YMCA MILTON KEYNES

COMMUNITY ACTION: MK

healthwatch Milton Keynes

Inequalities in Milton Keynes: A joint summary

Contents

Contents....1
Introduction....2
Background....4
Methodology....5
Demographics....6
People and Intersectionality in summary....7
Summary of Findings....10
Conclusion....12
Recommendations....15

Introduction

Bedfordshire, Luton and Milton Keynes Integrated Care Board (ICB) and the Bedfordshire, Luton and Milton Keynes Integrated Care Partnership (ICP), known as the BLMK Health and Care Partnership hold a joint priority to tackle health inequalities.

To achieve this, both the Board and Partnership recognise that working with, and listening to communities, particularly seldom asked, and therefore seldom heard communities within Bedfordshire, Luton and Milton Keynes is essential. Only with their shared experiences can the Integrated Care System (ICS), as a whole, better understand what barriers people face in accessing health and care services.

The ICB commissioned the Reverend Lloyd Denny, from Luton, to undertake a review of health inequalities in Bedfordshire, Luton, and Milton Keynes. During a first phase of this project, the University of Sheffield was commissioned to undertake a literature review. This literature review brought together both national and local research and reports into a single report evidencing historical health inequalities in Bedfordshire, Luton, and Milton Keynes, the people within our communities who faced the greatest health inequalities, under-representation, and themes of their biggest barriers.

In August 2022, the ICS convened an Inequalities Steering Group which invited proposals from local Healthwatch and Voluntary and Community Sector partnerships to deliver a second stage of the project which included in-depth engagement and listening activities, with a focus on intersectionality, to capture experiences of health inequalities within specific groups identified within the literature review.

The specific groups and themes identified in the literature review were:

Communities	**Themes of Inequalities experiences**
Gypsy and Roma Traveller Communities	Culture and Religion
People from ethnic minorities living in deprived areas	Communication barriers that exist
People with a learning or physical disability living in deprived areas	Knowledge and understanding of the health service
Homeless people	Cultural competency of NHS staff
Migrants	Accessible language and messaging about poor health prevention
People identifying as LGBTIQ+	

Healthwatch Milton Keynes, YMCA Milton Keynes and Community Action: Milton Keynes worked in collaboration to provide insight from across all community groups and themes identified in the literature review, with the aim of providing the ICS Inequalities Steering Group with:

- Rich insight into the experiences of the Milton Keynes community – Delivered by Healthwatch Milton Keynes through a programme of assertive outreach methods, listening events and a digital survey
- A detailed picture of existing intelligence and data from the VCSE, connecting with these communities that have recently worked, or are currently asking our communities very similar questions – Delivered by Community Action: MK through a programme of insight gathering, research and listening events
- Detailed insight into the intersectional nature of inequalities with specific communities – Delivered by YMCA Milton Keynes through face-to-face and virtual interviews.

Background

Healthwatch Milton Keynes, YMCA Milton Keynes, and Community Action Milton Keynes are charity organisations who were set up to work with the people and the voluntary groups within Milton Keynes to ensure that the people who live and work here are supported to achieve the outcomes they need and want.

YMCA Milton Keynes

YMCA Milton Keynes was established in 1981 and in that time has supported over 10,000 young people aged 18-35 through emergency accommodation and supported housing. They are the largest provider of dedicated supported housing to young people in Milton Keynes. YMCA Milton Keynes work with young people who have experienced homelessness and provide them with, not only a safe place to stay, but a range of support services that empower them to belong, contribute and thrive.

Community Action: MK

Community Action: MK is the local infrastructure support charity for the Voluntary and Community Sector (VCSE) in Milton Keynes. They provide advice and guidance for VCSE groups around governance issues and funding, are the local Hub for volunteering and have run a number of Community Development projects across the City. A large focus of their work is to enable the VCSE sector to communicate the needs of their beneficiaries to policy makers and service providers, and to support the Sector to come together and collaborate through a range of networks

Healthwatch Milton Keynes

Healthwatch Milton Keynes is the local independent champion for people using health and social care services in Milton Keynes. Our main statutory functions as local Healthwatch are:

- To obtain the views of people about their needs and experience of local health and social care services
- To make reports and recommendations about how those services could or should be improved
- To promote and support the involvement of people in the monitoring, commissioning and provision of local health and social care services
- To provide information and advice to the public about accessing these services and the options available.

Methodology

In collaboration Healthwatch Milton Keynes, Community Action:MK and YMCA Milton Keynes designed a line of questioning, drawn both from the inequalities themes from the literature review and input from the ICS Communications and Engagement team. The questions can be found in Appendix 1. The collaborative agreed that the questions provided a foundation for conversations but that each community and for many individuals, different approaches to gathering insight and evidence would be required.

It was agreed that for many people, the inequalities they experienced were so much a part of their everyday lives, that they may not identify certain experiences as an inequality, and this would require flexibility in approach, time and the numbers of people engaged with. We also acknowledged that difficulties being experienced by all residents in accessing health and social care in the current environment added a layer of complexity when exploring experiences of inequalities in accessing services with those who were identified as typically experiencing even greater barriers.

The agreed line of questioning was designed to allow people to tell us, in their own words, what had worked well, what hadn't, and what they thought would improve their experience. All three organisations used these questions to guide conversations with individuals, with groups, and with representatives of the voluntary and charity groups working with Milton Keynes' residents.

Due to the interconnections of the activities between the three organisations within this project it was important to avoid duplication when engaging within our communities. Regular meetings were held to discuss any emerging themes and enabled a consistent approach to any alterations to the framework that might have needed to be made.

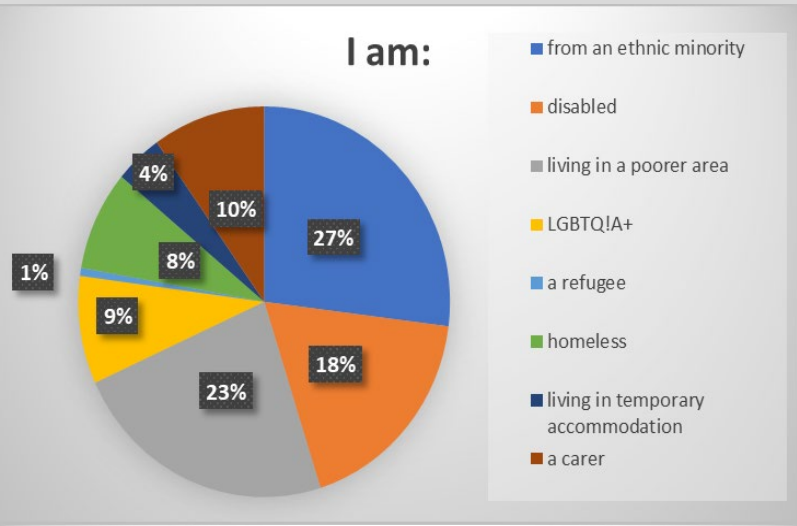
YMCA focused on engaging with younger people who have experienced homelessness. Their approach included conducting informal discussions in groups, and individually with YMCA residents.

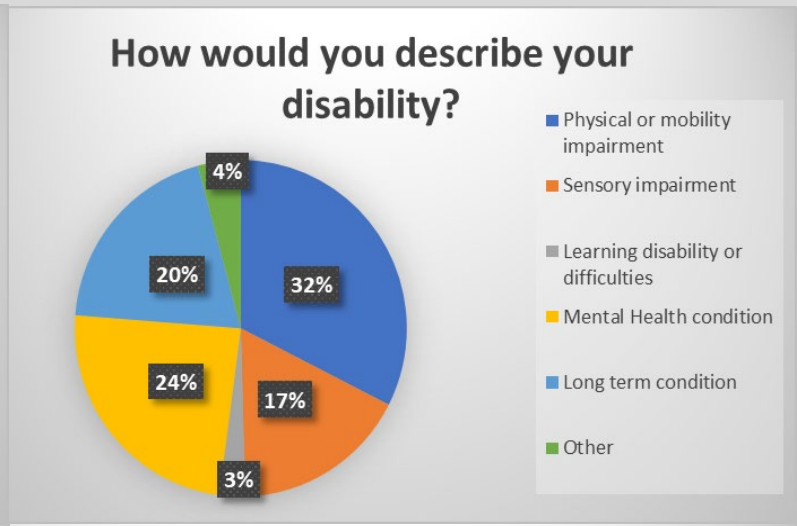
Community Action held discussions with Voluntary and Community sector groups that provide support to Milton Keynes residents and drawing on recent insight and evidence held in their Community Insights system.

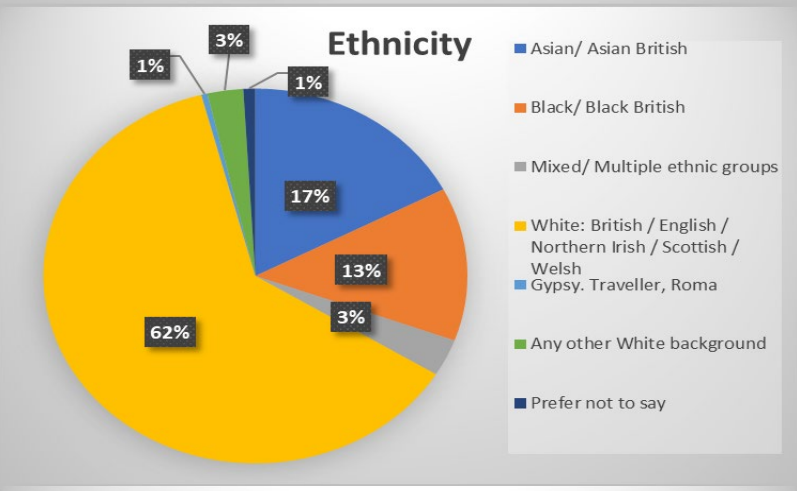
Healthwatch Milton Keynes ran a survey and conducted interviews with residents at planned outreach events, and drop-in visits to spaces including Community Larders and local groups such as MK Snap, Carers MK and the Somali Outreach Project.

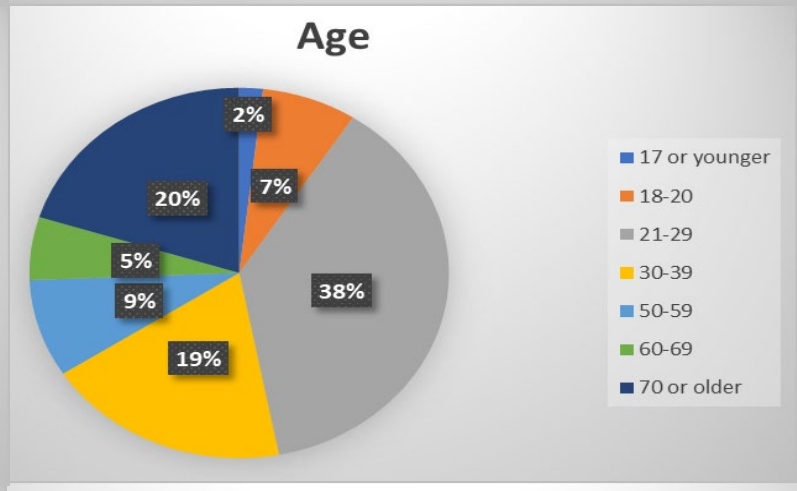
Community Action: MK and YMCA Milton Keynes, and Healthwatch Milton Keynes drew findings into three detailed reports. As part of the collaborative agreement, Healthwatch Milton Keynes then analysed data and insight across all three reports to draw out a cohesive Milton Keynes Place-Based picture of the inequalities that the identified communities and residents experience. Once this was drafted, a further meeting was held to agree the content and evidence of the summary and draw recommendations from the collected data.

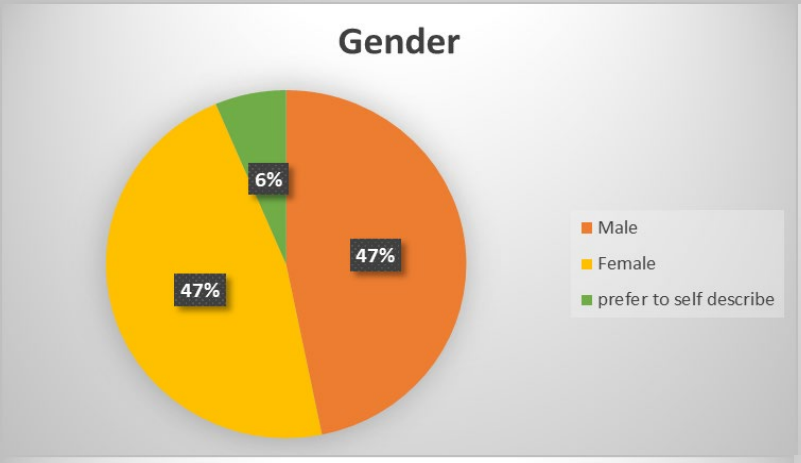
Demographics

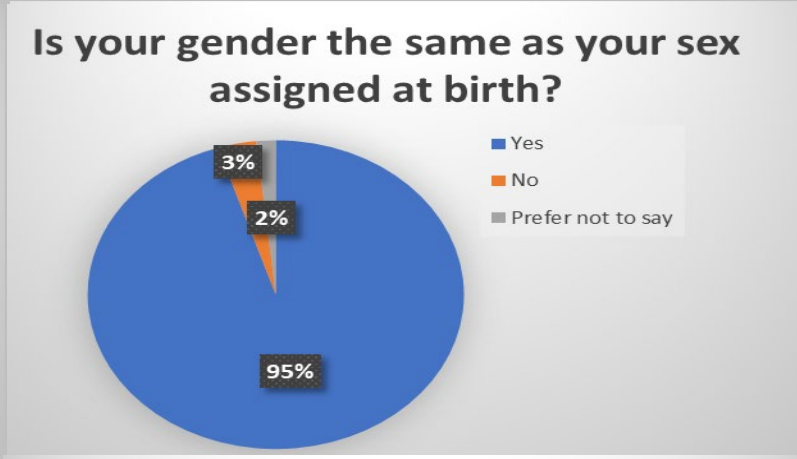


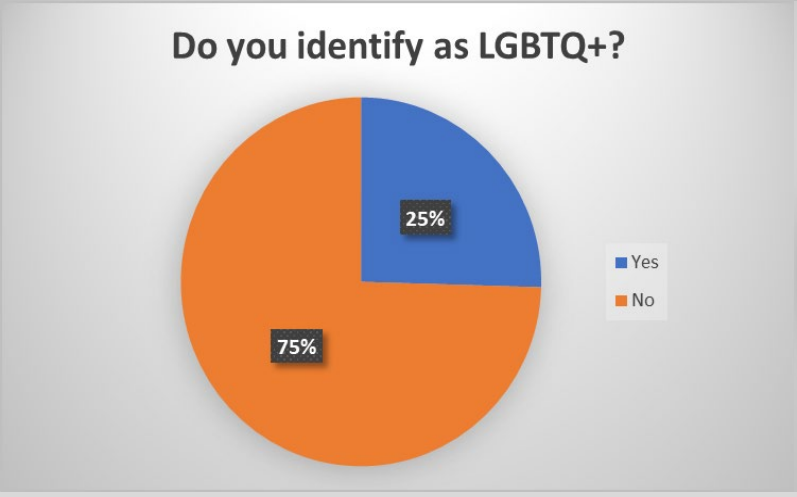


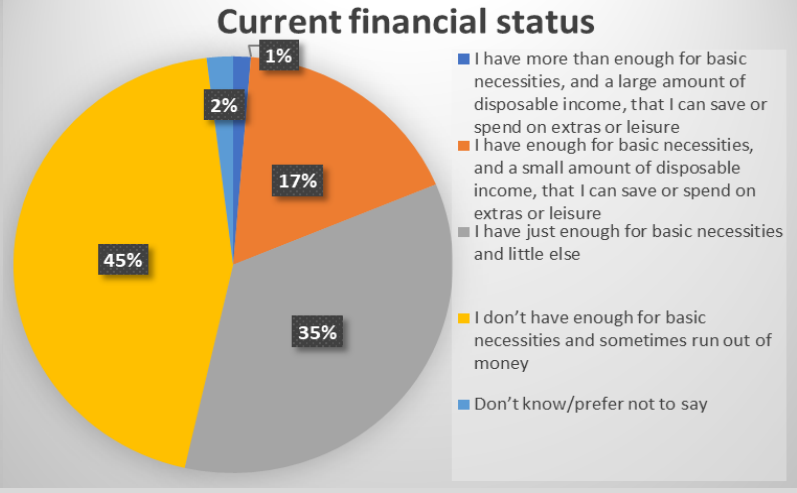












People and Intersectionality in summary

YMCA Milton Keynes

YMCA Milton Keynes spoke to 47 young people who live at YMCA Milton Keynes based in central Milton Keynes. Residents were asked to provide basic demographic information that they felt comfortable to share, recognising that half of YMCA residents have a background of significant trauma which could include growing up in the care system, or having direct experience of the criminal justice system. For young people with these experiences, they can find direct or structured questioning challenging, or can find even a basic level of interviewing as an interrogative experience. Some residents can also question the motive(s) of professionals seeking their information. Therefore, flexibility and informal approaches to listening to their experiences was essential.

All the young people interviewed felt comfortable to share their information and views with a trusted professional in a familiar setting. YMCA staff conducting listening activities clearly explained why they were collecting the information, and how the information would be used. All young people reacted positively to the idea that health and social care commissioners were interested in hearing from them directly.

The young people interviewed identified the following aspects of how their social and political identities combine to affect their experiences of health inequality:

- The residents interviewed were aged 18-35
- Young people were asked to self-identify their gender. 6% of respondents identified as other, 3 were transgender men
- Young people were asked to self-identify their ethnicity. Those responding as 'Mixed other' included Bermudan and American, Black British, and Caribbean and Jamaican and Irish
- 34% of respondents self-identified as LGBTQIA+. This included those that identify as lesbian, bisexual, pansexual, and transgender.
- 49% of respondents identified as having a disability, including mental health conditions. 13% declined to answer the question.

The interviewer noted that many young people who did not self-identify as having a disability later spoken of multiple diagnoses in their comments, including depression, anxiety, PTSD, autism and learning difficulties.

Healthwatch Milton Keynes

Healthwatch Milton Keynes had **144** responses to their published Inequalities survey and held listening interviews with **151** people through outreach events, focus groups and our assertive outreach work.

The residents we interviewed and heard from identified the following aspects of how their social and political identities combine to affect their experiences of health inequality:

- 58% of survey respondents that didn't identify as having a disability or long-term condition attributed their health inequalities to their age, ethnicity or their gender/gender identity
- 31% survey respondents were carers
- 27% of people engaged with were from ethnic minority groups
- 18% of all people sharing their experiences identified as having a disability
- 23% of all people sharing their experiences lived in deprived areas of Milton Keynes
- 9% of all people sharing their experiences identified as LGBTQ+
- 4% of all people sharing their experiences lived in temporary accommodation
- Other intersectional inequalities trends were noted for older women across all communities, people on lower incomes, people living in council housing and religious beliefs.
- 1% of people said whilst they were more than financially stable, their disability or carer responsibilities meant they experienced unequal access to care

Community Action: MK

Community Action: MK spoke to voluntary sector groups who work within Milton Keynes with the communities identified in the Literature Review, excluding those working with homelessness to avoid duplication. They carried out 13 interviews with groups / representatives, using a mixture of video calls, phone calls and in person meetings depending on the group's preference.

Q:alliance are the LGBTQ+ support charity for Milton Keynes. Each month they directly support around 50 adults and 35 young people (11-18). There is an estimated population of 10,000 LGBTQ+ in Milton Keynes and Q:alliance provide indirect support to all who identify as LGBTQ+ through awareness raising and diversity training for local groups and businesses to improve the overall awareness and understanding within the wider community.

The Ethnic Minority Achievement Team work with around 45 Gypsy, Roma and Traveller (GRT) families per year (around 200 individual adults and children). 90% of the GRT families the EMA team support are from the Irish Traveller community and 10% have English gypsy heritage.

Talent Unlimited directly supports around 40 adults fairly evenly split between males and females, 90% white British and between 18 and 50, with most under 30.

Talkback offer support with personal development skills, support in colleges and communities, and employment skills to people with Autism or Learning Disabilities.

Camphill Communities support over 70 residents who have learning difficulties, autism, and/ or mental health needs. Support is provided in small family units where individual living skills are developed and quality of life is enhanced, and where individuals are at the centre of their own care and support.

The Centre for Integrated Living supports people through a wide range of free and confidential information on any disability related issue for people with a disability, their families, and carers.

The Macmillan Cancer Support Research Project collected information from people from Black and Minority Ethnic groups to understand the barriers that prevent the uptake of MacMillan Cancer support services

The Wisdom Principle focus on mental health support for Black and Minority Ethnic communities.

Welcome MK provides support and assistance to meet the needs, both immediate and longer term, of refugees and migrants arriving in Milton Keynes.

Summary of Findings

There is strong public awareness of the current pressures both on the NHS and on Social Care, with people experiencing challenges accessing the services they need. As the nation recovers from the Covid-19 pandemic, many of us are facing long waiting lists for diagnostics and surgery, difficulty getting an appointment with a GP, accessing an NHS dentist or social care support. However, for some people and communities such challenges and barriers to health and care support preceded the pandemic and have worsened because of where they live, what they earn and who they are.

The current levels of pressure and capacity issues within health and social care and the cost-of-living crisis has not created inequalities of access, care and support in the health and care system, but it is impacting greater numbers of people, so people and communities that were already experiencing inequalities in access, care and support are even more greatly impacted.

"I really need to see a GP and a dentist, but I've been told I can't see a GP because I don't have the ID. I can't afford to see the dentist. I'm in a lot of pain. I worry about my kids' teeth"

Healthwatch Milton Keynes, Community Action:MK and YMCA Milton Keynes have set out our individual findings in three separate reports. We then drew together the demographic data and insight from direct engagement with residents and analysed this alongside the insight provided by representative voluntary organisations and community groups. This analysis reflected a number of common themes and experiences for the people and communities we engaged with.

Accessibility – People from the communities we spoke to shared that they experienced barriers to accessing the help they needed. This could be by having to convince a receptionist they needed to see a GP, or convincing a GP that they needed a referral, convincing 111 that they weren't exaggerating, convincing consultants of their own experience of their condition, convincing a Social Worker that they had care needs. There was a strong common experience of this issue drawn out from our insight. People experiencing poorer health outcomes shared with us a sense of greater challenge with the language, capacity, or confidence needed to self-advocate when speaking with professionals.

I always feel rushed which makes me nervous and forget what I want to say. As this has been an ongoing situation throughout my life, it is now ingrained behaviour and I constantly feel of little or no importance. Long waits and impatient staff over the years also increase my nervousness and inability to approach health and care services in a relaxed manner

Communication – Individuals from all communities shared challenges around communication. This included D/deaf people being given phone numbers to services or staff talking to them while wearing masks. For some residents, they felt that as soon as the front-line staff member heard their accent, saw their skin colour, or even the way they dressed, they began to experience barriers to the right support they needed. Unconscious biases held by professionals led to assumptions or judgements being made before the person had a chance to relay their need.

"Giving birth as a black woman in A&E, it's… my sister died. As a black person, or anyone from a different ethnic origin, there always seems to be a bad outcome or complication somewhere"

Cultural Competency and personalisation - Many felt assumptions based on stereotypes are being made about them by professionals. This included assuming what their views about certain illnesses based on their gender, ethnicity, mental health status or religious beliefs, assuming the level of engagement, or action they would take with the professional's advice, and making assumptions about their level of understanding, which included over or underestimating a person's capacity to understand information provided.

Insight from the voluntary sector reflected many of these experiences through the demand and type of help being requested by people from these communities. Many VCSE groups, including YMCA Milton Keynes and Healthwatch Milton Keynes are seeing increasing demand from residents seeking help to advocate for their rights to access health and care.

"CIL volunteers aren't trained advocates, but they are calling the gas company, or GP or Council on the client's behalf"

The barriers people face have a common theme - communication. This includes the professional to service user communication and inter-organisational communication that breaks down or does not happen. For people in the communities that we heard from, this translates to challenges discussing, and accessing the help they need but also struggling to access good, integrated support when moving between, or receiving care from two or more services.

No one we interviewed reported being offered an interpreter, and many people said they had to rely on either hearing friends and family, or on spouses or children to interpret for them.

"If English isn't your first language, you may have a male family member take you to the appointment but how can you feel comfortable if the appointment was to talk about a female thing, a personal female issue?"

Conclusion

Accessibility

We heard that accessibility issues were almost equal to communication issues, when it came to barriers people said they experienced. Our findings evidenced that experiences of accessibility challenges were relatively evenly split between experiencing physical access issues to services, and accessibility to appointments, referrals, or even information about the services that were available. People with physical disabilities found that having to attend A&E or Urgent Care because they were unable to get GP appointments was particularly difficult because the long wait times could be physically impossible for them. This was also noted as an issue for people with mental ill health or neurodiverse conditions. People in the communities we spoke to told us they felt doubly penalised because they tended to avoid contacting the GP due to worries about staff attitudes towards their particular characteristic, and so their needs were more acute and complex by the time they were seen.

We also heard that trends toward access to support through digital methods is causing barriers for people with low levels of literacy, people who don't speak English very well, and people who can't afford an internet connection, or the devices needed to use the internet.

"I can't get an appointment, when I do get through on the phone, they say you have to access the online portal. When I say I can't, they hang up on me"

Improving accessibility must start with increasing the knowledge people and communities have of what services are available to help them, and how access such services. In particular, ethnic minority groups and elderly people without easy access to the internet reported this as a barrier.

While there is a wealth of support provided by VCSE groups across Milton Keynes, as well as the statutory services themselves, there is no one place to find this information with information scattered, and often in digital and inaccessible formats. GPs or Social Workers may have limited knowledge of the services themselves, and very little time within an appointment to find and provide information to support and other services that can help people.

"I know when I should get help but don't always know where to get it from. Thank goodness for Healthwatch and the other charity groups who make sure I get the information I need - the professionals don't give it out!"

Knowledge of support available for people and communities can be complicated by inconsistency and complexity of access points and poor integration in the health and care system. When people were asked whether the messages about looking after your health were easily available, almost half said the messages were, but that information about where to go or how to follow the advice was not. Clear information about access points to support, for example, whether a referral by a GP is necessary, whether self-referral is possible and information about an expected care pathway is required.

Communication

The law states that Health and Care information must be made available in a format that people can understand (The Accessible Information Standards[1] and the Equalities Act[2]) and is also pledged by the NHS Constitution:

> *"The NHS also commits to inform you about the healthcare services available to you, locally and nationally; and to offer you easily accessible, reliable and relevant information in a form you can understand, and support to use it. This will enable you to participate fully in your own healthcare decisions."*

Cultural Competency and Personalisation – The people and communities we heard from told us that they need to be seen as a whole and unique person but often felt like assumptions based on their age, ethnicity, gender, disability, or symptoms created barriers to their needs as an individual.

This call out for 'cultural competency' was raised by people within the LGBTQI+ community, faith communities, ethnic minority communities, people with physical or sensory disabilities, mental ill health, neurodiverse people, as well as people living on low incomes. The theme that came through was that care, rather than being 'person centred', was centred around the set of symptoms/ condition, what worked for the professional, or what worked for the organisation. This means that there is little to no flexibility in the approach taken for the person.

People from ethnic minority groups told us that they often felt that health professionals didn't see them as a whole person, and that they had strong sense that they weren't really being cared for or cared about because the appointments were so rushed and there was no 'small talk' asking about the family or the person's day.

Religious people told us that felt that there was no place for their faith to be part of discussions around care and treatment. Whether discussions were around lifestyle or around medication, they felt that their particular belief system was seen as separate to themselves, their illness or their recovery and they felt that their beliefs should be integrated into the conversation to support more appropriate clinical care.

People with Mental ill health felt that a lot of the care or treatment they receive is done to them, not with them, and felt that they were not involved in discussions about the benefits, or side effects, of available treatments. These

[1] https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/
[2] https://www.legislation.gov.uk/ukpga/2010/15/section/149

people also told us that they had concerns about Diagnostic Overshadowing, when other issues they have were overshadowed by, or attributed to their mental health condition. They shared that they often felt 'fobbed off' with pills on the first attempt to talk about their mental health. Those who had an existing diagnosis told us that they were worried that if they talked about what they were experiencing, they would be sectioned.

"With mental health, I didn't get any support with my schizophrenia. Other people think you are scary, so they put you to one side. I didn't get support. When I was in the Marvel House, for people with schizophrenia and serious illness, people who can't cope and that. It was [not good], you don't see no one. You're locked away. It's worse than prison. No one can visit, you can't leave. It's all security gates. They have rooms with support workers, and I know they are trying to help you but as soon as they know you have schizophrenia, they manipulate you and treat you like you have a big issue"

People who identified as LGBTQI+, shared common experiences of Primary care and told us that GPs who don't always have a good understanding of their specific needs and concerns, which influences a reluctance to access health services. For many people in the LGBTQ+ community this is resulting in many people reaching crisis in their physical and their mental health before they seek treatment.

"I've moved homes about 4 times in the last 2 years, and I've changed GPs twice. I put Mr down on all of my forms, but they changed it to Mx. They didn't ask me, they just changed it. I think it could have been linked to my hormone injections, I think they just assumed. Mx is still misgendering me, it's not how I identify... I signed up as a Mr so why would they change that? It's super frustrating. Mistakes get copied over from previous GP's so you can't even get away from it".

Opportunities for health and care professionals to have wider discussions about an individual's life can draw out important information to provide more relevant and more person-centred care, for example, identifying financial and access challenges, understanding what pronouns an individual would like to be addressed by, how their individual beliefs could inform their care and treatment plans, or a person's caring responsibilities.

Recommendations

The recommendations made in this report are based on the findings of the three contributing organisations and have been formulated with the needs of residents experiencing inequalities as well as with ICB priorities in mind.

The authors of this report believe that focussing on the suggested groups will allow for an inequalities coproduction process to be piloted, and perfected before rolling the programme out to the wider system, particularly communities with more complex intersectional inequalities and needs. For example, the authors of this report suggest that the coproduction concept should be embedded and proven before it is broadened to the Gypsy, Roma, Traveller communities. This group experiences far higher levels of inequality than most other population groups and the system will need to tailor longer-term, sustainable approach and resources to build trust with people who have little reason to believe that their cultural needs will be considered, or their input valued.

The groups within the recommendations have been put forward because it has been demonstrated that they experience high levels of inequality, and because they have strong support from groups and organisations who will be able to aid them in a coproduction journey. It is strongly suggested that any coproduction involves least one VCSE sector organisation or group who can consult & engage with their service users or community to introduce and facilitate engagement in the coproduction of each new service or project development.

The resources produced in coproduction with these groups will provide a good foundation for developing the resources needed by many of the other people who experience similar inequality in access and communication.

Recommendation 1)

Coproducing a set of identified service gaps, and a set of reasonable adjustments to health services, physical spaces and communications to make them more appropriate and inclusive for the focus population groups

We recommend that this coproduction work begins with the following groups:

- People with learning disabilities
- Young people affected by mental ill health, including Autism Spectrum Conditions

Recommendation 2)

Coproduction to design training and resources for health providers that would support them to increase their awareness of cultures, needs and conditions relating to the focus population groups

- LGBTQ+

Healthwatch Milton Keynes

Suite 113, Milton Keynes Business Centre

Foxhunter Drive

Linford Wood

Milton Keynes

MK14 6GD

www.healthwatchmiltonkeynes.co.uk

t: 01908 698800

e: info@healthwatchmiltonkeynes.co.uk

@Healthwatch_MK

Facebook.com/HealthwatchMK

healthwatch Milton Keynes