[5] are particularly relevant to this project. The public consultation on the latter ended on 15 July 2021.

2.3 This project is relevant to three key goals in the proposed Race Equality Plan:

- **Goal 1:** To ensure that all Black, Asian, and Minority Ethnic people feel confident in accessing and using social services and social care services when they are needed.

- **Goal 2:** To ensure that all Black, Asian, and Minority Ethnic people who access social care services are provided with the highest quality support that is accessible, dignified and culturally appropriate.

- **Goal 6:** To improve qualitative and quantitative data, research, evidence, analysis, intelligence and understanding to support and drive continued progress, including a significant increase in the lived experience data gathered from Black, Asian and Minority Ethnic people.

2.4 The duties which fall on public bodies, including social services, from legislation are also relevant. They include the Equality Act 2010, the Social Services and Wellbeing (Wales) Act 2014, and the Wellbeing of Future Generations Wales Act 2015.

2.5 The Social Services and Wellbeing Act places duties on a local authority to promote well-being for people who need care and support, and carers who need support. This includes people who do not have needs which meet eligibility criteria, but who do have needs for care and support that may be met in other ways e.g. through the provision of information, advice and assistance, and preventative well-being services.

2.6 The Act requires a local authority to have regard to an individual's views, wishes and feelings, and promoting and respecting their dignity. There is also a clear requirement to have regard to the characteristics, culture, and beliefs of the individual, including, for example, language.

2.7 Estimates from the Annual Population Survey for the year ending 31 December 2020 show 5.6% of the Welsh population describing themselves as Asian, Black, 'Mixed/Multiple ethnic group' or 'Other ethnic group'. The proportion of the population identifying in this way varied considerably by local authority from 1.3% in Powys and Pembrokeshire to 13.2% in Newport and 20.1% in Cardiff.

2.8 The table below shows estimates for each local authority area. Areas where the data quality is considered to be “limited” or “low” are marked.

Table 1: Ethnicity by local authority area, year ending 31 December 2020

Local authority area	People who are Black, Asian and minority ethnic	
	No.	Per cent
Isle of Anglesey	*	*
Gwynedd++	3,100	2.5
Conwy++	3,000	2.6
Denbighshire+	3,600	3.8
Flintshire+	4,400	2.8
Wrexham++	3,100	2.2
Powys++	1,700	1.3
Ceredigion++	1,300	1.7
Pembrokeshire++	1,700	1.3
Carmarthenshire	7,400	4.0
Swansea	20,900	8.5
Neath Port Talbot++	2,400	1.7
Bridgend++	3,700	2.6
Vale of Glamorgan++	2,700	2.1
Cardiff	74,700	20.1
Rhondda Cynon Taf+	9,500	4.0
Merthyr Tydfil++	1,300	2.2
Caerphilly++	2,800	1.6
Blaenau Gwent++	1,300	1.9
Torfaen+	3,000	3.3
Monmouthshire+	3,200	3.5
Newport	19,800	13.2
Wales	**174,900**	**5.6**

Source: Welsh Government, Annual Population Survey 31 December 2020
Notes: * Data is disclosive or not sufficiently robust for publication
+ Data is considered as being limited quality
++ Data is considered as being low quality

2.9 In a Welsh Government statistical article published to support the work of the First Minister’s Covid-19 BAME Advisory group, of the 1,462,000 people in employment in Wales, 5.2% identify as Black, Asian or minority ethnic. The following table shows there are slightly higher than average numbers working in social care and in healthcare[6].

Table 2: Employment in selected, specific, high risk occupations in Wales by ethnicity and occupation, 2019

Occupation	White		BAME	
	No.	%	No.	%
Social care workers	68,900	82.8	5,400	7.2
Healthcare workers	106,200	88.8	13,400	11.2
All occupations	**1,385,400**	**94.8**	**75,900**	**5.2**

Source: Welsh Government. Extracted from Table in Statistical Article: Coronavirus (COVID-19) and the Black, Asian and Minority Ethnic (BAME) population in Wales.

The need for social care

2.10 Inequalities and the relative disadvantage of ethnic minority groups suggest there are high levels of need for care and support. It is suggested that historically, social care provision has fared poorly in understanding, responding to, or even investigating these needs[7]. Past research has emphasised the importance of closing the health gap for people in these population groups and it is now a priority. It is also suggested that the growth of various ethnic communities and linguistic groups, each with its own cultural traits and health profiles, present a complex challenge to healthcare practitioners and policymakers in terms of achieving equitable access[8].

2.11 Although undertaken more than 15 years ago, a report for the Joseph Rowntree Foundation drew the following conclusions[9].

- Both the numbers and proportion of older people from Black and Minority Ethnic groups in the population are rising and will continue to rise for the foreseeable future.
- Black and minority ethnic older people have considerable health and social care needs, and these needs occur in a comparatively younger group of Black, older, people than White, older, people.
- Despite the existence of considerable health and social care needs, Black, older, people's knowledge and use of services are low compared to White, older, people.
- There is some evidence Black and Minority Ethnic, older, people are more likely to face a greater level of poverty and have lower levels of income than white, older, people.
- Black and minority ethnic older people are more likely to live in poorer quality housing, which lack basic amenities and this may impact on their health.
- The notion that the extended family will look after their 'elders' may be a myth and certainly masks the level of true need.

2.12 One might question whether the situation today is different and if so, to what extent. More recently, and perhaps more forcefully, the Equality and Human Rights Commission declared persistent racial inequalities in health and access to health and social care, and in levels of

loneliness, among other social and economic disparities[10]. Its report for Wales[11] also concluded the existence of barriers to health, particularly for people from ethnic minorities or for whom English is an additional language. Barriers to accessing health services were a particular issue for Gypsy, Roma and Traveller families, and access to mental health service provision is a key challenge for refugees and asylum seekers.

2.13 While the report for Wales addressed healthcare, it did not comment on access to, and use of, social care by ethnic minorities. However, it did reference access to services in further compounding people's feelings of loneliness and not belonging, finding increased levels of loneliness in Wales, particularly for some ethnicities. One in four people from ethnic minority groups reported being lonely in Wales in 2016-17.

2.14 Findings from the Public Engagement Survey on Health and Well-being undertaken by Public Health Wales during the pandemic suggest coronavirus and the lockdown restrictions have had a greater impact on the mental health and wellbeing of Black, Asian and minority ethnic residents[12]. In particular:

- Nearly a third of respondents (30%) reported feeling very anxious compared with 1 in 5 white respondents.
- A third of respondents' report feeling isolated, compared with 22% of white respondents.
- 1 in 5 respondents were worrying a lot about their finances, compared with 15% of white respondents.

2.15 This is reinforced by the Welsh Government. In advice on population needs assessments issued in March 2021 to Regional Partnership Boards[13], it stated it is clear Covid-19 impacted on the whole population but has had greater health and wellbeing impacts on certain groups more than others, including older people and people in ethnic minority communities.

Responding to need

2.16 Section 14 of the Social Services and Wellbeing (Wales) Act 2014 requires local authorities and local health boards to prepare needs assessments of the area's population every five years. Assessments identify the need for care and support of individuals and carers, the range of services required, how far needs are being met and how services will be delivered. Each area was then required to produce a wellbeing plan which responded to identified needs.

2.17 A rapid review was undertaken of the population needs assessments and wellbeing plan documents using a selection of word searches for "ethnic" "minority", "race", "BAME" and "BME". A summary table of findings is provided in Appendix 2. The documents varied in coverage of matters relating to minority ethnic groups, from no content to a mixture of general commitments such as in Cardiff e.g. "To deliver public and third sector services and workforce that are representative of the city and its communities, especially Black, Asian, and Minority Ethnic communities".

2.18 Overall, there is scant coverage of the specific needs of people from ethnic minority groups, particularly in respect of social care. We assume, and hope, the intervening years since the

documents were produced in 2018 will have generated more action, and more specific action, to help people and carers from minority ethnic groups. This project will seek to capture this. This literature review has started the process. By way of early examples:

(i) The Cultural Competency Toolkit, developed by the equalities charity Diverse Cymru, provides guidance on how staff can take action to overcome the barriers that Black and Minority Ethnic people often face when accessing services because of difference in culture[14].

(ii) The Minority Ethnic Elders in Mind project (Cardiff and the Vale) responded to the issues identified around significant health differences experienced by minority ethnic elders and the lack of support for them. It also provides weekly drop-in advice and guidance sessions to support people with issues relating to, amongst other things, care homes, health, and language barriers.

(iii) The Minority Ethnic Elders project in North Wales has sought to influence statutory and voluntary organisations to provide better services in North Wales. Barriers identified include interpretation and translation support.

2.19 There is some coverage of the needs of ethnic minority communities in a national population assessment report prepared by Social Care Wales in 2017[15]. The key points are as follows:

- Development needs include an increase in support for older Black, Asian, and ethnic minority people.
- Social isolation is present particularly in Black, Asian and Minority Ethnic groups.
- There is specific support available in (some) regions to meet the needs of minority ethnic communities.
- One region specifically mentioned loneliness and isolation, two regions mentioned specific health needs, some regions mention specific issues around domestic violence and abuse (including female genital mutilation). Examples of support included: advocacy; specialist domestic abuse and sexual violence support; support through local places of faith and community centres.
- Some regions would like to increase their understanding of the care and support needs of minority ethnic communities.

2.20 Concerns have long been expressed about how local services respond to the needs of increasing numbers of older people, particularly the needs of older people in minority ethnic groups given the other challenges of, for example, language and cultural issues. There are issues about access to relevant information about services, and studies have reported the feeling social services should be aware of changing family patterns and that the extended family may not be able to provide care.

2.21 Several studies emphasise that minority ethnic communities are not homogenous, with differences on many issues including culture, language, and health status. Another study[16] reported that attitudes towards unpaid caring and professional care services are not consistent across ethnicities. It points to the resources available to people in different

groups and communities vary, including the degree to which extended families, friends and neighbours help to meet care needs. It also stated people from some ethnic groups may be less likely to access professional care services due to a lack of cultural sensitivities in the service and/or a lack of information and networks connecting them to it.

2.22 Research in Wales in 2009 concluded that the research literature points to ethnic minority groups being 'overlooked' by social care services[17]. The extent to which this statement holds true today is unknown, but is something this project can seek to explore.

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3. Accessing care and support

3.1 Desktop research was conducted using a series of keywords as search terms. These were generated from the specification for the programme of work. They are listed in Appendix 1. This chapter and the following chapters summarise the findings and highlight issues which need to be considered and / or addressed if access to care and support by people from minority ethnic populations is to be improved with greater use of services and support as a result. The prime focus of this chapter is older adults but some of the barriers identified will be relevant to other groups within the population, including carers, people with learning disabilities, and people in Gypsy and Traveller communities.

3.2 While social care and support is the focus of the project, there is considerably more research into barriers to accessing health services by people from minority ethnic communities. The review highlighted some common ground between the barriers and issues identified for health services and the research undertaken in social care. Therefore, this summary draws on both.

3.3 In considering care and support needs, it is important to recognise who needs the support. There are two equally important groups who need support, albeit to different levels and in different forms. First, individuals with and without disabilities who require support or more support as they get older. Second, the informal carers of individuals such as spouses, partners or children who are often taking the place of, and preventing the need for, social care support. In minority ethnic communities, both groups can suffer because of barriers to accessing the help they need. While some of the barriers e.g. awareness of what help is available locally, are also experienced by the population as a whole, research has found people from Black, Asian and minority ethnic groups experience more barriers[18].

3.4 Findings of the literature review specific to carers is covered in the next chapter.

Barriers

3.5 Several studies covering health and social care identify barriers exist which prevent people from minority ethnic backgrounds from accessing services and support. The issues may act as barriers to receiving any care and support, or receiving care and support of the type and in a way which fully meets people's needs[19],[20].

3.6 In confirming the widely held views that older people and their families from minority ethnic communities have problems accessing help from services, one study also referenced the poorer overall health they experience[21]. Another study (albeit from 2005), highlighted several issues[22]:

- Small but significant differences in the incidence of specific health problems among different ethnic groups.
- The mental health needs of older people from minority ethnic communities have been particularly neglected.
- Lower levels of awareness and understanding of problems such as depression and dementia within minority ethnic communities.

- There was insufficient evidence on whether integrated or separate services are more effective to meet the needs of people from ethnic minority communities, but the need for services to be more culturally appropriate and sensitive.

3.7 Some of these themes are reflected in other work published in 2008 by the Race Equality Foundation[23].

- Older people from minority ethnic groups continue to receive poorer treatment from health and social care services; they are also often under represented among those using services.

- Stereotyped assumptions on the part of professionals may also act as a barrier to service use.

- Barriers to accessing services include lack of information, language difficulties, and differing expectations about how services can help.

3.8 The barriers set out in this chapter should be considered against the broad background set out in Chapter 2. Given that some studies date back to 2005, the real question is whether the situation has changed since then and if so, how and to what extent?

3.9 The following broad issues appear from the literature to be behind the main reasons why people from minority ethnic communities do not access, or try to access, social care services and support.

- Language

- Communication and information

- Awareness and understanding

- Culture, beliefs, and values

- Attitudes, assumptions and stereotyping

- Stigma

- Mistrust

3.10 The literature does contains a range of barriers which may explain why people from minority ethnic communities to not take up services and support. These are reported in different ways and formats. There are both similarities and differences between the lists. The following table shows two different examples of lists.

Table 3: Examples of types of barriers to accessing services

Types of barriers	
Example A[24]	**Example B[25]**
Societal: e.g. education, employment, stereotyping and prejudice, lack of understanding, choices society makes (e.g. funding defence over tackling poverty) **Institutional:** location, physical access, administrative barriers (e.g. rules, forms to access, processes, systems etc), poor or no communication, lack of cultural sensitivity. **Personal:** psychological barriers (e.g. shame or embarrassment), poverty (disadvantaged individuals have a higher incidence of chaos in their lives), transport a problem, cultural or religious issues, family concerns, lack of basic skills or education (including literacy), lack of job or personal skills.	**Physical:** e.g. a wheelchair user is unable to enter a building because there are steps so they can't get to the entrance. **Psychological:** the way an individual thinks about a service e.g. it may be they have a fear of the dentist. **Financial:** how much it might cost to access a service. **Geographical:** some individuals may live some distance from services and support. **Cultural and language: i**f information (signs, leaflets, posters) about services is in English only, people with a different first language will not be able to find out about the service. If information uses specialist (technical) language, a person may not understand it and may become anxious or worried about the service **Resource**: an individual needs to access may not be available due to staff shortages, capacity vs demand, or a lack of money for the service.

3.11 There are interrelationships between the issues listed above. In some cases, there are, dependencies e.g. effective communication depends on language, specifically whether information can be provided in a person's first language, which may not be English. Each of the above are explored in more detail in the following pages.

Language

3.12 Language appears frequently in the literature as a barrier to services. If people do not speak the dominant language i.e. English, it prevents people from knowing what is available and how to access help. Even where printed information in minority languages is available, this may not help those older people who have a limited level of literacy in their first language. Where there are family members of friends who can translate the information and communicate it to them, it can mitigate the extent to which it is a barrier. Where there is no one to do this, it will exacerbate the effect. However, even when family members or friends are used as interpreters, in health services for example, it can pose issues of confidentiality. It can also risk information being filtered either deliberately or because the family member, carer, or friend cannot interpret accurately. This could happen particularly where there could be embarrassment.

3.13 Good quality interpreting and translating services are considered important. Where not available, or not easily available, or available in a timely manner, it can delay actions designed to deliver care and support e.g. assessments of need. One study has suggested a lack of interpreting and translation can make some older people from minority ethnic groups especially reliant on local volunteers and bilingual workers in voluntary organisations to be able to access services. While the help serves a valuable purpose, it can lead to feelings of dependency upon such support[26].

3.14 The problems of language contribute to, but are not the only factor in, awareness and understanding of what help is available.

Communication and information

3.15 Older people from minority ethnic groups tend to be less aware of what services are available and how to access them but this does vary between different communities[27]. Barriers to access may stem from a lack of provision of information, poor communication by members of the workforce delivering the information, or weaknesses in the system to facilitate communication e.g. the lack of quality interpretation and translation services highlighted earlier.

3.16 The lack of information may relate to information not being available in an individual's first language or available but not in a suitably accessible format. Even if information is available in printed format, literacy is another factor which can sometimes affect the ability to absorb and understand the information and thus affect awareness of services. If information is available via electronic means, access and IT skills mean it may well be more likely to be accessed by family members, friends, or community organisations to be relayed to individuals.

3.17 Research in healthcare settings report professionals failing to explain issues properly, or not listening to the individual, therefore preventing full patient participation in decision-making processes. In one study of their experience of the health and social care system, some participants reported an expectation of self-reliance, leaving them reliant on family members, friends, and local community groups for accessing information relevant to their care needs[28]. Language difficulties add complications to communications, which means ethnicity plays a key role in shaping the overall experience of accessing care. A negative experience on one occasion can cause apprehension and/or reluctance to engage again when support is needed.

3.18 Studies of health services show that disparities and unmet needs can stem from issues such as communication between the healthcare professional and the patient/family[29]. This was associated with lack of sensitivity to cultural/religious differences, lack of availability of translators and low availability of training for healthcare professionals.

Awareness and understanding

3.19 Some research has found that, generally, individuals from ethnic minority groups are less satisfied with health and social care services, have a lesser understanding of health and social care systems, and because of disparities in accessing health and social care services, are also more likely to have unmet needs when using services[30,31]. Assumptions made by patients and service providers may prevent people from minority ethnic communities from accessing health and social care services. It has been found they often

do not perceive health and social care services as available or accessible. These perceptions could be due to having negative previous experiences of seeking help.

3.20 There is a direct link between communication and information and awareness and understanding of what support is available and how to access it. That said, some issues may go deeper than information provision. For example, there may be relatively little awareness of some older people's mental health issues within certain ethnic communities. For example, Asian languages do not have an equivalent word for dementia, which means symptoms may be unrecognised or misunderstood[32]. Similarly, there might be confusion over the meaning of “independent living” among minority ethnic users, or potential users, of services[33].

3.21 The same study also highlighted a lack of familiarity with social care services among some older people in certain minority cultures. This too may prevent people from requesting services or lead to misunderstandings about their role. A low, or lower, uptake of social care services by older people from minority ethnic communities may also result in demand being overlooked or underestimated by commissioners. Medical services, which are better understood, and free from stigma, are often considered more acceptable than social care services.

Culture, beliefs, and values

3.22 Research by the Joseph Rowntree Foundation found that older people in minority ethnic communities felt that majority services often did not meet the needs of culture and beliefs that are important to different minority ethnic communities[34]. This includes a lack of knowledge and respect for religious beliefs and practices. It also emphasises that different communities often have a different view of health and well-being, and find their own views of complementary medicine or a holistic approach to health needs are not seen as being important or relevant. Some frustrations were also reported, with older people feeling the Western mindset simply saw communities as "problems" rather than respecting the fact different communities had real strengths which should be valued.

3.23 Culture, beliefs, and values can also underpin expectations about the care and support which can be provided may differ. Ethnicity plays an important role in expectations and can be a major influence on satisfaction with services.

Attitudes, assumptions, and stereotyping

3.24 Assumptions about the support which is available to older people within minority ethnic communities can also be a barrier to them getting the help they need. Studies, including a study in Wales, have cautioned against assumptions that family support will be available or that ethic groups “will look after their own”[35,36]. This is seen as a long-discredited stereotype of minority ethnic families but one which can still surface in the attitudes of some practitioners and policymakers[37].

3.25 The British Psychological Society acknowledges the term “Black, Asian and minority ethnic” can be somewhat misleading[38], First, because it may suggest different communities can be seen as a single, collective whole, thus not acknowledging the unique needs of individuals. Second, because there is enormous variety among such communities in the UK, with immense diversity in many aspects such as religion, country of origin and culture.

3.26 Stereotyped assumptions on the part of professionals can lead to other outcomes which result in a lack of service take-up and utilisation. For example, GPs being less likely to refer minority ethnic patients to relevant agencies such as social care, and fewer checks by social workers because of the assumption of extended family care[39]. The research goes on to suggest that while the organisation of care provision for older people in minority ethnic communities is, or at least in 2019 was, based on a set of assumptions and generalisations about cultural identities, family networks, and the role of women primarily as carers, things are rapidly changing. This included changes to household composition, including smaller homes. Although informal support might be available in certain circumstances, this cannot be relied upon[40].

3.27 The possibility of stereotyping can also apply to issues of loneliness and isolation[41]. Black and Asian adults over 65 are almost twice as likely to report having no close friends compared to White and mixed or 'other' ethnicity adults of the same age. Despite these higher rates, it is often assumed they are protected from social isolation and loneliness because they are perceived as being likely to live in multigenerational households with traditional family practices and support. The research argues that such stereotypes are damaging because they fail to acknowledge the diverse experiences and needs of different minority adults.

3.28 It has been said that *"Having a clear ethnic lens, free of stereotypes and prejudices is tantamount to effectively serving the community."*[42]

Stigma

3.29 Stigma is seen as an ongoing risk for health and wellbeing among vulnerable groups, particularly minority ethnic communities. Studies have highlighted this as a barrier to accessing health and social care services[43]. Research has linked the concept of stigma with several interrelated elements, including stereotyping, labelling, loss of status, power exertion, and discrimination. It has identified two main dimensions: externalised and internalised.

- Externalised: stigma directed at individuals by others e.g. friends, family, other members of the community, wider society.

- Internalised: stigma which stem from an individual's own sense of devaluation and discrimination.

3.30 Taking "(ii)" first, individuals in some minority ethnic groups may perceive themselves as outsiders in their community. Other might prefer to conceal a health condition e.g. being HIV positive. Both can affect an individual's propensity to use health and social care services. In some communities a lack of understanding and the stigma attached to mental illness may prevent families from seeking help. This may particularly be the case where the community culture places great emphasis on self-reliance.

3.31 In the case of this report, externalised stigma would include that directed at individuals by members of the workforce involved in delivering social care and support, whether they work for a public, private or third sector organisation. One study on best practice referred to an inspection of community care services for ethnic minority older people in 1998. It found that although procedures existed for involving Black elders in their assessments and developing

care plans, the practice was dependent upon the knowledge and skill of individual workers. Without appropriate training, knowledge and skills, some White staff did not have the confidence to make judgements, and in some cases, staff still took the view that ethnic minority families "look after their own". It concluded "there was a danger that white ethnocentric values result in inappropriate assessments"[44].

3.32 According to research into dementia services commissioned by the Social Care Institute for Excellence[45], lower levels of awareness about dementia and the existence of stigma help explain why people from minority ethnic communities are under-represented in dementia services. It said carers may feel reluctant to ask for help, although support in the form of carers' groups and respite services may be appreciated. It also highlighted that different communities may have differing views about whether they wish these services to be culturally specific or mixed.

Other relevant issues

3.33 Two other themes, namely workforce and Covid-19, came to the fore, to varying degrees, when searching the literature. These are reflected below given that overall, they reinforce some of the barriers reported earlier in this chapter.

Workforce

3.34 There are marked differences in the proportion of the workforce from Black, Asian and minority ethnic backgrounds across the UK. Social Care Wales reports that in 2020, 3.5% of the domiciliary care workforce are from Black, Asian and minority ethnic backgrounds[46].

3.35 There is a body of literature on minority ethnic people who work in social care and the issues they face, or can face, in their work and careers. While this is outside the scope of this project, a 2020 study of the challenges for social work in a multicultural society does provide some useful perspectives from social workers:

- Communication problems caused by the lack of a common language.
- Communication problems caused by different codes of behaviour, in interactions with professional services.
- Cultural differences in parent–child relations.
- Health problems without adequate medical help available.
- Structural barriers which made it difficult to adapt the social service system to the needs of the minority clients

3.36 Taking the last point, a study by the Joseph Rowntree Foundation of care and support for older people and carers in Bradford[47], albeit in 2010, reported a strong sense that services were run for the convenience and budgets of service providers rather than for the benefit of the service recipients. In addition, older people's individual preferences were felt not to be acknowledged because of a lack of understanding and sensitivity to the influence of lifetime experiences and cultural background.

3.37 The study went on to say that many of the older people's individual desires and expectations related to their cultural and religious values and beliefs, as well as their experiences in childhood and early adulthood. The study concluded that both general and specific individual expectations need to be satisfied in order for services to be acceptable and appropriate for older people

3.38 The issue of how social care can adapt to, and work effectively in, a multicultural society is not new. Research back in 1979 asked how a whole professional system can adjust to the realities of working in a multi-cultural society[48]. It highlighted the need to assess the culturally specific values which underlie the everyday assumptions and practice of social workers. This can facilitate relevant training which can result in effective delivery for minority ethnic communities.

3.39 Cultural competence training is also seen by some to be particularly important in rural areas and areas with lower ethnic density, where skills or experience in relating to racial and ethnic minorities may be lower[49]. Practitioners may lack confidence in working with older people from minority ethnic communities if they work in areas where they are not regular users of services. This would seem to be particularly relevant in Wales.

Covid-19

3.40 The impact of Covid-19 on the whole population, on older people and people with underlying health problems, and on public services including social care, are well documented and are not repeated here.

3.41 Recognising the impact of the pandemic on people from minority ethnic communities, the First Minister established a BAME Covid-19 Advisory Group and commissioned a report. The group concluded it was clear that health and social care messages had not been effectively disseminated to minority ethnic communities and that health and social care is seen as more difficult to access, with cultural and language barriers[50]. It recommended a review of existing health and social care in partnership with minority ethnic groups, organisations and patients to evaluate appropriateness of service to improve future delivery and reduce health risks.

Accessing help and support

3.42 It is recognised that ethnically diverse populations present multiple challenges for delivering effective services and support[51]. Specific challenges include language and communication, understanding, and accepting ethnic differences between the client and social worker.

3.43 This chapter has outlined the issues which can be barriers to older people in minority ethnic communities receiving help. While most of the research relates to older people and health services or health and social care services combined, it is reasonable to accept that the barriers in social care itself are the same or similar. It is also reasonable to suggest that the barriers will be similar for all minority ethnic groups who access, or seek to access, social care. The project which is underpinned by this review of the literature will seek to clarify the barriers and how they affect people in practice.

3.44 Research quoted earlier in this chapter has found that people in minority ethnic communities experience more barriers when accessing health and social care services compared to White majority groups. Barriers include, but are not limited to:

- Discriminatory practices including fear of racism and discrimination.
- Unfamiliarity with the health and care system.
- Lack of knowledge about care and support, what is available and how to access it.
- Communication (on both sides individuals who need help and professionals).
- Mistrust, sometimes as a result of previous negative care experiences such as experiencing a lack of cultural awareness, language problems, or culturally sensitive information and services
- Religious and family issues
- Stigma

3.45 Many barriers are said to be unique to minority ethnic groups. They can prevent or discourage individuals from accessing care and support. In the case of health services, the consequence of delays in receiving treatment for conditions, can affect the level and nature of social care needed later. Avoiding the use of health and social care services throughout the life-course could potentially lead to more serious health problems in later life, which may, to some extent, explain ethnic health inequalities in old age[52].

3.46 The findings of some research raises questions about the current views of older people in ethnic minority communities on social care[53]. It has been stated some older people in minority ethnic communities had lost faith in major services, preferring services from, and provided by, voluntary groups in their own community. This included services in the social care sector or relevant to the delivery of care and support within it e.g. sheltered housing, day centres, interpreters, advocacy, and befriending services. There was a view that the best routes to support, and individuals' most positive experiences, had been when their own community voluntary organisations were adequately funded to undertake these tasks.

3.47 However, others felt that the funding of community voluntary organisations let the mainstream services "off the hook". They felt the mainstream services should be addressing these issues and knew that, when budgets cuts were on the table, it was the community voluntary services who were the first to lose out. It is reasonable to assume the impact of austerity measures because of reductions in public expenditure in recent years will have had a negative impact on the ability of services to provide such support or the extent to which they can provide it. The project will explore this.

3.48 In the context of relationships, community and family, the changing values between generations was also highlighted. This is true of the UK more generally, but research has pointed out the possibility of a generational gap accompanied by a cultural gap between older and young people in minority ethnic communities. This is seen as something which could leave older people living alone and feeling lonely and isolated.

3.49 In an effort to address reports that people who are Black, Asian or from another ethnic group often feel that they miss out on services they need, a study in 2021 constructed a social care pathway with 7 steps[54]:

1. Recognition of Need
2. Decision to Seek Support
3. Identification of Social Care as a source of support
4. First Contact
5. Continuation of Contact
6. Ongoing social care relationship
7. Appropriate fulfilment of Needs

3.50 Important contexts for the pathway were seen as:

- Awareness of services.
- Access to social care (information, contacts, referral and services).
- Acceptance of social care as an appropriate source of support.
- Communication.
- Trust.
- Informal/family support.
- Prominent causal mechanisms were navigation, recognition of the caregiver role, and responsiveness (no doubt the responsiveness of services) to emergent needs.

3.51 To the above list can be added the suitability of services and support. For example, a study in the South of England reported that social care day services and care homes were not well tailored to cultural and religious needs, particularly for the Asian community[55].

3.52 Within the broad context of how people from minority ethnic communities access services, it is also important to consider the “how?” i.e. what specific route is used to access, or to be put in touch with, social care.

3.53 In 2020-21 in one local authority in Wales, 2 out of every 5 contacts with adult social services (41%) came though health services, with a further 17% of referrals via the police. Self-referrals and referrals from a relative accounted for just over a quarter of total referrals (28%). This pattern of accessing social services highlights the importance of all public services ensuring they work effectively together in a multicultural society to meet the needs of people in minority ethnic communities. The same set of statistics showed that 7% of referrals to social services were made by other departments in the authority. Therefore, the findings of this project will be relevant to the full range of services delivered by local authorities not just social services, and to the NHS.

3.54 A key finding of research into satisfaction with social services was that many participants do not know how to ask for help from social care services[56]. In this study, four ways were identified in which people in South Asian and White British groups had come into contact with social services:

- Word-of-mouth, which was the most common. This is dependent on knowing the right people.

- Medically-focused e.g. via a GP. This was also fairly common but was not always successful.

- Enablers (organisations, groups)

- The “informed” – individuals who knew how to find out about services, and some used the internet. They had knowledge from past experience as a service user or carer, or from having worked for social services.

3.55 Considered in the context of this chapter i.e. older people in minority ethnic communities, the proportion of “informed” individuals is likely to be relatively small e.g. in respect of language issues and/or use of the internet. They may rely on family members, who may also be informal carers, to do this. The word of mouth route would also be less of an option where someone’s circumstances are characterised by isolation and loneliness.

3.56 The same study found both differences (e.g. languages) and similarities (e.g. the importance of care staff having a kind manner) between South Asian and White British service users and family carers. People with a good understanding of the social care system were more in control of their care. People with a poor understanding were uncertain about how to access further care, or why a service had been refused or withdrawn. More White British than South Asian people had a good understanding of the social care system and a good understanding of the social care system is an important factor in being able to access services.

3.57 This is backed up by research in Glasgow[57]. It showed the level of awareness of services among older people from minority ethnic communities is low. There was a lack of knowledge about how to go about accessing social services and a general lack of information about services. There was often reliance on other organisations like day centres, or word of mouth from others, to gather information. Research in 2016 suggested the personalisation agenda has added complexity with those who are cared-for and their carers taking on the role of employer and other administrative burdens[58]. It also argues the impact of austerity means that for many accessing care becomes increasingly difficult and costly.

4. Carers

4.1 While individuals in minority ethnic communities encounter barriers and other matters which affect their take-up of personal care and support, the position of carers in such communities is equally important.

4.2 A previous literature review has shown that most barriers reported earlier in this report are potentially relevant to all carers, irrespective of ethnic group. They include attitudinal barriers e.g. not wanting to involve outsiders in care of family members, not necessarily seeing the need for services, and practical barriers such as lack of awareness of services[59]. The review goes on to say:

- The number of carers from minority ethnic groups and their support needs are increasing, but they often fail to access services.
- There is some evidence that compared with the population as a whole, minority ethnic users tend to be less satisfied with social care services.
- Language and concerns about services' cultural and religious appropriateness are the main perceived barriers to accessing social care specific to minority ethnic carers.
- Other barriers identified by carers from minority ethnic groups are potentially relevant to all carers, irrespective of ethnicity. This highlights the importance of people understanding what help is available, and reducing barriers faced by all carers.

4.3 Studies investigating satisfaction with services reported a mixture of satisfaction and dissatisfaction. That said, the research quoted above also points to the dearth of research investigating satisfaction with social care and barriers to access among minority ethnic carers.

4.4 Research into carers for people with health problems, specifically stroke survivors[60], emphasise the vital role that informal carers, often family members, play in supporting post-stroke disability. As populations age, the numbers of carers overall and those from minority ethnic groups in particular, are rising. Carers from all ethnic groups, but especially those from minority ethnic groups, frequently fail to access support services. The research identified several interconnected themes including service gaps between hospital discharge and home and cultural aspects of caring and using services. Accessing services is reported as demanding effort and persistence on the part of carers. If carers believe services are unsatisfactory or that they, rather than formal services, should be providing support, they are unlikely to persist in their efforts. Cultural and language differences add to the challenges faced by minority ethnic carers.

4.5 Carers in ethnic minority communities are said to face particular difficulties in accessing and using support services, over and above those experienced by white carers[61]. Low uptake of services by carers from ethnic minority communities cannot be attributed to their lack of interest in receiving support. Many are unaware of the services that exist to support them. A lack of language-matched information is perceived as one of the greatest barriers to accessing services. This is reinforced by other studies of respite services[62] where low

uptake of respite services by carers may be accounted for by a general lack of awareness of the availability of these services but also where clear preferences for service delivery are not met.

4.6 Four main reasons put forward as reasons for low uptake of support by carers in ethnic minority communities are[63]:

- Services are not perceived as being needed e.g. carers felt that they already had adequate support.
- Service characteristics e.g. carers may want to use services but cannot because of factors such as cost or low availability; and lack of information about services.
- Reluctance to use services e.g. caring viewed as the role or duty of the family.

4.7 The last point above should be considered with some caution given a theme coming through in research reported in the previous chapter. The belief that people from minority ethnic communities will be looked after by families is not necessarily the case, and is seen in the context of stereotyping.

4.8 In seeking to improve the support available for carers in Black, Asian and minority ethnic communities, Carers UK puts forward a broader list of reasons for low take-up[64]:

- Stigma of caring for particular conditions, e.g. HIV or mental illness.
- Language and literacy barriers combined with a lack of knowledge of entitlements.
- Cultural barriers which hinder access to services. Notions of duty to care for relatives. Unacceptable to take outside help. Misconceptions about extended family support that may not exist.
- Fear of disclosing personal information, e.g. mental illness, HIV, addiction or domestic violence.
- Lack of culturally appropriate practical services.
- Black, Asian and minority ethnic communities are seen “as one” and yet are extremely diverse.
- Particular barriers faced by refugees.

4.9 Carers UK point out that Black, Asian and minority ethnic carers face the same challenges as all carers, but encounter barriers such as cultural barriers, stereotyping and language. These can increase the chances of them experiencing poorer health, poverty and social exclusion.

4.10 In a study of the literature on dementia care, anxiety and reluctance about letting other people come into the home to provide care or support was frequently reported[65]. The lack of choice was also a factor, with matching carers with clients by language, religion or gender being rare and hard to achieve. This means that care options are considered unacceptable in certain communities.

4.11 In Scotland, the Disability Rights Commission reported a feeling and concern that minority ethnic communities have to 'fit' into services rather than services being designed around their particular needs[66]. There was a sense that little had changed for people on the ground despite the enactment of equalities legislation and protestations of good intent.

4.12 Although some time ago, Mencap highlighted several factors which prevent carers from accessing or taking up support[67]. Some of these appear in more recent research. They include:

- Lack of information and knowledge of the services available to carers, the financial support they can get and how to get it.
- No understanding of how services operate and consequently what their rights are.
- Lack of knowledge of, for example, learning disability, how it affects the person they care for and what they can do to help.
- Lack of cultural understanding in social services.
- Receiving a poor-quality service from social services and, for those with a social worker, experience of a lack of consistency in the relationship.

4.13 Research by the Department of Health and Social Care in relation to Covid-19 noted the pandemic occurred against the backdrop of austerity and reduction in services alongside longstanding barriers to people from minority ethnic communities and their carers accessing services[68]. The work concluded that these combined led to the disproportionate impact of COVID-19 on minority ethnic communities. It also indicated a strong believe there was differential treatment in social care because of their race. For some involved in the study, the pandemic magnified existing differences.

Young carers

4.14 In considering the position of carers, due consideration must be given to young carers in minority ethnic communities. From the literature which could be accessed for this review, there appears to be little research specifically on the subject. However, in a study in 2019[69], Barnardo's concluded that the concept of a young carer is unfamiliar to many communities. Helping the family and extended family is something which is expected and often the impact on the child is not realised or understood. Often, families do not want agencies involved as there can be a deep mistrust of social services or authorities and they are fearful of families being split up. Young children were far too often being relied upon as interpreters often interpreting technical and deeply personal medical information between patients and doctors. This risks misdiagnosis and exacerbating anxiety within families.

4.15 The research went on to say families in Black, Asian and minority ethnic communities are more likely to be impacted by inequalities and adversities such as mental health issues, poverty and domestic abuse, which puts an additional strain on young carers within these households. Reflecting one of the themes highlighted in the previous chapter from research with adults, it also referenced stigma as a factor in acknowledging mental health and disability issues and in seeking support.

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5. Gypsies and Travellers

5.1 This section has been kept separate from the earlier section of the report because of the distinct characteristics of the Gypsy and Traveller community, namely as a collection of peoples who have a history as nomadic Irish Travellers, Roma, English Gypsies, Welsh Gypsies, spanning some 500 years.

5.2 The Equality and Human Rights Commission report "*Is Wales Fairer"* published in 2018[70] found that:

> *"Gypsy, Roma and Traveller families continue to experience difficulties in accessing quality health and social care services. Poor access to health and social care provision, combined with mistrust and reluctant uptake of health and social care services, has a negative impact on Gypsy, Roma and Traveller health and well-being."*

5.3 As a starting point, this is the only up-to-date official assessment of the challenges faced by the Gypsy and Traveller community in Wales. In fact, there is little specific research in the literature review applying to Wales, which identifies much in the way of policy development or service delivery consideration for this section of minority ethnic communities in the sphere of social care delivery.

Policy approaches

5.4 The Welsh Government's own plan "Enabling Gypsies, Roma and Travellers"[71], is quite detailed. It sets out the policy approach in health services, education, employment and the importance of sites. However, it is very light on social care, except for references to people facing abuse. It is likely that the pandemic in 2020/21 has put much of this work to one side. The Welsh Government set out some specific actions for improving health outcomes including.

- Ensuring Gypsy and Traveller Health Needs Assessments are conducted and results fed into service planning.
- The training of health practitioners on equality and cultural awareness to ensure barriers to healthcare for Gypsies Roma and Travellers are reduced.
- Developing a system to ensure central reporting of Gypsy, Roma and Traveller health outcomes to better understand inequalities and target support.
- Establishing mechanisms to promote sharing of good practice for the improved health outcomes of Gypsy, Roma and Traveller communities.
- Ensuring Gypsy, Roma and Traveller communities benefit from the Healthy Child Wales Programme to create the conditions for every child to have the best start in life
- Supporting Gypsy, Roma and Traveller communities to participate in sport and physical activity.
- Ensuring Gypsies, Roma and Travellers are considered in the development of a loneliness and isolation strategy.

5.5 What is difficult to assess is the extent to which policy approaches have succeeded at all. There appears to be a lack of case studies and information to say whether there have been improvements in engaging the Gypsy and Traveller community.

5.6 The other noticeable feature is that the Welsh Government's document does not contain a distinct section on social care, and it does not feature in the section on health. However, in a following section on being 'united and connected' there are a range of commitments to:

- Ensure the provision of high quality, accessible advice, information and advocacy services to enable Gypsies, Roma and Travellers to exercise their rights and make informed choices.

- Explore ways in which the relationship between social services departments and Gypsy, Roma and Traveller communities can be improved to ensure the needs and rights of these communities are understood.

- Support the recruitment of a wider pool of foster carers with Gypsy, Roma and Traveller backgrounds to ensure vulnerable children from these communities are able to maintain their cultural way of life.

5.7 An earlier Welsh Government document[72] set out a range of outcome measures for Local Health Boards to respond to by 2016, including:

- Establishing the knowledge and understanding of healthcare staff in relation to Gypsies and Travellers in terms of their cultural identity, using the results to develop further training within equalities training. It was recommended that such training was developed and monitored with Gypsies and Travellers themselves and organisations that work with them

- Working as appropriate with partner agencies, to have completed a first Health Needs Assessment of Gypsies and Travellers in their area and to have reported the results to Public Health Wales and the Welsh Government.

- Ensuring that as far as possible all healthcare staff had undertaken the *Treat Me Fairly* equalities training e-learning package developed by the NHS CEHR and NHS Wales.

5.8 To what extent these measures extended more broadly to other areas of public service provision is difficult to assess. The assumption is that health policy/ delivery has been prioritised above other areas, with local authorities having to ensure that they comply with the duties set out in the 2010 Equality Act and the Social Services and Wellbeing (Wales) Act 2014.

5.9 Much of the research seems to focus on key points for the profession. There are examples of local authority-based "plans" but many are generic in their explanation of the local authority's duties in law to all those in need or care and support, which includes Gypsies and Travellers.

5.10 Swansea Council's policy in 2017, for example, refers to efforts being made "*to ensure that services are culturally sensitive and equally accessible to Gypsies and Travellers*".[73] There is little else at a policy level which identifies key challenges or steps to be taken to engage this community.

5.11 The Scottish Executive[74] has a specific plan, which includes a range of actions across different services and a section specific to health and social care. The plan has been extended to October 2022 because of the challenges of the pandemic. It aims to improve access to services through:

- Working with Gypsy and Traveller communities to raise awareness of rights and entitlements.
- Ensuring that public services are responsive to Gypsy and Travellers' needs and preferences.
- Testing and sharing effective approaches to improving experiences of health and education services.

5.12 There is also an update letter from the Scottish Executive[75] in March 2021, which identifies ways in which they have been able to make progress more swiftly than anticipated because of the pandemic, as well as more slowly in some areas because of it. Some of the key highlights are:

- Being able to accelerate solutions to problems such as digital exclusion and the provision of online distance learning – 100 digital kits distributed to families by third sector partners.
- Providing information to Gypsies and Travellers on the pandemic through a Facebook information page, which has evolved into a wider part of their communications strategy.
- The Scottish Government funded third sector partners MECOPP to set up and run a Mental Health Community Support Telephone Service. This has been staffed by health care professionals, and was designed to best fit the Gypsy and Traveller community's needs.

5.13 Many of the challenges faced by the Gypsy and Traveller community mirror those which we have started to explain for the broader minority ethnic communities of which they are part. This chapter examines those articles, studies, and research pieces which set to explain the significance of the Gypsy and Traveller community, where those challenges to accessing care and support tend to be found, and the ways in which statutory bodies have attempted, sometimes without success, to engage that community.

5.14 Understanding the challenges, barriers and levels of access to social care and support first needs to be placed in the context of the history of the Gypsy Traveller community. Trust emerges and is sustained as a theme throughout the literature review. The challenges and barriers include mistrust rooted in their history, a lack of understanding of what services are available, and a disconnection with the language used by services in explaining their role when in contact with the Gypsy and Traveller community.

Challenges and barriers

5.15 The Gypsy and Traveller community is seen as an ethnic minority that has suffered some of the greatest of injustices for more than 500 years, which has affected whether, if at all, that community can trust the involvement of those in authority. Iriss fm[76], Scotland's social services podcast in June 2021 exposed the enormity of this challenge, outlining:

- How Gypsy, Roma Travellers are not a single group but arrive at that common term for travellers via different routes, they have different backgrounds, cultures and lifestyle.
- They have faced historic oppression and discrimination, poorer health outcomes, economic poverty and lower life expectancy.
- A level of cultural ignorance on the part of statutory services has led to inappropriate and misplaced interventions which means there is more importance which should be placed on professional judgement.
- The challenges of engaging have often been found in the issues of literacy barriers.
- Mistrust has its foundations in the forced removal of Gypsy Traveller children who were sent overseas as domestic and farm workers.

5.16 A distinct culture and way of life poses challenges to traditional services which struggle to respond to a community with a nomadic lifestyle. The cultural importance of family and resilience again is often at odds with the perception of the role of statutory services in intervening in people's lives to support them. Instead, the culture of stoicism and self-reliance means people tend to "make do", "not complain" and sometimes to improvise if aids and adaptations are needed[77].

5.17 Sarah Cemlyn[78] in research published in 2013 observes that the Gypsy Traveller community has a fraught relationship with services based on a fear of losing children to authorities, underpinned by historical experiences, threats, uncertainty, and the approach of social workers. She also alludes to the crisis response in child protection and youth justice, minimal community engagement / prevention, leading to further alienation, mistrust and damage.

5.18 Cemlyn also outlines barriers which include a lack of realistic and accessible information about services, the fact that social services tend to be geared towards sedentary lifestyles, a failure to respond to frequent movement of families, which has led to a neglect of children's needs. She also talks of the neglect / avoidance of wide issues facing Gypsies and Travellers, despite social work values.

5.19 On a more positive note, her study, which includes references to several sources, does consider some developments which have helped to respond to the challenges, and address the barriers. In particular she refers to a few authorities taking "*a proactive children's rights approach re unauthorised camping, or a reactive approach that developed through advocacy*". In addition, she highlights social work projects demonstrating outreach, engagement, advocacy, multi-agency development, resulting in the building of trust. She is also clear that more research on good practice is needed.

Disability

5.20 A research study[79] on disability and Gypsy Travellers led by DRILL (Disability Research on Independent Living and Learning) UK, examined how the voice of disabled people is absent from the policy development and literature based within the Gypsy Traveller community. The report from 2020 identifies a lack of knowledge about disability within the community, historic shame and stigma associated with disability was changing but where men were

more reluctant to seek help, a general consensus that Gypsy Traveller communities prefer to care for their own, based on stoicism and a distrust of traditional authorities. Those contributing to the study also reported numerous examples of previous poor access including: language issues, problems booking with GPs, attitudes of front line services.

Older people, dementia and end of life care

5.21 A prevalent theme in the research is the strength of family, community and preferring to support each other. This is especially true of the older generation. “We look after our own: Dementia in Gypsy and Traveller communities” by Samson Rattigan and Sarah Sweeney[80] found that campaigns raising awareness about risk reduction activities to prevent dementia are often not reaching Gypsy and Traveller communities, where a significant number of Gypsies and Travellers would not attempt to access support for dementia because they feel that they would not receive culturally appropriate care.

5.22 The report also outlines how a majority of Gypsies and Travellers share a strong preference for carers from within the Gypsy and Traveller communities. This is borne out in an article in The Carer[81] in March 2021, which highlights the perspective of the author who also has Gypsy Traveller roots. The opinion piece refers to the issue of service accessibility, the continued lack of understanding of cultural needs, and outlines some steps which should be helpful in addressing the problem. In improving the accessibility of services the piece states that the care sector must show a greater willingness to understand their way of life, customs and traditions that define who they are as a people.

5.23 The Care Quality Commission paper in 2016 “*A Different Ending: Addressing Inequalities in End of Life Care*”[82], states a lack of cultural understanding, an inability to understand cultural needs and unequal access to services as the major challenges. The report explains how an organisational lack of familiarity with people’s cultural preferences can be a barrier for people from minority ethnic groups, Gypsy and Traveller communities and others, and that commissioners and services in most areas had done very little to reach out to some parts of their community, including LGBT people, the Gypsy and Traveller community, and homeless people.

5.24 Delivering effective change in service provision is problematic because guidance from organisations such as the Care Quality Commission doesn’t filter to down to the front line of service provision. Because there are few Gypsy Traveller people accessing service, it makes it harder to get a critical mass of information for professionals to develop a level of understanding. It is also important for the development of pre-assessment communications tools to engage the community, and the care sector needs to work harder to create activities and care plans, which are specifically designed to draw out cultural, spiritual, social, personal and life history.

5.25 Many of these themes are picked out in a report from Action for Carers Surrey[83] which confirms the challenges that many carers face including how the role is less recognised in the Gypsy Traveller community, less valued, and that it can be culturally hard to look outside for help, especially if the person being cared for has mental health or addiction issues. Again, we find the issue of pride in self-reliance and keeping things within the community which can make it extra hard for carers.

Children and those in care

5.26 One of the significant features of the distrust in traditional services is rooted in the involvement of children's services. proportionately there is a high number of Gypsy and Traveller children in care[84] and that this has been steadily growing as the following data from 2009 to 2015 for England demonstrates:

Table 4: Gypsy and Traveller children in care, 2009 – 2015

	2009	2010	2011	2012	2013	2014	2015
Total "in care" population	60,910	64,460	65,520	67,080	68,110	68,840	69,540
Traveller of Irish heritage	30	40	40	50	60	70	90
Gypsy / Roma*	30	60	90	120	180	210	250

Source: Supporting Gypsies, Roma And Travellers Understand Social Work Involvement. Published by the Travellers Times, December 2015
Note: * From 2016, the ethnicity of Gypsy / Roma was split to reflect diversity and the fact they are two distinct groups.

5.27 Sarah Tweeny[85] observes that in children's services, the challenge of nomadism is that travellers encounter services across local authority boundaries and that those responsible for children's services when allocating the responsibility for vulnerable children to local authorities, "*policy makers unintentionally neglected to consider the nomadic habits of Gypsies and Irish Travellers in their care planning rationale*". Although the work was based in England around the application of the Children Act 1989, pre dating Social Services and Wellbeing (Wales) Act 2014, it was clear that there was no elaboration in the Children Act 1989 outlining a process to be followed for children who regularly move between local authority boundaries.

5.28 Such a legislative gap could result in two conflicting risks. Either, the over-involvement of professionals, who too speedily take action whilst children are in their area of care, or ignorance of Gypsy and Traveller issues leading to the needs of children being left unmet.

Support for practitioners

5.29 One of the key features of the research has been the effort made to equip professionals in supporting their work to engage that community. There are a range of examples of reviews and plans elsewhere in the UK which seek to address the deficiency in the way that historically this community has been engaged.

5.30 Some professional bodies such as the Royal College of General Practitioners[86] have attempted to consider the role of commissioning when planning services for Gypsies and Travellers including:

- Information sharing between different agencies as a key factor in improving access for Gypsies and Travellers, especially given their high mobility and complex needs.

- Community engagement is important for professionals to establish a relationship with the wider network of people, and makes sure that a trusted relationship is gradually set up. This would also contribute to the design of a service that meets the community's perceived need and develop a sense of ownership.

- How travellers do not want dedicated services, but would much rather be able to access the same high quality services as everyone else, which will also reduce 'singling out'

5.31 A report by the Royal College of General Practitioners sets out the following suggestions for practical steps to better address the barriers of accessing services including:

- Outreach: helping to establish a connection to local communities, in order to build the initial relationship and raise awareness among travellers on the range of services available.

- Mobile units and clinics: whilst bringing services directly to sites might be a way to establish some rapport, it does not ultimately help fostering integration in mainstream services. Community building and health education are positive alternatives.

- Patient access: due to the high mobility of these patients, accessible records and interoperability of care records software will be of great benefit to the continuity of care.

- Peer-education: a valuable means to get access to strong communities, gaining the trust of community leaders and role models can be very beneficial to reach out to the wider group, and gradually challenge some health beliefs and behaviours.

- Cultural awareness training: Gypsies and Travellers are often targeted by traditional forms of racism, the cultural competence of all frontline staff, including receptionists, is crucial to accommodate their specific needs.

5.32 The Social Care Institute for Excellence[87] has published a range of useful resources to evidence where attempts have been made to improve social work practice and the understanding of those responsible for policy decisions and service design. Its article "*Gypsy Travellers: Human rights and Social Work's role*" is based on work in Scotland, setting out how using a human rights approach can improve practice with the Gypsy Traveller community.

5.33 It examines the history and culture of Gypsy Travellers in Scotland, and how a better knowledge and understanding can lead to better valuing of a different culture. It identifies challenges faced by the Gypsy Traveller community, such as racial discrimination and prejudice, and the barriers they face in accessing services. It provides an overview of the Scottish Government framework, incorporating a human rights perspective on how culturally sensitive services, including social work, should be delivered to Scottish Gypsy Travellers. Drawing on examples from practice in Scotland and in other countries, it then looks at how services to Gypsy Traveller communities could be improved. Suggestions include a specialist Scottish Gypsy Traveller advocacy service, the promotion of awareness training, and for regulatory and inspection bodies to consider culturally sensitive practice in their scrutiny functions and findings.

5.34 Similarly, their video resource[88] on Gypsies follows a Gypsy Traveller as it explains how Gypsy Travellers are the largest ethnic minority group in many local authorities,

encountering high levels of stigma and discrimination, and barriers to accessing services linked to their nomadic lifestyle and culture. The suggestion is that Gypsy Traveller specific organisations are best placed to help with this problem, and that social care workers from Gypsy Traveller backgrounds have an advantage when it comes to gaining the trust of their service users.

5.35 Research in Practice, which brings together academic research, practice expertise and the experiences of people accessing services, published an online article89 in 2016 setting out how an improved understanding and awareness of the cultures and traditions within professional circles is necessary to ensure children at risk of harm are identified correctly, support provided to families is appropriate, and has the best chance of achieving its aim. The conclusion of the report sets out a number of measures which can be implemented to address the challenges for professionals particularly in children's services:

- Learn more about Gypsy and Traveller culture – to improve communication with Gypsy and Traveller families and learn to provide culturally appropriate support.

- Engage in cross-boundary collaborations. It is crucial for the wellbeing and safety of Gypsy and Traveller children that authorities and agencies involved in delivering care or support to "at risk" children begin to work more collaboratively across geographical boundaries. This means taking the initiative to communicate with Children's Services colleagues in other areas of the country and working together to support the needs of vulnerable children.

- Ensure culturally appropriate care for Gypsy and Traveller children. There is currently an absence of care placements which recognise and support the distinct cultural identity and needs of Gypsy and Traveller children. A shortage of Gypsy and Traveller foster carers means that children from these communities are often placed with people who may have little or no understanding of the child's background or culture. This can have major implications on the child's development and sense of cultural identity.

- Engage with other aspects of social services. A growing base of anecdotal evidence gathered through casework at *Friends, Families and Travellers* suggests parents experiencing domestic violence in Gypsy and Traveller communities may be hesitant to come forward because of fear of Children's Services involvement and that they will be separated from their children. Steps should be taken to ensure that parents and children are placed together, which both benefit the wellbeing of the children involved and also ensures that the adult victim of domestic violence does not doubly suffer.

- Consider the history of social services' engagement with Gypsy and Traveller families. Some members of the Gypsy and Traveller communities are suspicious of social workers and fear that professionals will take their children away from them. The source suggests asking the client if they would like to have an advocate from a local Gypsy and Traveller group or a trusted friend to join them in meetings and to offer additional support. In practice, the fear and suspicion some members of the Gypsy and Traveller communities have towards Children's Services can only be counteracted by building trusting and understanding relationships.

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6. People with learning disabilities

6.1 The prevalence of learning disabilities among some minority ethnic communities is said to be as much as three times that in communities which represent the majority of the population[90]. Affected individuals have been said to face a double disadvantage, arising from having a learning disability and being from an ethnic minority group[91]. More recent research concluded that Asian pupils (Indian, Pakistani, Bangladeshi and Other Asian) are half as likely to be identified with Autistic Spectrum Disorders as White British pupils, and Black Caribbean and Mixed White and Black Caribbean pupils are twice as likely to be identified with Social, Emotional and Mental Health needs as White British pupils[92].

6.2 A report by the Department of Health[93] said people with learning difficulties from minority ethnic groups and their families often face what is called “double discrimination”. They experience insufficient and inappropriate services, which may be caused by policy and services which are not always culturally sensitive, and wrong assumptions about what certain ethnic groups value, language barriers, and discrimination.

6.3 In 2020, the Race Equality Foundation[94] said the experience of carers, some of whom themselves have a learning difficulty, tends to be made worse by the low priority given by agencies to race equality, with institutional barriers and culturally inappropriate support and services often being overlooked as reasons for the low take up of mainstream services.

6.4 There is a variety of barriers for people with learning disabilities or their families and carers accessing services and support[95,96,97,98]. There is much in common with the barriers identified in previous chapters:

- Lack of accessible information regarding both learning disabilities and the support services available to them, and language barriers, which can be complicated by the use of jargon and complex medical terms.
- Lack of equivalent term for learning disability in some languages, leading to lower understanding e.g. low knowledge of autism or beliefs that it is a curable condition.
- Lack of culturally appropriate services in terms of, for example, respite provision, mixed gender activities and dietary needs. “Patchiness” of some services provision.
- Role of the family dynamics in determining engagement with services.
- Stereotyping - viewing minority ethnic communities as a single, homogeneous group, thus overlooking differences within and between communities.
- Lack of social contact: the taboo of same and blame attaching to learning disability in some communities results in parents receiving very little support from within their communities.
- Difficulty understanding the system: “I don’t know what the rules are and I do not know who can tell me the rules”.

- Lack of confidence, or feeling intimidated, when communicating with professionals, and being unnecessarily suspicious of professionals and authorities. Also, the attitudes of some professionals e.g. making assumptions about families, family circumstances, and intellectual capacity due to language difficulties.

6.5 They have been reports of families having problems dealing with professionals who, in some cases, demonstrated low levels of autism awareness and a lack of cultural competence[99]. This led to misunderstandings with parents and carers. There have also been suggestions that people from minority ethnic communities actively avoiding contact with support and services because they are wary of professionals and public bodies. Similar problems may occur in relation to engaging with local support groups e.g. autism groups.

6.6 A lack of understanding was a strong feature of one study, which included the quote "*We don't know the system. We're going round in circles*"[100]. It reported the following needs:

- Effective identification of the needs, concerns and aspirations of different local communities.
- Making sure people understand what is available and how local systems work.
- Getting to grips with personalisation of services.
- Developing local responses with community organisations.
- A competent workforce.
- Working together.
- Being able to measure the impact of policies and practices on different minority ethnic communities.

6.7 Families from minority ethnic communities gave a consistent message that too many staff from statutory agencies:

- Do not follow up the action they have agreed and effectively lack professional ownership.
- Are reactive rather than planning ahead with the family.
- Do not ensure families have the right information to pursue matters themselves, effectively keeping people disempowered.
- Move on too quickly to enable a proper degree of mutual trust and understanding to be developed (i.e. continuity of care).

6.8 It has been said, albeit in more than a decade ago, that many services did not have special policies to follow but just relied on good managers and staff to ensure services were provided to staff from ethnic minority communities[101]. A core theme at the time was that meeting the needs for people from minority ethnic communities was marginalised.

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7. Key issues and themes

7.1 There is a considerable body of literature on ethnicity in all aspects of society, particularly healthcare, which has been the subject of considerably more research than social care. Literature on minority ethnic groups and health was not necessarily excluded from this literature review given some of the issues on access to, and take up of, services are the same, or similar to, those for social care. This review has been constrained by the resources available for it and the inability to access some journals, for which subscriptions are needed. Nevertheless, the selective literature has covered considerable ground and provides a solid foundation for the project.

7.2 Drawing on the results of the review, this section highlights key themes emerging from the literature review. These will inform the subsequent stages of the project, including the programme of engagement which will explore the key issues as they apply or are experienced in Wales. Ultimately, they will help shape the action which will need to take place as a result of this project.

7.3 There is much in past research to suggest that in broad terms, people from minority ethnic communities are underrepresented as users of social care services and support. There are also gaps in knowledge of the current position in many areas. Inevitably, research tends to be focused on parts of the UK where there are relatively large populations and communities. Much of the research in this report was undertaken between 2000 and 2015, with relatively little more recent research. The latter may be partly due to the lack of access this project had to academic research databases.

7.4 The need for more action to improve access to, and future delivery of, services and support for people from minority ethnic communities is clear from work commissioned by the Welsh Government during the pandemic. It concluded health and social care messages had not been effectively disseminated to minority ethnic communities and that health and social care is seen as more difficult to access, with cultural and language barriers

Barriers to accessing and taking up social care

7.5 For practical reasons, the literature review was undertaken in four parts: barriers to social care for people from minority ethnic communities, carers, Gypsy and Traveller communities, and people with learning disabilities. While the results are reported separately in the previous chapters, they have much in common as far as the type and nature of issues and barriers, which affect their take-up and use of social care and support.

7.6 Barriers are defined in different ways by various studies but by way of a summary drawn from information in the previous chapters, the following is an expanded list of the main reasons why people from minority ethnic communities do not access, or try to access, social care services and support (in no specific order):

- Language – particularly where English is not someone's first language, which means reliance on others – family, friends, or professional interpreters – to translate in personal or written communication.

- Information – lack of information in a language and format suitable for an individual, and inability to access it if there is overreliance on digital delivery.

- Communication – the way someone working at every point in the social care system, irrespective of role, interacts with people from ethnic minority communities. Issues include understanding of, and sensitivity to, cultural and religious differences.

- Knowledge and awareness - what services are available and rights and entitlements e.g. under the Social Services and Well-being (Wales) Act 2014, and how to access services.

- Understanding – of the organisations which commission and /or provide social care and support, how they operate and how the "system" works. Might also relate to specific conditions such as dementia, for which there is no equivalent word in some languages.

- Design of services and support or elements of it – which do not reflect the variation in cultures and beliefs between different minority ethnic communities, or which for older people in particular may not be available in an individual's first language.

- Culture, beliefs, and values – which can affect the acceptance of help, particularly if considered inappropriate, and expectations of care and support.

- Attitudes, assumptions, and stereotyping – including possible misconceptions of the informal support and care available to people in minority ethnic communities e.g. care from the extended family might not always be available; loneliness and isolation might be overlooked.

- Experience – particularly where a person or family member has encountered problems or difficulties in obtaining help in the past, and had a bad experience in the type of care provided or the way in which it was provided e.g. lack of cultural awareness, language problems, or culturally sensitive information and services.

- Lack of trust and / or confidence – in public authorities and the "official" or "formal" dimension of some of their work, or of "outsiders" being in someone's home to provide care and support.

- Stigma – which might be directed at an individual by others, or which might be on the part of the individual themselves. Could be related to specific conditions such as Alzheimers or learning disabilities.

- Discrimination – the possibility of systems and practices which discriminate, intentionally or unintentionally, and individuals' fear of racism and discrimination.

7.7 The above are not mutually exclusive. There are overlaps between many of the above and interdependencies e.g. language, information, communication, cultures, beliefs and understanding. For this reason, a holistic approach is needed if action to encourage greater take-up and use of services by people from minority ethnic communities is to be effective.

7.8 The effects or impacts of the barriers can also be exacerbated by broader issues of poverty, where people live and the local infrastructure e.g. the location of services and transport, and education.

Action to address barriers

7.9 There may be a case for greater emphasis and/or action to address some of the barriers, depending on local circumstances, past action, and what is already in place to address the issues. However, to be effective, action must cover the range of barriers or potential barriers highlighted above. Taking action on one issue but not another could undermine its effectiveness and impact e.g. promoting services and support and how to access them without ensuring members of staff who will come into contact with a person, at every stage in the process, are well informed on cultural issues and beliefs puts at risk the acceptance and/or take-up of care and support.

7.10 A greater emphasis on action to increase the take up of social care by people from minority ethnic communities is good. However, this must be accompanied by the recognition of the differences between different minority ethnic communities. A “one size fits all” approach will not work for elements of the action needed.

7.11 Research referenced in Chapter 3 produced a 7-step pathway as part of work to address the possibility of people from minority ethnic communities missing out on care and support. Below is an enhanced version of the pathway. It has been expanded to highlight more of the specific steps involved before or during contact with social care and to include action to address some of the broad barriers, which were highlighted earlier in this Chapter. It has also been adjusted to reflect circumstances in Wales.

Table 5: Steps in an enhanced pathway for access to, and take-up of, social care and support

1.	**Knowledge and understanding** of the social care system in Wales (a universal need for individuals, family members, and people in communities)
2.	**Recognition** of need
3.	**Acceptance** of the need for care and support (care and support other than that provided by family or friends)
4.	**Identification** of social care as a source of support
5.	**Knowledge** of how to make contact / how to access help
6.	**Decision** to seek help or to seek more information about help available
7.	**First contact** with social care department or Information, Advice and Assistance single point of access (which may be made by the individual who needs to support, or a family member or friend on their behalf)
8.	**Knowledge** of rights and entitlements
9.	**Assessment of need, outcome(s), and response** from social services (in line with duties under the Social Services and Wellbeing (Wales) Act 2014)
10.	**Provision** of an appropriate package of care and support
11.	**Ongoing delivery** of social care and relationship with provider
12.	**Positive outcomes** and fulfilment of needs

Source: Developed from a 7-step pathway in Preston (2021) Diversity and inequalities of access in social care - Social Care Access for BAME and LGBT+ populations: a rapid realist review. National institute for Health Research

7.12 The above is not entirely a linear process. There is a cyclical element to the stages after initial assessment of need and provision of care and support, which is informed by periodic reviews of needs and further developments caused by possible changes over time in a person's condition and needs.

7.13 The above steps are relevant to individuals who need help and to individuals who may seek help on behalf of someone. This may be a family member (who may or may not be the person's carer), a friend or, in the case of young people with learning disabilities, a parent. Barriers or difficulties can occur at any step in the pathway. The precise nature of those barriers will vary according to the specific circumstances of the person who needs help. One example is language in the case of an older person whose first language is not English. Another example could be transport to access support such as a day centre or support group where the person from a Gypsy and Traveller community is living on a remote site which does not have public transport links. Where there is a cost to the care and support, affordability could also present a difficulty.

7.14 Without further action to address the key issues which are within the control of social care organisations – commissioners and providers - at all points in the above, there is scope for things to go wrong, resulting in a reluctance to take up support or to withdraw from it. The barriers identified in this report, and the findings of the review of the regional population needs assessments and wellbeing plans covered earlier in this report, suggests there is much more to do, hence the importance of this project.

7.15 It would be wrong to look at future action and development as only for social care. If it is to have maximum impact and benefits, parallel action must be taken by the NHS in Wales. As stated in a previous chapter, in one local authority, 2 out of every 5 referrals to adult social services came via health services, which may be primary or secondary. While it is not known how many people from minority ethnic communities are included in those figures, it does highlight an important consideration. The first step of the route or potential route into social care is by no means always direct to social services. The NHS is one intermediary step. Others could be third sector community and voluntary organisations, housing organisations, and the police. The way those services are delivered, their sensitivity to and understanding of cultural issues and beliefs, the explanations given about social care and support and the possible need for it, and the way referrals are made and actions by social services, can all affect an individual's propensity to take up social care and support.

7.16 There are several channels through which people will receive information about social care. These include the person themselves finding and obtaining information (if they are able to without difficulties of language or access to information via IT). They also included family and friends, other professionals (e.g. GPs), people in communities including community groups and organisations. "Word of mouth" is a common way in which people find out about services but could sometimes be a negative influence if the other person or persons have had difficulties with seeking social care previously or a bad experience of receiving it. Third sector and community organisations can play an important role in ensuring greater awareness of social care services and people's rights and entitlements, whether as an individual or as an informal carer.

Appendix 1: Search terms

The following is a list of the main search terms used in the literature review. Some searches were conducted on individual words but the majority were conducted on combinations of words e.g. “ethnic minorities + social care”. The literature which could be accessed was also used to identify more potential sources of research – research themes or organisations publishing reports and other information – which were followed up.

- Ethnic
- Ethnicity
- Minority
- Minorities
- Social care
- Social services
- Black, Asian and minority ethnic
- BAME
- Access
- Inequalities
- Barriers
- Challenges
- Older people
- Wales
- Gypsy
- Travellers
- Learning disabilities

Appendix 2: Needs assessments and wellbeing plans

The table below summarises the key findings from a rapid review of population needs assessments and wellbeing plans prepared in accordance with the requirements of the Social Services and Wellbeing (Wales) Act 2014. A rapid review was undertaken of the population needs assessments and wellbeing plans using a selection of word searches for “ethnic” “minority”, “race”, “BAME” and “BME”.

Region	Main points identified
Cardiff and Vale of Glamorgan[102],[103],[104]	Joint population assessment cited Cardiff is by far the most ethnically diverse local authority area in Wales. Arabic, Polish, Bengali and Chinese are the four most common languages spoken after English and Welsh. Higher levels of poverty among some minority ethnic groups. Higher incidence of violence, abuse and harassment against ethnic minority people and Muslim people. Gap in knowledge of on effective interventions for minority ethnic communities to tackle loneliness and isolation. Need for increased timely access to low level mental health services; joined up information, advice, and services, especially among people with dementia and some BME groups. Gaps in data on ethnicity within mental health databases for community and inpatient care. Separate wellbeing plans. No references to ethnic groups in Vale plan. Cardiff plan commitment to deliver public and third sector services and workforce that are representative of the city and its communities, especially Black, Asian, and Minority Ethnic communities
West Wales[105],[106]	Reported the Black and minority ethnic population was slightly less than 2% of the total population (approximately 8,100 people), which was less than half of the average for Wales). It did, however, acknowledge that since the 2011 Census, there has been inward migration. It highlighted a lack of consistent data to inform our understanding of some groups within the population, including Black and minority ethnic groups, but it did report rates of caring amongst among this part of the population were significantly lower – around half - than for the whole population, around half that of the general population. This was considered partly explained by the lower age profile found in Black and minority ethnic groups. Action plan appears to have one reference to Black and minority ethnic groups (among other groups), which relates to violence against women, domestic abuse and sexual violence.
Western Bay[107],[108]	Information and communication tailored to ethnic minority groups considered to be under-developed. Need to recognise the information needs of Black and Ethnic Minority Groups in Swansea, with the need for public service staff to be more aware of cultural issues in supporting carers from Black and minority ethnic groups. Higher prevalence of hearing impairment in Black and minority ethnic communities. Certain vulnerable population groups including minority ethnic communities may need more help to access the care and support they need. Far more focused work is required to understand, at a strategic level, the needs of the population of Western Bay. Significantly more work is required to improve knowledge on subjects and cohorts, including ethnicity.
Cwm Taf[109],[110]	No references to minority ethnic groups in population assessment or wellbeing plan

Region	Main points identified
Powys[111],[112]	In the North of the county, there appears to be a higher-than-expected incidence of referrals involving people in Black and ethnic minority groups. This was seen as a possible a statistical anomaly but more research into the data was needed. Gap in ethnicity data for carers but was reported to have improved. No references to action in the well-being plan.
North Wales[113]	Black and minority ethnic groups often more at risk of conditions such as glaucoma and may not access health messages due to language or cultural barriers. Future work needs to consider different issues affecting (amongst others) Black, Asian and minority ethnic people and a person's religion and beliefs. Risk factors for poor mental health disproportionately affect people from higher risk and marginalised groups including (amongst others) Black and ethnic minority individuals. Gap in specialist support, e.g. floating support, for Black and ethnic minority people, but ethnicity is not a barrier to support. Support needed for Black and minority ethnic people that cannot be met by support services such as BAWSO. More cases than expected involving BME people where multi-agency risk assessment conferences held to share information on highest risk domestic abuse cases. Better training for care workers to meet needs and support for people with challenging behaviour with no family members, and for people from minority groups such as Polish, Chinese, Indian and Sri Lankan people. Although numbers are very low, cases are increasing gradually over time. Reference to national research showing that ethnic minority elders are more likely to suffer discrimination in accessing services. The Minority Ethnic Elders project has sought to influence statutory and voluntary organisations to provide better services in North Wales. Barriers identified include interpretation and translation support. Wellbeing plans published by two individual authorities and two others each covering two local authorities (individual reports not referenced). Word search did not reveal any actions for ethnic minority issues.
Gwent[114]	Newport has the second largest number of people from minority ethnic communities of all the Welsh counties (after Cardiff). Ethnicity is important issue because, as well as having specific needs relating to language and culture, persons from ethnic minority backgrounds are more likely to come from low-income families and suffer poorer living conditions. Evidence shows that people from some ethnicities are 6 times more likely to experience sight loss but are less likely to engage. Action plans for 2018-2023 prepared individual by local authorities in the region (individual reports not referenced). Word search did not reveal specific action for Black and ethnic minority groups.

References

[1] Welsh Government (2018) A Healthier Wales: Our Plan for Health and Social Care. Cardiff: Welsh Government

[2] Parliamentary Review of Health and Social Care (2018) A Revolution from Within: Transforming Health and Care in Wales, Final report.

[3] Welsh Government (2017) Prosperity for All: The Welsh Government's well-being objectives. Cardiff: Welsh Government

[4] Welsh Government (2020) Strategic Equality Plan 2020-2024: Equality aims, objectives and actions. Cardiff: Welsh Government

[5] Welsh Government (2021) An Anti-Racist Wales: The Race Equality Action Plan for Wales. Cardiff: Welsh Government

[6] Coronavirus (COVID-19) and the Black, Asian and Minority Ethnic (BAME) population in Wales (2020) Cardiff: Welsh Government

[7] Vickers, T., Craig, G., Atkin, K. (2012) National Institute for Health research Methods review 11

[8] Szczepura, A. Access to health care for ethnic minority populations (2005) Postgraduate Medical Journal Vol 818 Issue 953

[9] Butt, J. and O'Neill, A (2004) Let's Move On: Black and minority ethnic older people's views on research findings York: Joseph Rowntree Foundation

[10] Equality and Human Rights Commission (2018) Is Britain Fairer? The state of equality and human rights. London: Equality and Human Rights Commission.

[11] Equality and Human Rights Commission (2018) Is Wales Fairer? The state of equality and human rights. Cardiff: Equality and Human Rights Commission.

[12] Public Health Wales (2020) How are we doing in Wales? Public Health Engagement Survey on Health and Wellbeing during Coronavirus Measures: A focus on ethnicity

[13] Welsh Government (2021) Population Needs Assessments - Supplementary Advice to Regional Partnership Boards.

[14] Getting in on the Act (2017) The main principles underpinning the Act: voice and control, prevention and early intervention, well-being, co-production and multi-agency. Social Care Wales

[15] Social Care Wales (2017) Care and support in Wales: National Population Assessment Report. Cardiff: Social Care Wales

[16] Barnard, H. and Turner, C. (2011) Poverty and ethnicity: A review of evidence. York: Joseph Rowntree Foundation

[17] Winckler, V. (Ed) (2009) Equality issues in Wales: a research review. Bevan Foundation research Report 11 Equality and Human Rights Commission

[18] Harries, B. Harris, S., Hall, N., Cotterell, N. (2019) Older BAME people's experiences of health and social care in Greater Manchester: lessons for policy and practice.

[19] Moriarty, J. (2008) Better Health Briefing Paper 9 Race Equality Foundation

[20] Butt, J. and O'Neill, A (2004) Let's Move On: Black and minority ethnic older people's views on research findings York: Joseph Rowntree Foundation

[21] Szczepura, A. Access to health care for ethnic minority populations (2005) Postgraduate Medical Journal Vol 818 Issue 953

[22] Moriarty, J, (2005) Update for SCIE best practice guide on assessing the mental health needs of older people Social Care Workforce research Unit Kins College London

[23] Moriarty, J. (2008) Better Health Briefing Paper 9 Race Equality Foundation

[24] Implementing promising community interventions Chapter 23 Community Tool Box online

[25] Unit 1 Health, Social Care and Children's Services
Online resource – Education? Compulsory Unit for Single and Double Award
http://resources.hwb.wales.gov.uk/VTC/2012-13/22032013/hsc/eng/unit_1/u1-a-and-b/u1-a-and-b1.htm

[26] Moriarty, J. (2008) Better Health Briefing Paper 9 Race Equality Foundation

[27] Black and minority ethnic older people's views on research findings (2004) Butt, J. and O'Neill, A. JRF

[28] Harries, B. Harris, S., Hall, N., Cotterell, N. (2019) Older BAME people's experiences of health and social care in Greater Manchester: lessons for policy and practice.

[29] Calanzani, N., Koffman. J., Higginson, I.J. (2013) Palliative and end of life care for Black, Asian, and Minority Ethnic groups in the UK (2013) London: King's College, Marie Curie Foundation, Public Health England

[30]Greenwood, N. Habibi, R., Smith, R., Manthorpe, J, (2015) Barriers to access and minority ethnic carer' satisfaction with social care services in the community: A systematic review of qualitative and quantitative literature in Health Soc Care Community 23(1):64-78.

[31] Harries, B. Harris, S., Hall, N., Cotterell, N. (2019) Older BAME people's experiences of health and social care in Greater Manchester: lessons for policy and practice.

[32] Moriarty, J. (2008) Better Health Briefing Paper 9 Race Equality Foundation

[33] Stuart J. (2006) SCIE Race Equality Discussion Paper 01: Will community-based support services make direct payments a viable option for black and minority ethnic service users and carers? Social Care Institute for Excellence

[34] Butt, J. and O'Neill, A (2004) Black and minority ethnic older people's views on research findings York: Joseph Rowntree Foundation

[35] Calanzani, N., Koffman. J., Higginson, I.J. (2013) Palliative and end of life care for Black, Asian, and Minority Ethnic groups in the UK (2013) London: King's College, Marie Curie Foundation, Public Health England

[36] AWEMA (2003) in Radical Statistics Issue 100 17 Willis Myths and statistics: An exploration of the assumptions connected to ethnicity and family support Rosalind Willis

[37] Vickers, Tom and Craig, Gary and Atkin, Karl (2012) Research with black and minority ethnic people using social care services. SSCR methods review, 11. NIHR School for Social Care Research, London, UK.

[38] British Psychological Society ( ) Evidence briefing: Dementia, accessibility and minority groups

[39] (Hubert, 2006) In Harries, B. Harris, S., Hall, N., Cotterell, N> Newcastle Univsity, Manchester University (2019) Older BAME people's experiences of health and social care in Greater Manchester: lessons for policy and practice

[40] Chalal, K. (2004) Chahal K and Ullah A (2004) Experiencing ethnicity: discrimination and service provision, York: Joseph Rowntree Foundation

[41] (2020) Older ethnic minority adults have fewer close friends UCL Institute of Education

[42] Cox, C.B., Ephross, P.H. (2009) Ethnicity and Social Services Oxford scholarship Online

[43] Owuor, J.O.A., Nake, J.J. (2015) Internalised stigma as a barriers to access to health and social care services by minority ethnic groups in the UK. Better Health briefing Paper 36 Race Equality Foundation

[44] Moriarty, J, (2005) Update for SCIE best practice guide on assessing the mental health needs of older people Social Care Workforce research Unit Kins College London

[45] Moriarty, J., Sharif, N., and Robinson, J. (2014) SCIE Research briefing 35 Black and minority ethnic people with dementia and their access to support and services.

[46] Social Care Wales (2020) Domiciliary care workers on the register. Social Care Wales online

[47] Cattan, M., and Giuntoli, G. (2010) Care and support for older people and carers in Bradford Their perspectives, aspirations and experiences. Joseph Rowntree Foundation

[48] Ballard R. (1979) Ethnic Minorities and the Social Services. In: Khan V.S. (eds) Minority Families in Britain. Studies in Ethnicity (In association with the Social Science Research Council). London.

[49] Manthorpe, J. et al (2010) Supporting Black and minority ethnic older people's mental wellbeing: accounts of social care practice Social Care Institute for Excellence Report 38

[50] Ogbonna, E. et al (2020) Report of the Socioeconomic Sub-group Chair of the First Minister's BAME Covid-19 Advisory Group. Cardiff: Welsh Government

[51] Soydan, H. (2017) Ethnicty. Oxford Bibliographies online

[52] Harries, B. Harris, S., Hall, N., Cotterell, N. (2019) Older BAME people's experiences of health and social care in Greater Manchester: lessons for policy and practice.

[53] Black and minority ethnic older people's views on research findings Butt, J. and O'Neill, A. (2004) York: Joseph Rowntree Foundation

[54] Preston, L (2021) Diversity and inequalities of access in social care - Social Care Access for BAME and LGBT+ populations: a rapid realist review. National institute for Health Research

[55] Boelman, V. et al (2014) BAME Needs assessment in West Sussex. The Young Foundation

[56] Willis, R., Khambhaita, P., Pathank, P. and Evandrou, M. (2014) Satisfaction with social care services among South Asian and White British groups University of Southampton Centre for Research on Ageing, Briefing Paper 4

[57] Malzer, S. (2013) Barriers to Accessing health and social care service for older people from black and ethnic minority ethnic backgrounds in south Glasgow: The Advocacy Project

[58] Elias, J. et al (2016) Towards a new deal for care and carers. Political studies Association Commission on Care

[59] Greenwood, N. Habibi, R., Smith, R., Manthorpe, J, (2015) Barriers to access and minority ethnic carer' satisfaction with social care services in the community: A systematic review of qualitative and quantitative literature in Health Soc Care Community 23(1):64-78.

[60] Greenwood, N., Holley, J., Ellmers, T. Mein, G., Cloud, G. (2015) Qualitative focus group study investigating experienced of access and engaging with social care services: perspectives of cares from diverse ethnic groups caring for stoke survivors.

[61] improving support for black and minority ethnic (BME) carers. Institute for Research and Innovation in Social Services, Insights 7

[62] Netto, G. (1998) "I forget myself": the case for the provision of culturally sensitive respite services for minority ethnic carers of older people

[63] Greenwood, N., Habibi, R., Smith, R., Manthorpe, J. (2015) Barriers to access and minority ethnic carer' satisfaction with social care services in the community: A systematic review of qualitative and quantitative literature in Health Social Care Community, 23(1):64-78.

[64] Carers UK (2011) Factsheet Half a million voices: improving support for BAME carers

[65] Kennin, C. et al (2017) Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-syntheses of qualitative studies BMC Psychiatry 2017; 17:316 Published online.

[66] Creating an alternative future: What does it mean for Scotland's Black and Minority Ethnic communities? Disability Rights Commission

[67] Mencap (2006) Reaching Out: working with black and minority ethnic communities Midland Mencap

[68] Department of health and Social Care (2020) BAME Communities Advisory group report and recommendations

[69] James, E. (2019) Caring alone: why Black Asian and minority ethnic young carers continue to access support. London: Barnardo's

[70] https://www.equalityhumanrights.com/sites/default/files/is-britain-fairer-2018-is-wales-fairer.pdf

[71] *Enabling Gypsies, Roma and Travellers,* Welsh Government 2018

[72] *Travelling to Better Health Outcome Measures*, Welsh Government, 2015

[73] Gypsy and Traveller Policy 2017, Swansea City and County Council

[74] *Improving the Lives of Gypsy Travellers 2019-2021.* The Scottish Executive

[75]https://www.gov.scot/binaries/content/documents/govscot/publications/correspondence/2021/03/gypsy-traveller-action-plan-letter-from-scottish-government-and-cosla/documents/letter-from-scottish-government-and-annex-1/letter-from-scottish-government-and-annex-1/govscot%3Adocument/Community%2BLetter%2B3%2B-%2BGTAP%2B-%2BMarch%2B2021.pdf

[76] "The Relationship between Social Worker and Gypsy Traveller communities" (June 2021) podcast with Annie Bryant and Davie Donaldson

[77] Health and Social care needs of Gypsy Travellers in West Sussex 2010 commissioned by NHS West Sussex and West Sussex County Council

[78] Research re social work with Gypsies and Travellers 1983-2012, Sarah Cemlyn - University of Bristol

[79] Unwin, P, Meakin, B., and Jones, A. (2020) *Including the Missing Voices of Disabled People in Gypsy, Roma and Traveller Communities*, School of Allied Health and Community, University of Worcester

[80] We look after our own': Dementia in Gypsy and Traveller communities by Samson Rattigan and Sarah Sweeney, July 2018, published online by Friends, Families, and Travellers

[81] *What Is Preventing Gypsies and Travellers From Accessing Person-Centred Care?* Barry Price, published online by The Carer (March 2021)

[82] A Different Ending: Addressing Inequalities in End of Life Care published by the Care Quality Commission in 2016

https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf

[83] "Carers in the Gypsy, Roma and Traveller Communities" published online by Action for Carers Surrey

[84] "Supporting Gypsies, Roma And Travellers Understand Social Work Involvement" (December 2015) Travellers Times

[85] https://www.researchinpractice.org.uk/children/news-views/2016/june/improving-social-work-practice-with-gypsy-and-traveller-communities/

[86] "Improving access to health care for Gypsies and Travellers, homeless people and sex workers" (September 2013), p22 Royal College of General Practitioners

[87]Social Care Institute for Excellence 2017 MacLennan, K. et al

[88] Social Care Institute for Excellence 2012

[89] https://www.researchinpractice.org.uk/children/news-views/2016/june/improving-social-work-practice-with-gypsy-and-traveller-communities/

[90] Mir, G., Nocon, A., Ahmad, W. *et al* (2001) *Learning Difficulties and Ethnicity*. London: Department of Health in Cambridge University Press (2018) learning disabilities and ethnicity: achieving cultural competence

[91] Singh, I. and Orimalse, A. (2009) Ethnic minority groups, learning disability and mental health Science Direct online

[92] Strand, S. (2019) Ethnic minority children not equally identified with Special educational needs Oxford University

[93] Learning difficulties and Ethnicity: Updating a Framework for Action (2012) Foundation for People with Learning Difficulties; London: Department of Health

[94] Race Equality Foundation Better health briefing Paper 20 (2010)

[95] Fulton R. and Richardson, K. Race Equality Foundation (2010) Towards race equality in advocacy services: people with learning disabilities from black and minority ethnic backgrounds Better health briefing

[96] Mencap (2006) Reaching Out: working with black and minority ethnic communities Midland Mencap

[97] Slade, G. (2014) Diverse perspectives: The challenges for families affected by autism from Black, Asian and Minority Ethnic communities The National Autistic Society

[98] RCPysch publications (2011) Minority ethnic communities and specialist learning disability services Report of the Faculty of the Psychiatry of Learning Disability Working Group

[99] Learning Disability Today (2014) Watching brief: BAME autism support

[100] Poxton, R. et al (2012) Reaching out to people with learning disabilities from Black and Minority Ethnic communities. Foundation for people with learning Disabilities

[101] Caton, S., Starling, S., Burton, M., Azmi, S. and Chapman, M. (2007) 'Responsive services for people with learning disabilities from minority ethnic communities', British Journal of Learning Disabilities, vol 35, No. 4 pp 229–235.

[102] Cardiff and Vale of Glamorgan (2017) Population Needs Assessment

[103] Cardiff City Council (2018) Cardiff's Wellbeing Plan

[104] Vale of Glamorgan Public Services Board (2018) Wellbeing Plan 2018-2023

[105] West Wales Care Partnership (2017) West Wales Population Assessment

[106] West Wales Care Partnership (2018) West Wales Wellbeing Plan 2018-2023

[107] Western Bay \(2016) Population Assessment Report. Engagement Report

[108] Western Bay (2018) Area Plan for care and Support Needs 2018-2023

[109] Cwm Taf Regional Partnership Board (2017) Population Assessment

[110] Cwm Taf Regional Partnership Board (2018) Wellbeing Plan 2018-2023

[111] Care and Support Population Assessment for Powys (2018)

[112] Towards 2040: The Powys Well-being Plan. Powys Regional Partnership Board

[113] North Wales Collaborative (2017) Population Assessment

[114] Greater Gwent Health, Social Care and Wellbeing Partnership (2016) Population Assessment: Gwent Region Report

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