

# COMMUNITY ACTION: MK

## Community Action: MK Research Project for the Denny Review Final Report December 2022

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### Background and Introduction

Following the initial phase of Denny Review research across Beds, Luton and Milton Keynes (BLMK), Community Action: MK were commissioned to undertake engagement at Place level (Milton Keynes) to find out more about the reasons why the communities identified in the Denny Review face such health inequality, and begin to explore what could be done to address this.

The initial phase of the Denny Review was a rapid evidence review to improve understanding of health inequalities in communities within BLMK and identify good practices to address them. The evidence

collected confirmed that the communities most affected by health inequalities in BLMK include ethnic minority groups, including Gypsy, Roma, and Traveller communities, people living in deprived neighbourhoods, people with disability, and people experiencing homelessness, migrants, and people who are LGBTQ+. These groups experience health inequalities from unfair distribution and the impact of wider determinants of health to access health care services.

As the local Infrastructure Organisation in MK, we have strong relationships with a range of voluntary, community and social enterprise (VCSE) sector organisations working across the City at grassroots level. We know these organisations possess a great deal of knowledge about the challenges the people they work with face, as well as the ideas the communities they support have around solutions. Grassroots VCSE groups are often uniquely placed to gather such insight, and this research aimed to ensure this information was collected and used within the Denny Review.

Community Action: MK identified key groups working within the communities of focus, and arranged one to one interviews with them to talk in detail about the health inequality the people they work with experience. The information we gathered helps to create a clearer picture of the specific challenges faced by each group and enables us to identify some tailored solutions based on real community needs and lived experience.

Below is a summary of the findings, followed by more detailed information from the interviews broken down by community, recommendations for future work to address health inequality in MK and the actions we have taken as a result of the research.

The information gathered from the VCSE groups we spoke to was fascinating and insightful, and really helps us to understand why the health inequality we see in some communities exists. It also uncovers some really practical steps that could be taken to address some of the issues faced, in the short, medium and long term. It offers health providers the opportunity to take action that will start to reduce health inequality, focusing not only on how to improve access to services, but also how services need to change so they are appropriate for all groups of people. As one VCSE group simply put it, "If services are designed for the mainstream, they won't work for people that sit outside of that and unless this changes those groups of people will continue to experience health inequality."

## Summary of Recommendations

The research produced a set of recommendations relating to each population group. Although the details of many of the recommendations are specific to individual communities, they fall within three categories:

### **1) Adapting services and spaces to be appropriate and accessible (Reasonable Adjustments), and Service Gaps**

Many of the recommendations outlined in our report relate to making reasonable adjustments to existing services so they are appropriate, welcoming and accessible to the communities this research focused on. Many of these adjustments would be relatively quick and easy to implement.

The report also highlights some of the gaps in health services experienced by the communities of focus, and highlights what additional services would help reduce health inequalities within the population groups that experience them the most.

- Some examples of desired reasonable adjustments we heard included:
  - Providing a comfortable waiting area for people with autism that have sensory sensitivities (dimmer lighting, less noise and crowds etc)
  - Providing alternative ways to make appointments for those who cannot c early morning phone calls etc
  - Ensuring patients within certain communities are supported to understand the information / medication they are given within health appointments by providing a written summary, a post appointment 'de-brief' (perhaps via a staff 'champion') and by being given time and encouragement to ask questions within their appointment).
- Some examples of gaps in service that need to be filled included:
  - Need for much more advocacy support across a range of communities
  - Specialist support needed for people with autism around eating disorders
  - More outreach health workers and taking services (eg vaccinations) into certain communities / community hubs is required
  - Need for more 'in home' support to combat social isolation and provide practical assistance (like that provided by Homestart and to support people with learning disabilities and other disabilities etc)

## **2) Training, education and increasing awareness**

Many of the recommendations outlined in our report relate to training for health providers that would support them to increase their awareness of cultures, needs and conditions relating to the focus population groups. It is important that the content of any training be co-produced and informed by members of the focus communities.

- Some examples of training topics included:
  - Terminology and pronouns relating to members of the LGBTQ+ community
  - Understanding of different cultural norms and needs relating to some ethnic minority groups
  - Understanding of autism and neurodiversity, physical disability, mental health conditions and learning disability (eg ensuring 'do not resuscitate' isn't wrongly applied to some people in hospital with learning disabilities, understanding the specific needs and challenges relating to certain mental health conditions and recognising the difference between neurodiversity and personality disorders)
  - Understanding of the communication needs and challenges relating to some communities

## **3) Communication / information**

Many of the recommendations outlined in our report relate to changes and improvements around communication and the presentation of information.

- Some examples of recommendations relating to communication include:

- Co-producing communication materials with the focus communities so they are culturally appropriate and accessible
- Ensuring the communication needs of each individual are explored and logged (eg for those with hearing or sight impairment, learning disabilities or autism)
- More opportunities for community members to express their needs, challenges and ideas to health providers
- More time given in appointments to people with certain needs and /or from certain cultures
- Greater availability of translators

## Summary of Common Themes

Although the experience of, and reasons for health inequality are different within each of the focus communities, there were some common themes across many of the groups we spoke to. These were:

- **Cultural Competency**

- The lack of understanding of different cultures was raised as a big issue that impacts health inequality as services provided are often not appropriate or welcoming for all communities.
- The needs and norms of different ethnic minority or faith groups are not always known or considered by health professionals / services.
- Terms and experiences relating to the LGBTQ+ community are not always known or considered by health professionals / services.
- Specific training for health providers was recommended, as well as adjustments to make services more appropriate.

- **Advocacy**

- The need for and lack of advocacy services was something that came up again and again across a range of groups, including people with physical disabilities, people with autism and neurodiverse conditions, people with mental ill health and people with learning disabilities.

- **Lack of proper understanding of conditions and needs**

- Many groups reported instances of their service users' health needs not being understood by health professionals, including autism and neurodiversity, physical and learning disabilities and mental illnesses (for example autism being misdiagnosed for personality disorders, mental health issues 'shadowing' other illnesses and benefit assessors lacking sometimes basic knowledge relating to disability).
- More training on key needs and conditions recommended to decrease inequality.

- **Food and healthy eating**

- Diet and food was something that came up across a range of groups as causing health issues.
- Tailoring diet advice depending on foods eaten within different communities is needed to make it accessible.
- Understanding of the complex relationship with food that people with autism can have is needed, and bespoke services are required as eating disorders and unhealthy eating are extremely common in this group, and mainstream services do not effectively support.
- Management of weight, diet and diabetes needs intensive support within the learning disabled community.

- **Accessibility**

- Transport was a big issue amongst many of the groups we spoke to preventing people from accessing health services
- Environments and processes within some health services are not suitable for some people (eg people with autism because of noise, bright lighting, crowds etc, those with disabilities because of long waiting times that cannot be endured with some disabilities, or ambulances not being able to accommodate individuals' wheelchairs and roadside Gypsy, Roma and Traveller community members not being able to access same day appointments before they move on).
- Fear of discrimination or being made to feel uncomfortable is a barrier for some in terms of accessing health services (eg within LGBTQ+ and Gypsy, Roma and Traveller communities).
- The process for booking GP appointments is difficult or impossible for many of the people the groups we spoke to work with (early morning telephone calls, online bookings etc)
- We heard that for many of the members of the communities of focus, accessing healthcare has a negative impact on their health - causing extreme anxiety and stress. Processes need to change to prevent this.
- The need for services to go out to where people are more often was recommended time and again across most of the focus communities.
- Affordability of healthy choices or activities (eg food, wellness activities, transport to activities)
- Dental and mental health support are hard to access.

- **Lack of bespoke services**

- Many groups highlighted the need for services to be tailored in order to be effective for individuals and communities.
- Recognition that this is difficult, but is absolutely key if we want to reduce the inequalities faced by the communities highlighted in this research.
- Impersonal, quick and/or virtual/phone appointments and services are just not suitable for many people that need more time to process information, understand, build trust and communicate etc.

- **The need for lived experience to steer services**

- The groups we spoke to told us that in order to ensure health services are accessible and effective for communities, members of those communities need to be enabled to feed in their lived experience, express the barriers they face and work with health providers to design solutions and amended services.
  - VCSE groups that work at grassroots level can facilitate some of this work if supported to do so.
  - Feedback needs to go somewhere and when communities give their time and knowledge, they need to hear back about the impact it has had. Circular communication and equal partnerships between health services asking for input and people with lived experience need to be set up.
- **Opportunities for prevention work and early support**
    - Throughout the research, opportunities to prevent ill health are highlighted. This work would mean that pressure on health services are reduced in the long run.
    - The importance of supporting people as early as possible was highlighted (whether this is by managing diabetes, early counselling for refugees that have experienced trauma, or by creating an understanding and culture of healthy living in creative ways that are meaningful to different communities).
    - The need for long term relationships to be formed within communities to build trust, tackle barriers, address wider determinants of health and increase confidence to take action on solutions is required. This means long term, embedded community development work.
- **Communication**
    - Communication was a big issue across focus communities and ranged from language barriers, methods of communications being inaccessible, medical terms causing confusion, difficulty speaking to health professionals and a lack of access to information. Extreme situations such as giving birth on floor and 'do not resuscitate' measure nearly being wrongly imposed are examples of the dangers of miscommunication (see below),
    - The need to adapt communication depending on the individual was highlighted.
    - Communication is complex and sometimes people from different cultures need to be communicated and cared for in specific ways to feel comfortable.
    - Some people process information differently, so need to receive information differently.
    - Information is not reaching all communities, so people do not know what services are on offer (eg migrants, some ethnic minority groups and Gypsy Roma and Traveller communities)
    - Digital and written communications aren't right for everyone.

## **Autism and Neurodiversity - Detailed Report**

The main VCSE groups we spoke to that specialise in support relating to autism and neurodiverse conditions were Talkback and Talent Unlimited. We also had some input from MK Centre for Integrated Living and the Disability Resource Centre, as well as drawing on information within the CA:MK Team from

their experience of working with VCSE groups that support autistic and neurodiverse people, and the information that has been added to the MK Community Data Tool.

- Talent Unlimited provides a safe place for autistic adults to socialise, share and develop their skills. They also market what users produce through their website.
- Talkback aims to improve the lives of autistic individuals and those with a learning disability by giving them the tools to thrive through a range of services. They provide the opportunity for continued personal development, help build meaningful friendships and create the confidence to embrace new experiences.

## Communication

A lack of face to face GP services is an issue as we learned that people with autism often prefer these to virtual appointments and they often don't like to speak on the phone or via automated systems. Unexpected phone calls are also particularly stressful for some people with autism and sleep patterns can be different.

*"For some people with autism, 8am can feel very early, so having to call GP surgeries at 8am to get an appointment is impractical and excludes them. This shouldn't be the only way to get appointments as it is in many surgeries" - **Talent Unlimited***

Also, some people are not comfortable discussing or disclosing their autism diagnosis on the phone in front of people they live with. All of this can mean they avoid making the phone call and do not seek medical attention when they need it. It was suggested that PCN's could have an autism champion that manages the communications with the autistic clients e.g. emails and phone calls and has dedicated time to meet individuals at the door and undertake a debrief of their appointment after speaking with the GP.

*"Citizens Advice MK have set up a vulnerable persons helpline - can there be an autism champion within these networks who can speak directly with individuals, as well as avoiding having to use automated systems?" - **Talkback***

It is important that people with autism are supported to communicate effectively when attending health services, in terms of being understood and understanding the information being given. We were told that it's often beneficial if people with autism have advocates in health appointments with them, and the right to take a trusted person with you to appointments should be promoted.

*"Visiting the Doctor can create anxiety due to not wanting to 'feel stupid' in front of a GP by asking 'silly' questions" - **Talkback***

We were told that often individuals with autism can feel intimidated by medical professionals, and lack the self esteem or confidence to ask questions.

*“Not asking questions during the appointment can lead to individuals ‘beating themselves up’ when they get home as they feel they should have asked questions, when they get home and don't know what their new medication is for, for example.” - Talkback*

We were advised that providing honest answers and not just saying what they think the Doctor wants to hear requires trust between the individual with autism and the professional. Processing information can also take longer for people with autism, so conversations and appointments will take longer than those for people without autism. Working with health providers to allow people with autism the time to ask questions would be beneficial, as would specialist training for GPs, receptionists and other health providers around autism and how to make services more accessible, welcoming and helpful.

*“Health professionals should understand that their patient has autism and may only process information after the appointment. Therefore, staff should simplify language, take time when speaking, be mindful of tone of voice and allow the patient in the room the chance to understand. Having the ‘whys’ and ‘because’ conversations during appointments are important” - Talkback*

If GPs and other health providers had a system that made them aware the patient they were calling or seeing was autistic, this could be helpful. It was also suggested that communication preferences should be gathered and noted, or asked to the individual by receptionists, GPs etc.

*“If GPs had an electronic system that flagged up if a person is autistic, and if information has been collected and noted on the ways that individual prefers to be communicated with, they could tailor their approach accordingly.” - Talent Unlimited*

We were told that people with autism often have difficulty remembering and processing spoken information in a medical appointment. Having a written summary to take away with them would be very helpful. We learned that online communications of health messages can be effective for many people with autism, but websites need to be simplified otherwise some people with autism will become frustrated and give up. Written information must be accessible. Talkback says that health information is welcomed, but it needs to be in an easy to understand format that is not off-putting for people with autism. Consultation with individuals about what information they already access and what information they would like to access would be beneficial - along with discussions around putting health advice into practice.



*"Providing easy read information as Mencap recommends would help to increase people with autism's confidence with medical services. So a letter with a picture of a clock and calendar to communicate the appointment time for example. Paragraph after paragraph is not appropriate. The National autistic Society has an easy to read website version. Can this model be used for health information?" - **Talkback***

Medical communications can be ignored due to lack of understanding by some people with autism, for example not following up on a Doctor's letter, or for other reasons.

*"They need to be more lenient with the '3 strikes and you're out' rules when it comes to not responding to appointment letters etc. - reach out to people as things may be going on. Reminders, texts etc can also be useful." - **Talkback***

We were told it is important that commitments are kept with people with autism, otherwise this can cause a lot of stress.

*"Delivering on what we say we'll do goes a long way - e.g. ensuring you contact someone with autism when you say you will. Autistic minds can be very literal. The anxiety caused by not receiving a call when expected could negatively affect someone with autism for the whole day" - **Talkback***

A single 'place' where all autism related resources are available in MK (not restricted to but including health) was suggested as something that would be really useful. This could include support options, services, information about autism etc. Currently everything is separate and difficult to find.

## **Accessibility**

Transport is an issue for some people with autism and often there is limited access to community transport. We were told that some specialist appointments given outside of MK, for example in Oxford, are often impractical. In many cases individuals do not meet the criteria for community transport initiatives (e.g. dial a ride) but still have difficulties accessing appointments.

*"If health specialists could come to MK and see all people with transport issues on a designated day in a dedicated clinic that would help to solve the problem." - **Talent Unlimited***

Using a taxi service to travel to the medical appointments can cause anxiety for some autistic people as they may not want to speak to a stranger at the taxi company or will be very worried about the taxi being late.

*"Providing arranged transport for people that need it in order to attend the appointment would be great. Let's do everything we can to empower people to get to their appointment" - Talkback*

We were told that for some people with autism, medical environments, particularly waiting rooms within health centres, hospitals and other health care settings are unsuitable for them due to sensory sensitivity. A large, bright, busy, noisy room is difficult for some people with autism to tolerate, and they may be put off going back for further support with their health, or from attending appointments in the first place. A small quiet room with adjustable lighting for people with sensory sensitivities would help with this.

*"A person with autism was restrained in A&E because she couldn't cope with the waiting room. She told us all she needed was a broom cupboard to reduce the sensitivities" - Talkback*

Measures to reduce the stress experienced by some people with autism when attending medical appointments would be welcomed by Talkback.

*"Can reception staff meet people before they walk into the GP surgeries perhaps." - Talkback*

## **Lack of understanding of autism and neurodiversity**

It is felt that often GP receptionists lack understanding of autism, and can 'block' appointments.

We were told that autism is sometimes mis-diagnosed and mistaken for a personality disorder. In other cases patients have been told they are too old to be diagnosed with autism. More training to healthcare providers to increase understanding of autism was recommended.

*"It all comes down to understanding and education of professionals. Seeing each person as an individual." - Talent Unlimited*

Talent Unlimited's current avenues to express issues and lived experience of their beneficiaries is the MK Mental Health Alliance and CA:MK. They used to have the Health Partnership, but this is no longer operational.

*"There are good signs in mental health services that these messages are getting across - whether that filters down to the GPs? It's very varied." - Talent Unlimited*

Talkback told us that the Hospital put a lot of effort into working with them to ensure the needs of autistic people are met, for example creating easy read documentation and sending text reminders, but that more can be done. Better links need to be made with PCNs, but the work Talkback is involved with through the Mental Health Alliance provides opportunities to link with The Bridge and The Crown PCNs as a start. The opportunity for people with autism to have 'their say' is very important, it was stressed.

*"The 'experts by experience work' with the hospital was great - certainly pre pandemic we have been invited to the hospital a couple of times as a group to consult on out-patient waiting rooms. Etc. The hospital have attended our group 3 or 4 times this year to get views on documentation for example, and MK hospital Chaplaincy and PALS have engaged with us too. The hospital are great, they have really embraced us but there is lots of work to do... there is a lot of work, but there is a real chance."- Talkback*

There are existing opportunities for engagement with autistic people in MK, where a greater understanding of lived experience could be gained and co-design facilitated. Talkback's bi-monthly user meetings would be a great option, and professionals providing support are welcome here.

*"An example of good 'consultation' and involvement with people with Autism in MK was a sensory garden project at The Campbell Centre." - Talent Unlimited*

## **Common Health Issues**

We heard that people with autism are more prone to intestine related health issues and being overweight or underweight. In some cases this is due to complex issues relating to food that are specific to people with autism and specific to individual people with autism (as the underlying reasons are not always the same).

*"Some foods make some people with autism sick, and to some, foods taste rotten, or disgusting. This can lead to having an unvaried diet, eating unhealthily, becoming ill, and being under or overweight. Food addiction can also be an issue" - Talent*

## **Unlimited**

*"Some people with autism have a complicated relationship with food - 'healthy living' is huge and texture and taste is a big part of it" - Talkback*

We were also told that around one third of people with anorexia are on the autistic spectrum.

Cooking healthy food was highlighted as a support need within the autistic community.

*"Some people with autism may struggle with cooking a meal. Takeaways and ready meals are very accessible and are often chosen over cooking food. Education regarding food and support to cook meals would be beneficial - via social worker assistance perhaps." - Talkback*

Despite all of these diet related issues and eating disorders, there is no specific support for adults with autism to help them address their specific needs around food issues, and because of the complex autism specific causes of issues, mainstream services are unlikely to be effective.

Anxiety was flagged up as a common issue for people with autism, with certain situations causing a great deal of stress, as well as general mental health issues.

*"The mental health side of autism can be traumatic including the diagnosis or lack of it." - Talkback*

## **Recommendations**

### **Adapting services and spaces to be appropriate and accessible**

- Avoid out of area appointments for autistic/neurodiverse people with transport issues, and/or consider if specialists could come to MK and see all people with transport issues on a designated day in a dedicated clinic. Could this be facilitated by the ICS?
- Autistic specific support is required relating to diet, healthy eating/cooking (potentially via social workers), food issues and eating disorders. This is an urgent matter and is perhaps something that the ICS could investigate.
- Better access to community transport, or new initiatives involving VCSE, Private or Public sectors that can help people with autism / neurodiversity access transport more easily. Could ICS investigate this?
- Alternative ways for autistic people to access appointments aside from the early morning call to GP surgeries (as early mornings are difficult for some with autism, as are phone calls).

- More face to face appointments for people with autism as often they do not like to speak on the phone, and/or may not be comfortable discussing their diagnosis on the phone at home in front of the people they live with.
- Ensure that phone calls with people with autism are scheduled at a particular time so they are not unexpected and stressful, and pay special attention to ensuring they are undertaken on time. The same goes for appointments.
- Follow up on missed appointments and lack of response to medical letters by people with autism to explore the reasons for this. Text reminders etc may also be useful.
- Reasonable adjustments to be made to medical waiting rooms and other medical environments for people with autism such as providing a small, quiet room with adjustable lighting. Could work be done with PCNs and hospitals to achieve this?
- More advocates to attend appointments with autistic people, and promotion of the right to take a trusted person with you into appointments.

### Communication / information

- A single 'place' where all autism related resources are available in MK (not restricted to but including health) would be useful. This would include support options, services, information about autism etc. Currently everything is separate and difficult to find. Could the ICS support this, linking with VCSE Local Authority and linking with MK Council's Midos initiative?
- Consultation with individuals about what information they already access and what information they would like to access would be beneficial - along with discussions around putting advice into practice
- Work could be done with GPs to allow people with autism the time to ask questions - processing information can take longer so conversations and appointments will be longer than those for people without autism. Trust between the individual and the professional also needs time to build so individuals are responding openly and honestly, and do not feel intimidated.
- Receptionists, GPs etc asking the individual about their communication needs and preferences and receptionists or other staff meeting patients with autism before they walk into GP surgeries to make them feel more comfortable.
- Systems that flag up a person's autism and notes (gathered beforehand) around their communication needs and preferences so that receptionists, GPs and other health providers can take this into consideration when communicating would be helpful.
- Written summary of what is discussed in medical appointments for people with autism to take away with them. Could a simple template be designed for GPs to use for this? Can VCSE work with PCNs?

### Training, education and increasing awareness

- Training for health providers, including GPs and GP receptionists etc, on autism and neurodiversity generally, and how to support and communicate effectively. This could include how to make sure autistic / neurodiverse people understand the information given in medical appointments and that they are supported to feel comfortable and able to ask questions. Could this be something facilitated by ICS or that the VCSE are funded to do?

- Training to GPs and other health professionals on diagnosing autism and the differences to personality disorders. Also, that people of any age can be diagnosed (never 'too old').
- Promote Talkbacks user meetings as a place for health service providers (NHS, Local Authority, VCSE) to connect directly with autistic and neurodiverse people.
- Mencap has easy read recommendations and the National Autistic Society has an easy to read website version. Can these resources and model be used for health information?
- PCN's could have an autism champion that manages the communications with autistic clients e.g. emails and phone calls and avoiding automated systems, and has dedicated time to meet individuals at the door and undertake a debrief of their appointment once they have left. Citizens Advice MK have set up a vulnerable persons helpline - perhaps a model to replicate?
- More opportunities for organisations working with autistic/neurodiverse people, and for autistic/neurodiverse people individually to directly communicate with health providers to feed in lived experience and co-design services. Build on work with the Hospital. Initiate links with PCNs.

### Community Action: MK and VCSE Actions Taken

- Community Action: MK raising the need for specific eating disorders and diet support for people with autism to ICS.
- CA:MK has linked Talent Unlimited to MK Dons SET to provide specialist advice in tailoring their diet and healthy living sessions for people with autism within their Health Inequalities project funded through CNWL.
- Community Action: MK has flagged the need for specific eating disorders and diet support for people with autism to CNWL - and explore potential funding in the future.
- Talent Unlimited is exploring funding for collating autism related information, resources and services on their website.
- Community Action: MK has asked the team developing the Midos database to include autism and neurodivergence as a category in their cross sector database for the area that we and other VCSE organisations will use.
- Community Action: MK has a neurodivergence section on our signposting directory on our website
- Talkback delivering a 'wellness course'

## Living in Deprived Communities - Detailed Report

We spoke to Sonal Mehta, currently working with the ICS to create stronger partnerships with the VCSE across BLMK, and previously having worked as a community pharmacist in The Lakes Estate (one of the

most deprived estates in MK and the country) to gather information around health inequalities in deprived areas generally.

The first phase of the Denny Review revealed that living in deprived areas and being from an ethnic minority community or having disabilities led to particularly bad health outcomes. We therefore also asked specialist organisations working with those groups specific questions about experiences the people they support have of living in areas of deprivation.

## Accessibility

We were told that sometimes individuals living in deprived areas, that are in a mental health crisis, and have School aged children, found accessing appointments difficult. They would often prioritise getting their children to School over attending appointments.

Sometimes access to green space is limited, as are community spaces making it difficult for positive activities to run in deprived areas.

We heard that having a pharmacy within deprived communities is a positive.

*“There was a lot of anger when the pharmacy was going to be taken away. There was a pharmacist that worked on the surgery side, she was very good at advising people about what they can access via their surgery” - Sonal Mehta*

We were told that many people living in The Lakes Estate don't want to leave the estate, so taking health and wellbeing services or activities into the estate is very important.

It was highlighted that a lot of health inequality experienced by people living in deprived areas is complex and due to the wider social determinants of health, and the lack of access to all sorts of things across many aspects of life and over generations. We were told that whilst people might have the knowledge about what to do to stay healthy, they may not have access to them.

Important that the assets within deprived communities are appreciated and that community members are involved in initiatives to ensure they are effective, appropriate and accessible.

*“You need to work with local people and piggyback off what they already do. Don't go and do things 'to' them do them 'with' them.” - Sonal Mehta*

Taking advantage of opportunities such as the regeneration initiative in MK was highlighted, as well as looking at what can be built upon.

*“There's plenty of things that you can build on on the Lakes Estate instead of reinventing the wheel. When you stop looking at the community as a problem that*

*needs to be solved, you'll be able to see there are lots of good things that have gone before." - **Sonal Mehta***

## Communication

We were told that some people living in deprived areas may pick up and believe information relating to health that isn't based in fact or from a trusted source, but that it is important that healthcare providers handle this situation sensitively.

*"People need to be treated as humans. For example childhood immunisations, even if the information they have is based on information that isn't factual or not from the NHS, professionals still need to be sensitive towards the questions and where the original information comes from. Being listened to and taking people's concerns on board may impact people's ability to have conversations with healthcare professionals and feel comfortable doing so. You have to validate someone's feelings even if the information they base their feelings on are wrong. Being respectful that people have opinions." - **Sonal Mehta***

Using the fact that taking certain actions may increase how long you live isn't always the most effective incentive when communicating with people living in deprived areas, we were told, as sometimes people lack a sense of hope and purpose.

*"Some people may feel their life isn't enjoyable and therefore, do not see the point in living longer. For example giving up cigarettes. If you haven't got any hope then you might not want to 'live for longer'" - **Sonal Mehta***

## Common Health Issues

We were told that people living in disadvantaged areas tend to suffer from chronic pain more, and access to holistic treatment options are often not affordable in the same way they may be for others.

*"Some people may access addictive pain relief for the numbing effect." - **Sonal Mehta***

Sometimes people living in deprived areas lack confidence and self esteem, we were told.

*"Need to build people's confidence first in response to criticism around not having aspirations to leave the Lakes Estate" - **Sonal Mehta***



## Intersectionality - people with autism and neurodiversity living in deprived areas

When we asked whether people with autism / neurodiversity living in deprived areas experience greater challenges relating to health inequality, we were told that they do by the specialist organisations engaged in this research.

Noise is often particularly difficult and uncomfortable for people with autism to tolerate. Noisy neighbours are a big issue in areas where anti-social behaviour is more prevalent or where properties are poorly soundproofed. This leads to distress, complaints and animosity with neighbours.

There was also concern for autistic people that are vulnerable.

*"Some autistic people are vulnerable and can be taken advantage of. For example befriended and stolen from, bullied etc. In areas where people are more desperate for money due to economic disadvantage, or under more stressors themselves this may be more likely." - Talent Unlimited*

We were told it is difficult to get moved when issues arise, and difficult to get complaints listened to early on.

*"Often if people with autism were supported early, and issues with neighbours addressed early, they would not escalate." - Talent Unlimited*

It is also more difficult for economically deprived individuals with autism to afford transport to access specialist appointments, exacerbating health inequality and disadvantage.

*"Living in deprived communities increases anxiety around safety" - Talkback*

We heard that navigating and accessing online services can be a barrier to people living in deprived areas. Some people within these communities may be on a low income or may not be willing or able to use the internet, this then makes accessing online services really difficult.

Anxiety about safety may also be higher among people with autism living in deprived neighbourhoods. This concern could be a mental health 'trigger', resulting in people living within certain neighbourhoods, not wanting to go outside due to the concerns about 'what' could happen. We heard that the environment you live in can affect one's mental health. Anti-social behaviour in a neighbourhood can have a big impact also.

## Intersectionality - people with disabilities living in deprived areas

When we asked specialist organisations engaged in this research whether people with disabilities living in deprived areas experience greater challenges relating to health inequality, we were told that they do.

*"People living in deprived communities may not have endless use of a telephone or internet facilities to access support. This is even worse post Covid now more services are online or over the phone" - Talkback*

*"I tend to think the worst of the areas are the ones that can't communicate so well. They haven't got endless use of a telephone or they don't have endless use of internet facilities. Automatically that is going to knock them back." - MK CIL*

We heard from a former health trainer of the benefits of community based roles when working in areas of high deprivation with mixed population groups.

The Disability Resource Centre told us that the people with disabilities living in deprived areas often struggle to understand how to access the services they need, where to go and how to navigate the system. We also heard that disabled people living in deprived areas are often experiencing financial difficulties.

## Intersectionality - ethnic minority communities living in deprived areas

In terms of whether people from ethnic minority communities living in deprived areas experience increased challenges relating to health inequality, we were told that yes, they do. It was stated that all areas of life will impact health inequalities - whether this is caused by living in deprived areas or other factors. Some of the wider determinants of health mentioned include perinatal issues, neurodiversity, finance, cost of living, discrimination at work and the legal issues relating to this, engaging with Police (if more able to, could help prevent issues) and domestic violence.

We also heard that among the Somali community, diet can be an issue and in particular for young men, smoking and the consumption of khat.

## Intersectionality - people with learning difficulties living in deprived areas

Isolation is also a big issue within the LD community, and we were told that individuals that are isolated are often not picked up quickly enough. Isolation is particularly prevalent amongst those living in more deprived areas of MK.

*"Those living in social care settings can become extremely isolated - especially if neighbourhoods are intimidating.." - Camphill Communities MK*

## Recommendations

### Training, education and increasing cultural awareness

1. Education to professionals about the importance of listening and respecting patient's reactions and opinions on health matters, even if the basis of opinion isn't factual, in order to build a positive relationship and help to educate.
2. 'Good things' can provide online courses to update people's skills - There are also initiatives to provide funding for equipment in order to access the internet <https://www.goodthingsfoundation.org/>

### Adapting services and spaces to be culturally appropriate

- Stop looking at deprived communities as a problem that needs to be solved, look at the assets, opportunities (Regeneration) involve residents in solutions and action rather than 'doing things to' people and build on the good things that exist and have gone before (don't 'reinvent the wheel').
- Support people in mental health crises to access appointments, when also caring for children (especially if appointments clash with school runs etc)
- Take services out into communities where possible, as there is often a reluctance to travel outside the estate or area. Including holding health events within communities
- Recognise the value of pharmacies within communities and use them to support and promote community health and available services
- Provide accessible and affordable health and wellbeing activities, access to green space, confidence/self esteem raising activity and holistic treatments. Including more community spaces to run positive activities in.
- Providing housing for people with autism in quiet neighbourhoods and within homes that are well soundproofed.
- Early support for people with autism around and issues with neighbours so they are addressed early and do not escalate.
- Wider provision of safeguarding and support for vulnerable people with autism to prevent them being 'befriended and potentially stolen from'.
- Quicker moves arranged for autistic people living in unsuitable homes (e.g. with antisocial neighbours etc).
- Reduce digital exclusion - current or new initiatives to provide sim cards

### Communication / information

- Appropriate communication for people who are digitally excluded

## Ethnic Minority Groups - Detailed Report

- The Wisdom Principle
  - The Wisdom Principle (TWP) is a BAME-led organisation working in Milton Keynes. They are members of MK Mental Health Alliance and MK Intercultural Forum. The Wisdom Principle have been involved in extensive engagement and outreach within BAME communities

within MK to understand more about Health inequalities, what causes them and how they could be reduced.

## Communication

We were told that both verbal and non-verbal communication can be difficult for some ethnic minority community members. Some non-verbal communications are not always understood, and the ways sentences are constructed can be difficult to understand with gaps being filled by assumptions. It was suggested that a way to overcome this is ensuring that health services have professionals within teams from such communities so they can understand and facilitate understanding.

In terms of what sources of health communication are most trusted, we were told that being told something verbally is effective, as opposed to leaflets etc. Stories are much more effective in some ethnic minority communities rather than purely factual information. Many people need real stories and examples to be added to communications. The opportunity to discuss the information is also vital to check that it has been translated and understood correctly.

## Accessibility

We were told that not knowing how to get help or what help is available is a big barrier to accessing health services amongst ethnic minority groups. It feels as though there is no definitive place to get all of the information across the piece and many don't know where to begin as it is such a complicated picture.

*"Not knowing where to get help or understanding the different segments of the service is an issue. For example, the routes and where referrals go to." - The Wisdom Principle*

Fear of harm, experiencing discrimination or abuse, and fear of authority can all lead to some people from ethnic minority groups avoiding accessing health services and support. This is exacerbated by the fact that Community members are often quick to share stories relating to negative experiences of visiting GP or other health providers. TWP advised us that now is an opportune time where people from ethnic minority communities want to arm themselves with information. Topics include health conditions such as perinatal, neurodiversity and HIV but also information linked to the wider determinants of health such as information about pro bono support and domestic violence. The interaction between health and the law is really complicated and can be difficult to negotiate. It likely has more layers of stigma attached to it than other topics.

Going to where ethnic minority communities are was explained as important to increase access to health services. Introducing services in a familiar, informal space can help to remove fear and normalise the

idea of accessing them before people need them, so if and when they do need support they will feel able to access the right services.

The Wisdom Principle would welcome more opportunities to be able to directly communicate the issues faced by ethnic minority groups relating to health care to health providers and decision makers.

“There is so much we would want to say to specific service providers e.g. through stories we have heard. We would like to find a footing to sit at that table and say we have heard from this many individuals about this and this is what their recommendations are and these are our thoughts”.- **The Wisdom Principle**

The Wisdom Principle told us that they meet groups that are really organised, and function really well for their communities but stay parallel to the mainstream services. However, they do wonder what unintentional barriers may be there due to these groups working closer to the mainstream services.

We were told that there seems to be ethnic oriented community groups that provide feedback to mental health charities such as Mind BLMK and Rethink Mental Illness as opposed to mainstream groups. TWP did wonder why this was and the challenges present to result in this.

It is felt that there are not enough opportunities for individuals from ethnic minority communities and support organisations to feed in experiences to health providers and take part in co-designing solutions and services.

“How do these very organised communities that are self run, self funded who are constantly in this knowledge base, able to access service providers? Is there something that says if you are a group of more than 100 people that you can approach a GP and write to them [about a particular issue] - something structured, something that has a pathway that feeds back” - **The Wisdom Principle**

There is also a lack of feedback when information from ethnic minority communities is collected. People give their information and time and don't hear what, if anything, happened as a result of it. There needs to be pathways for that circular communication from service providers to communities, as well as from communities to service providers. At the moment it feels there is a lack of openness from service providers.

*“When all of this research is done, often it does not return to the community. Therefore you (people from ethnic minority communities) feel, well I fed into it, I'm not yet seeing the change and we understand that change takes time but sharing the progress of the journey does not.*

*Doing this [sharing the progress] is very transparent, immediate and clear and gives people grace and patience to endure the slow pace [of change] that is necessary as it is a big piece of work/change that is interconnected and there is so much to consider.” - **The Wisdom Principle***

Unfortunately, we were told that there were many issues and barriers with providing feedback. Feedback being effective requires both parties involved to be on a common footing, including shared language and shared sense of power or impact of feedback. This footing or connection between people from an ethnic minority community, and mainstream services rarely exists impacting effective feedback. The person providing feedback and the service collecting the feedback do not share the same aims, language and pre-understanding. This impacts both parties, making both the request for feedback from services ineffective and the response or engagement with feedback by people from ethnic minority communities less likely.

Additionally, the type of feedback that services want to collect is chosen by them and this may not provide opportunities to include the type of feedback that service users/ community members want to provide/feel the service provider needs to hear.

*“Another reason feedback isn't always given is because services ask for feedback about the point of care but people want to provide feedback about the structure and strategy of the service - they want to say things like is your service diverse in your workforce? Are there people who look like me in your service? Rather than answering, was the greeting okay? What makes that service okay is making sure the service feels like it is representing you and is presented in a way that works for you - there is a reluctance to to expand feedback to not just be about transactional paths of services but to be more about how we structure services, how we fund services and how we locate services.” - **The Wisdom Principle***

There doesn't seem to be an openness from service providers towards welcoming different types of feedback as quoted above or a template to change in regards to feedback. It was felt that there is a way to go around the area of system change.

We heard that there are challenges around bringing service providers and community members together to provide feedback on services due to the expectation and accountability attached to meeting in person. For example, we were told that there have been great turnouts from service providers at events to hear

communities' voices and learn. But service providers did not attend the event that was held to allow community members to voice their opinions directly to these service providers.

The Mental Health Alliance provides an opportunity for The Wisdom Principle to feed information to health services (CNWL and Transformation Board) but there needs to be the opportunity for organisations to be honest about what is working and what isn't and health providers and other organisations need to be held to account around what they are doing with the information they are hearing about health inequality and the changes that are required and how funding is used. There is a keenness for structures to be co-designed that allow this honest, two-way, productive communication that results in real action and change.

*"If a space is facilitated well, there is space to harness some vulnerability into it, there is a willingness to share accordingly but holding it to account is where things are let down. How do you keep the conversation going as change progresses? It can't just be a one way information flow, it can't carry on like that. People aren't going to want to keep giving feedback without anything in return, without seeing any progress" - **The Wisdom Principle***

There are a great deal of community led activities happening within ethnic minority communities in MK, which are community led. Covid really highlighted and brought out community led responses, activities, expertise and skill. Therefore, there are a lot of incredible activities to link in with in terms of working jointly to engage with the community and address health inequality.

## **Cultural differences**

We were told that the 'white coat effect' can come into play within some ethnic minority groups, and that patients need to be given permission to give their opinions / suggestions, be advised that they are part of their own treatment and can say yes or no and have their responses acknowledged and respected.

*"Individuals may come from countries or regions where the professional tells you everything you need to know. However, within the UK, patients collaborate with the professional and can decline the service or interventions. To challenge a professional requires courage.." - **The Wisdom Principle***

If a GP is trained to expect patients to participate etc, as this is the majority cultural norm, they may not probe further in order to draw out issues amongst ethnic minority individuals that may be reluctant to communicate with Doctors. For example, if an individual does not tell a GP that they are feeling stressed, the GP may not explore this.

Some ethnic minority groups expect and need a more personal experience when seeking medical help in order to build trust, it was explained. This might include the professional asking about wider aspects of their life e.g. how their family are. They need a relationship or connection with one person, a face not just a service. They need to feel they are being treated as an individual. Often this familiarity and friendly interaction will 'warm people up' to speaking about their health concerns. The whole person, including their religion, needs to be considered.

*"People want to speak to a person, not a service. By putting a face to the service, knowledge and trust may be increased, which would improve individuals' experience of the service." - The Wisdom Principle*

The Wisdom Principle explained that they appreciate time is pressed for the NHS, but if certain cultures value this so much and they are not getting it, it creates health inequality. It was explained that for some ethnic minority groups, time equates to care, so being rushed through an appointment can lead individuals to feel the service is not there to care for them and their health, reducing trust and increasing reluctance to access services.

Younger people within ethnic minority communities are becoming more willing to speak about health and the barriers they face and The Wisdom Principle hopes that this will eventually have a positive impact on those experiencing health inequality.

Although there may be a good level of understanding around being healthy, some ethnic minority communities may not go to service providers for help. They may use natural remedies instead of mainstream remedies. There is huge self reliance within some ethnic minority communities and often individuals only seek support when issues are critical. There may also be a different perception of what healthy and unhealthy is, and in some Communities taking actions to prevent ill health is not a common practice.

It was suggested that more funding should go into supporting ethnic minority communities to co-create non-medical health services. That way Communities are involved from the inside and access isn't such a big jump. It is also the only way to redesign a system that was created for the mainstream, so that it is also fit for purpose for those people and communities that fall outside of the mainstream. Designing services that are appropriate, welcoming and accessible for ethnic minority communities is the only way to ensure they are effective and support the reduction in health inequality.

*"The system wasn't made for me, so it's never going to work for me" - The Wisdom Principle*

## **Mental Health**



We were told that the term 'mental health' does not translate into some languages, as it is just not a concept in some ethnic minority groups, although the same experiences in terms of mental health are being felt. A translation may not have the same meaning and translation can be over simplified when it is actually a complex task. Mental health issues and experiences may be communicated differently, which may lead to some symptoms or mental illnesses not being picked up, or individuals not accessing appropriate services. Some ethnic minority groups may think of spiritual health instead of mental health.

*"Some ethnic minority groups might express feeling stressed or anxious as a sense of feeling out of balance for example, but because they don't use the word stress the individual may never access services to help with stress." - The Wisdom Principle*

We learned that some mental health issues in some ethnic minority groups can just be thought of as normal to experience, e.g. PTSD in migrant communities, and support to deal with such issues will not be sought.

## Common Health issues

We learned that stress is a common health issue experienced by ethnic minority communities. Often they may be working a number of jobs, have a high number of children and get very little sleep - but this becomes the norm for them.

Other health issues that were highlighted included headaches, rashes, long term health conditions, muscle strain, high blood pressure (hypertension) kidney and liver issues.

In terms of weight, diet and food, we were told this is a complex issue. There are cultural differences in the way health and healthy weight are defined - and this might not relate to being overweight or having a high BMI, but whether weight allows a person to do the things they want to do.

*"A person might not see their weight as an issue just because they have a high BMI. If their weight starts to stop them dancing at church however, they may then see it as an issue" - The Wisdom Principle*

## Recommendations

### Adapting services and spaces to be culturally appropriate

- Workforce diversity within healthcare services
- It was suggested that more funding should go into supporting ethnic minority communities to co-create non-medical health services
- Mainstream/statutory services to link in with pre-existing activities to work jointly to engage with communities and address health inequalities.

- Designing services that are appropriate, welcoming and accessible for ethnic minority communities is the only way to ensure they are effective and support the reduction in health inequality
- Further research to explore barriers ethnic minority groups working parallel to mainstream services may experience
- Services can try to ask people what is going wrong, without the people receiving the feedback feeling like they have ownership of the feedback they are collecting
- Services should go out into communities where possible

### Training, education and increasing cultural awareness

- Cultural competency training for GPs and other healthcare providers and staff teams.
- Culturally sensitive education about what being healthy is and raising awareness of some health conditions not being 'expected' e.g. diabetes during pregnancy or stress
- Culturally sensitive approaches to weight, weight management and weight education

### Communication / information

- The Wisdom Principle would welcome more opportunities to be able to directly communicate the issues faced by ethnic minority groups relating to health care to health providers and decision makers
- The Wisdom Principle would like to co-produce something that allows groups to voice their views
- Include real stories and examples to outgoing communications
- Opportunities to discuss information to ensure information has been translated and understood correctly
- Sensitively and politely discussing current healthcare time constraints to avoid people feeling that services do not care
- Make appointments more personal when people are seeking medical help e.g. healthcare professionals to ask about wider aspects of a patient's life.
- Raise awareness of seeking help earlier - before crisis
- Raise awareness of seeking help for conditions such as PTSD
- GP's to facilitate deeper conversations. Just because someone does not mention something doesn't mean they are not experiencing it
- Structures to be co-designed that allow honest, two-way, productive communication that results in real action and change.
- Develop ways to discuss mental health and mental health symptoms/conditions if translations do not easily facilitate this
- Services to allow service users the opportunity to provide feedback on a range of issues, not just what the service provider wants to receive
- Reduce barriers that people from ethnic minority communities may feel when providing feedback as highlighted within the report

- There needs to be pathways for that circular communication from service providers to communities, as well as from communities to service providers. At the moment it feels there is a lack of openness from service providers

## Ethnic Minority Groups: Cancer Care Focus - Detailed Report

- MacMillan Cancer Support Research, Phase One, Project workers from Community Action: MK
  - Community Action: MK undertook research on behalf of Macmillan cancer care to understand why take up of their services is lower within ethnic minority groups, including what barriers are faced and what could help services become more accessible
- MacMillan Cancer Support Research, Phase Two, Project workers from Community Action: MK
  - Following the initial research, Community Action: MK undertook a second phase to dig deeper into the experience of faith communities within ethnic minority groups in terms of access to and experience of cancer support.

### Person centred and inclusive

We heard that more culturally appropriate advice is needed in regards to diet and access to food within hospitals. When health professionals discuss 'healthy eating', it was often felt that this advice was only related to narrow diets and did not provide specific advice around how to make food from all cultures healthier. People were often advised to eat 'healthy' diets but when provided with information around healthy food, were not offered culturally appropriate nutritional advice or meals - resulting in an increased difficulty to stay healthy. We heard that the approach currently used was not person centred enough. In regards to access to food in hospitals and nutritional advice, food could be offered along with meal plans or suggestions regarding cooking but they were only based on one culture. This included meals that people from some communities and cultures would not eat.

*"Healthy food, healthy diets, healthy lifestyle - it wasn't the food they (people from ethnic minority communities and faith groups) were eating - how can I change the food I already eat and make it healthy? - it caused some alienation and feelings of not fitting in. [Professionals] need to be aware of different cultures and religions and what is appropriate. " - CA: MK Staff member*

*"Their family member was bringing them food due to their lack of interest in hospital food - this meant they weren't eating 3 meals a day." - CA: MK Staff member*

Cultural awareness was discussed to help ethnic minority communities and faith groups feel better supported when connecting with health services/professionals in the future. We heard that cultural awareness training would be beneficial for health professionals and that cultural awareness of appropriate interaction between genders would help to alleviate barriers to interacting with some communities. Additionally, health professionals need to be aware of different cultural and religious aspects of healthcare. For example, a smear test and the cultural implications of this procedure.

We also heard that health conditions such as cancer can be stigmatised in some cultures and faiths. Therefore, privacy is important. If a health condition is stigmatised, it was advised that loneliness may be increased.

*“More cultural awareness - cultural training for specific groups. A barrier that we had when talking to groups as women, there may have to be a champion that meets the criteria of those in the group you are interacting with - males may not talk to females and females may not talk to males.” - CA: MK Staff member*

### Current service provision

We were told that there feels to be a lack of personal connection with service providers including cancer support such as fewer nurses and having a different GP on each visit. It was also reported that issues relating to healthcare do not seem to be heard and that when issues are raised, they are not followed up.

Additionally, in regards to current cancer care services, it was reported that these services seem to be tailored towards a single demographic. For example, we were told that breast prostheses are not inclusive enough.

*“When a lady had breast cancer and had her breast removed, prostheses in general, there wasn't anything for her body that suited her skin tone. So you've already got this alien thing that you've had taken away from you and you have this alien thing to be using to help you move on from this - she said 'you think when you've had cancer, you think you'll get better and you think you'll be the same as you were before but your not the same'. It's a different feeling and a different life that you're living. Especially if you have a body part offered to you that's not your skin colour, then that's really difficult”. - CA: MK Staff member*

### Communication and Language

We were told that health terminology can be a barrier faced when accessing cancer support for some ethnic minority community members. Complex information can create difficulties in understanding especially if English is a second language. Additionally, services may need to explain medical terms, especially if a child is translating for their older relative. Additionally, some information sheets are unavailable in different languages, creating a huge barrier to accessing and understanding health information.

*“In a lot of families, the only person that can translate is a child, this isn't always appropriate. [The translator] needs to be able to translate from English and also explain the medical terms. It can be difficult to find someone” - CA: MK Staff member*

In regards to translation, this can also be a barrier when accessing cancer support in 2 different ways. 1 using a translation service and 2 when using a family member. It was reported that although services may offer translation services, interpreters aren't always readily available. In regards to using a family member to translate, it was reported that sometimes females with English as a second language rely on males to translate. However, this may not be possible and/or cause the female to feel uncomfortable if the topic that needs to be discussed was a personal, female health condition.

*"Often 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 e.g. personal female issue?." - CA: MK Staff member*

Additionally, sometimes community members rely on the 'head of their community' for translation of health information due to a lack of English language skills. This reliance can be problematic and at times, information may not be passed on such as the need for health checks. The term 'gatekeeper' was heard and although community leaders are a great way into communities, sometimes leaders can become 'gatekeepers' and do not pass information on.

*"Education about the need for health checks for individuals would be beneficial - sometimes it (information) just goes to the gatekeepers and the other members are not even aware they should have it." - CA: MK Staff member*

We heard that awareness of Macmillan services were varied with some people having great knowledge of and supporting Macmillan and others having never heard of them before. Overall, it was found that knowledge of Macmillan cancer support services is better known amongst people from faith groups whose first language or household language is English.

### Accessibility and Trust

It was suggested that NHS services should allow time to build trust with people in a long term manner. Building trust takes time and developing trust to develop relationships with communities and understand what they need will require a long term commitment. It was suggested that trained volunteers or employed staff to help with this could be beneficial. Additionally, we were also told that age can sometimes correlate with how trusted a person's opinion or advice is and how well it is received. For example, within some communities, if a younger professional provides advice, it may not be as well received due to their age.

*"The second part of the research was about faith - you need to build trust, you can't just go out and ask sensitive questions e.g. about cancer. Not everyone wants to talk about it. You need to allow the time to build trust, not just putting in a service and expecting it to work or people to attend. ." - CA: MK Staff member*

We also heard that within some communities, there is a reluctance to ask questions of, or challenge health professionals. Such as Doctors as they can be very highly respected. Furthermore, sometimes people may not ask health professionals questions as they may be unaware of the support available.

In regards to accessing services, we were told that health support needs to go into communities to reach people and that outreach work is important.

*"Services need to go out into the community rather than the communities reaching out to the services. That could increase access. One of the recommendations was working with the existing networks." - CA: MK Staff member*

## Faith

We were told that faith and/or spirituality are not always well understood or considered by health staff/services. Some people from ethnic minority communities and faith groups feel that the NHS do not take consideration and care about the importance of spirituality in healing in relation to cancer. This is an aspect that is important for emotional wellbeing for people using a service and different cultures and faith groups do this in a different way. It was reported that this lack of consideration can make service users' healing process more complicated. Additionally, there may not always be appropriate spaces or support for service users to pray.

*"Not being able to pray may make them (patients with cancer) lose hope and they may just want to stay in hospital and sleep." - CA: MK Staff member*

Praying was mentioned during both interviews. It was reported that some faith communities have beliefs that cancer is a punishment or a test from God and faith leaders can advise people that praying is the only treatment. However, the person with cancer may have wanted to bring up their belief that God also provided Doctors and therefore, they pray and work with the Doctor. We heard that the recommendation to pray only, can prevent or delay people from accessing treatment. Therefore, there needs to be research into ways that faith, including prayer, can be used alongside medical interventions. Additionally, service users can feel that nursing staff not being allowed to pray for them can affect their healing.

## Recommendations

### Training, education and increasing cultural awareness

- Cultural awareness training for health professionals to maximise staff awareness of all cultural and religious aspects of healthcare. This training could be tailored around demographics of the area in which the service operates, and help them to take a faith and culturally sensitive approach to cancer care including recovery.
- Raise awareness of the importance of asking questions within health decisions/consultations - promote this way of interacting with healthcare staff

### Adapting services and spaces to be culturally appropriate

- Research/exploration into ways that faith, including prayer, can be used/included alongside medical interventions.
- Greater support and more availability of space for patients to engage in faith based activities e.g. praying within healthcare settings
- Wider variety of foods offered in hospitals/inpatient settings
- Named GP's for people with cancer to enhance their patient journey experience and maximise rapport
- More inclusive prostheses
- Outreach work and taking services to communities
- Trained volunteers or employed staff to help with building trust within ethnic minority communities

### Communication / information

- Health information to be available in a range of languages including leaflets and online resources, and in easier to read and understand formats that do not include complex medical terminology
- Greater use of culturally adapted eat well guides, and multicultural nutrition websites for healthcare services such as [here](#)
- Provide feedback during the stages of complaint management
- Greater availability of translators and promotion of these services in particular for female related health conditions e.g. gynaecology departments
- Share information around health checks and available services with community leaders as well as community members individually (as in some cases community leaders can withhold information / gatekeep)

### Actions

## Gypsy, Roma, and Traveller Communities - Detailed Report

Finding VCSE organisations to speak to that engage with Gypsy, Roma, and Traveller (GRT) Communities in MK was challenging. However, we were able to gain some insights from other professionals with experience of working with GRT groups in the City:



- Danny Conway
  - Danny worked for many years as a Local Authority Social Worker. He also worked as a Commissioner within Children's Services in MK. Danny's work has seen him focus on engaging with traveller communities in MK through Charing the Gypsy Action Forum, which brought together Gypsy Travellers and agencies to co-produce action.
- Ethnic Minority Achievement Team - MK Council
  - We received written responses to our questions from the Ethnic Minority Mentor working with GRT communities in MK

## Serious, long-term investment is needed to engage with GRT communities and tackle health inequality

The need for long-term investment to properly and helpfully engage with MK GRT communities was a point that was very strongly made. We were told that if GRT communities are supported consistently over a long period of time by trusted, named visitors into their communities, and supported to access health services, experience has shown they will. However, without this special provision that builds trust and offers tailored support, it was felt that health access will continue to be poor and health inequality will persist. This work may take years of effort and long-term investment, but have substantial health benefits.

*"GRT communities will engage and access health services if they are helped to. The last time I saw anything that really worked in MK was 2002-2006 when Health appointed a full time health visitor to the GRT communities, based out of Hilltops Surgery on Great Holme. Two of her notable successes were the complete re-building of the Calverton site and setting up of the Gypsy and Traveller Action Group. I fondly recall the inaugural meeting when a leading voice from the Irish Traveller Community said she didn't mind joining a group, as long as it had ACTION in its title. Most important was that the health visitor got the trust of the three communities: English Gypsies; Irish Travellers and those on the Roadside. This role was discontinued in budget cuts" - **Danny Conway***

The long term engagement required includes social work, support to understand what health services are available and support and guidance to access it. The EMA Mentor told us that GPs are accessed by most GRT community members that need them, and the service is good when accessed, but there is a lack of knowledge around what GPs can provide.

*"Knowledge around health is improving, but they (GRT Communities) often need to be told to see a GP/ Dentist by another professional as they do not know what services GPs etc can offer and do not engage with Family services etc" - **EMA Mentor***



We were told there is a great need for services (e.g. dentistry, physical and mental health services) to go out into GRT communities to engage directly, and take their services into those communities where possible. We were told that there are no current programmes or activities within GRT communities in MK around improving health. However, interventions during the pandemic were successful.

*"In the pandemic I supported and encouraged as well as myth busting with the NHS which worked well but there are no programmes in place to the best of my knowledge now" - EMA Mentor*

## Communication

In terms of health communication, we were told that anything that is written can be an issue as levels of literacy are low within the GRT community. Any health services that require something to be read or written can be problematic and a potential barrier to access altogether.

*"They (GRT Communities) usually ask me, or a school staff member they know well, to read any letters to them and explain what it means." - EMA Mentor*

Having the level of verbal communications to have health issues understood when communicating with health services is also difficult. It was also suggested that 'jargon' used by health practitioners can be difficult for GRT communities to understand, and 'strong accents' can make understanding information given over the phone difficult.

We learned that online information relating to health is rarely accessed by GRT communities, although social media is sometimes used, along with 'word of mouth'. Lack of online communications in the GRT community is also an issue in terms of having their voices heard around health.

*"There are options (to feedback re. health) through Healthwatch and if they raise any concerns I will signpost to PALS, CCG etc if needed, but as these are mainly online I suspect that they do not utilise the schemes." - EMA Mentor*

We were told that getting in contact with the right services at all is difficult, and referrals for specialist health support beyond the GP can be difficult as some GRT families 'don't know what to say and waiting lists are very long'. A better understanding of how referrals work, how to get them and how long they take would help.

## General barriers and issues

Particular support is required for roadside GRT communities (often made up of English Gypsies and Irish Travellers). Because they often don't know how long they will be able to stay in one place before being moved on, accessing local health services is very difficult.

We learned that there is often a perception amongst GRT communities that health centres 'look down on them', which can put them off visiting their GP or other health service and/or it is a stressful experience when they do.

*"[There is] a feeling like if you (GRT Community Members) go to the health centre, they (staff) are looking down on you and looking at you as an outsider like what are you doing here?" - **Danny Conway***

We were told that often GRT community individuals or families tend to try to solve health problems themselves before asking for help from the NHS. This means that when they tell a GP or other health provider they need help, it is very likely they do and that the issue needs addressing ASAP.

Again, we were told that the building of trust over the long term is crucial. This is the only way to gather lived experiences to truly understand the issues and barriers GRT communities face relating to health. This would also allow GRT community members to express ideas for change that would really work, and be part of co-designing solutions that will actually help them. However, we were told that GRT communities within MK are currently very disengaged.

*"It is only a few months ago that I was asked to approach the Gypsy and Traveller communities on the matter of access and barriers to health. I then met a thank you, but firm no... My general comment is these two communities, (that doesn't even include the people with no right to even temporarily put down in BLMK) are so disengaged that they do not even want to talk to anyone about their health needs and experiences, even though they still trust me" - **Danny Conway***

*"We did try to organise a multi agency meeting for the community but none attended on 2 occasions, this had a representative from Police, MH team both adult and child, community nurse and education." - **EMA Mentor***

## **Common health issues**

Danny Conway told us he believes the health inequality experienced within GRT communities is amongst the worst of any population group in MK. Health data and statistics would seem to back this up<sup>1</sup> with life expectancy thought to be 10 to 12 years less than that of the non-Traveller population. In 2011 14.1% GRT people rated their health as bad or very bad compared with 5.6% nationally. 42% of English Gypsies are affected by a long term condition, as opposed to 18 % of the general population. Gypsies and Travellers are nearly three times more likely to be anxious than the average for the general population and just over twice as likely to be depressed. One in five Gypsy Traveller mothers will experience the loss of a child, compared to one in a hundred in the non-Traveller community.

Health was reported as generally poor across the board, with environmental conditions exacerbating this.

We were told that mental health issues are common for GRT children, and quicker access to support from CAMHS would help, along with more regular visits to home educated GRT children to check on both attainment and mental health.

*“Although there is no written evidence to support this, I am aware that most of the GRT Community in MK wish to retain their heritage and values without the persecution that goes with this, my experience shows that the retention of the accent and poor regard for education, together with the expectation they will be discriminated against is a big problem for the school age children and appears to lead to the behavioural issues towards the end of year 5 through to year 8 where most have withdrawn from school.*

*There still appears to be a lack of aspiration with the youths believing that they are only good to run a home or undertake manual labour. There is a belief that they do not require an education as they will get work or enter college at 18. NEET is an issue within the community as are issues surrounding technology as the parents do not understand or allow themselves to be shown how to protect children online. Sadly this has not improved since the Covid pandemic and many older children are subjected to online bullying. At present I am aware of about 25% of the children aged 12-18 being subjected to significant bullying (racial abuse, threats of violence, sexual explicit content). This relates to the cases I have been made aware of by the parents or school.” - EMA Mentor*

Mental health issues were also cited as common amongst adults, and it was explained that stress is a big issue across the GRT community. We learned that violence is often used to settle disputes within some

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<sup>1</sup> Statistics from:

- Gypsy, Roma and Irish Traveller ethnicity summary - GOV.UK Ethnicity facts and figures ([Gypsy, Roma and Irish Traveller ethnicity summary - GOV.UK Ethnicity facts and figures \(ethnicity-facts-figures.service.gov.uk\)](https://www.ethnicity-facts-figures.service.gov.uk/gypsy-roma-and-irish-traveller-ethnicity-summary))  
-Tackling inequalities faced by Gypsy, Roma and Traveller communities - Women and Equalities Committee ([Tackling inequalities faced by Gypsy, Roma and Traveller communities - Women and Equalities Committee \(parliament.uk\)](https://www.parliament.uk/women-and-equalities-committee/tackling-inequalities-faced-by-gypsy-roma-and-traveller-communities))  
-University of Bedfordshire ([Written evidence - University of Bedfordshire \(parliament.uk\)](https://www.parliament.uk/written-evidence-university-of-bedfordshire))  
-Census data

parts of the GRT community, which again makes for a stressful situation, and statistics show that 20.4% of the GRT community is made up of lone parents compared with 7.2% nationally. 55% of the GRT communities the EMA Team support are living in a house/flat. At least 30% of these would prefer to live on a site but there is not space. 6 families were driven off of the site they were resident at, outside of Milton Keynes.

Stress is a particular concern for roadside GRT communities, as they never know how long they will be able to stay in one place. Their options are limited as when they apply for legal rights to use land they are refused, so their lifestyle is being made illegal. Ancient, cultural ways of life have been eroded making the lifestyles of Roadside GRT communities very difficult, with the Local Authority moving communities on via Environmental Health. All of this means that life as a roadside GRT community member is stressful, and makes some aspects of leading a healthy lifestyle more difficult (e.g. cooking healthy meals).

*"That uncertainty of lifestyle is so difficult - the government is trying to make their lifestyle illegal. Originally this would have been solved by the planning laws as people would be able to apply to stay at a site but the council would decline them" - **Danny Conway***

We were told that gynaecological issues seem to be common for women within the MK GRT community, with one suggestion being that this may be caused by women being encouraged to marry and have children very young in order to 'keep them pure'. There is also a reluctance amongst females in the community to talk about intimate health issues.

Dental health is poor and dental issues are common. We were told that dental care is very difficult for GRT communities to obtain.

Early cancer deaths has been a trend observed with GRT communities in MK.

We learned that mobility issues are often experienced amongst over 40 year olds in GRT communities, and the GRT community would benefit from knowing what support can be offered at home (e.g. for older people with dementia or other issues).

Access to fresh food is difficult for GRT communities, as many cannot afford it. We were told many community members are on benefits, and the cost of heating for example, for many on sites is extremely high (£150-200 p/w).

Access to support around parenting was suggested as a need in GRT communities:

*"I also feel they (GRT Community Members) would benefit from parenting skills/ new parent support as I see the same mistakes in child care being repeated time and time again as parents raise their children the way they were raised without much*

*exposure to alternative ways.” - EMA Mentor*

The EMA Team told us that around 30% of the school age children they support have mental health issues and/or are autistic, with 5% of children having a learning disability and one child a physical disability. There may be more adults supported by the EMA Team with physical disabilities (aware of 6) and mental health conditions (aware of 3) but they may not have disclosed this. We were told that in primary School males struggle with education more than females, and about 80% of the boys the EMA Team support require intensive additional support. In secondary school those struggling academically are evenly split between male and female. The EMA Team are aware of adults with physical disabilities.

*“Most adults seem to have health issues that are being managed by GP & local hospital but they do still struggle to make GP's understand what the issue is due to barriers on talking about bodily functions.” - EMA Mentor*

The GRT community are spread across MK, housed on either the site at Willen or at Calverton. Neither site has a footpath to link it to the main thoroughfares making walking the children to school dangerous and difficult.

## Recommendations

Fixed sites and housed travellers, - health visitor, and GRTs passing through.

Trusted long term engagement, flexible health provider and outreach to sites / individuals

## Training, education and increasing cultural awareness

- Specialist analysis and a deeper trawl of the health data relating to GRT communities is needed to get a real grasp and more detailed understanding of the situation. Concern that the extent of health inequality within the GRT community is unknown and the situation is likely to be alarming. More data would allow the biggest issues to be understood and explore the reasons for them.
- Training for health providers around GRT lifestyles to increase cultural competence and understanding of people's perceptions and experiences (so health professionals 'get where they are coming from'). I.e. understanding that GRT people are only likely to ask for help if they really need it, and females may be reluctant to speak to health professionals about intimate health concerns etc.
- Support GRTs to increase understanding of what health services can offer (e.g. GPs), how referrals work, how to get them and how long they take and what services are available at home.
- Training and support for GRTs around parenting skills.

## Adapting services and spaces to be culturally appropriate

- Long term, consistent, named visitors to GRT communities are needed to achieve positive engagement, trust, and to use lived experience to understand issues and support community members to co-design solutions that will work for them to reduce health inequality.
- Special provision for roadside GRT communities to access health provision, for example same day appointments to make access possible.
- Special work to make health settings more welcoming to GRT communities (to combat feelings that they are not welcome or 'looked down on').
- Services (eg dentistry, physical and mental health services) going out into GRT communities to engage directly.
- Digital exclusion is an issue - more ways to access information and services and feedback about services that aren't online or written would be beneficial.
- CAMHS support being available earlier and quicker, as mental health is a big issue for young GRT people.
- More visits to GRT children that are educated at home to monitor attainment and wellbeing (mental and physical)
- Make it easier for GRT communities to apply for legal use of land, including appropriate transit sites.
- Specific support to female GRTs to combat high prevalence of gynaecological conditions

### Communication / information

- Avoiding written communications or need to write as literacy is a common issue in the GRT community and could form a big barrier.
- Services communicating with GRT communities in 'simple English' and not using complex jargon or phone calls from professionals with strong accents.
- Forms for GRT communities being simplified (12 pages or more for Paediatric referral with terms that are not in everyday language is very difficult for example)
- Keeping GRT families updated on health issues in a verbal or very simple written way.
- Increase awareness of available services, including wider support such as Foodbanks, Community Fridges etc to increase access to healthy food, support to decrease heating bills and/or financial support.
- Communicate the importance of good dental health and how to access services

## The LGBTQ+ Community - Detailed Report

- Q:alliance are the LGBTQ+ support charity for Milton Keynes, and are particularly well placed to feed into this report as they are currently involved in research and pilot projects related to mental health inequality in terms of access and experience for LGBTQ+ people in MK. The below also includes input from the CA:MK team gained from speaking to a range of groups with LGBTQ+ users or directly to LGBTQ+ people in MK, as well as via some insights recorded on our MK Community Data Tool.

## Lack of knowledge and understanding relating to the LGBTQ+ community

One of the biggest issues facing LGBTQ+ people in MK relating to health provision is lack of knowledge and understanding. This includes a lack of knowledge around the LGBTQ+ community itself, as well as the issues they face. For example, poor knowledge around appropriate use of pronouns and what certain terms mean relating to sexuality and gender identity (a lack of cultural competency). It was noted that pronouns and terms are particularly important to younger LGBTQ+ people as a way to communicate who they are and how they feel - so a firm understanding and recognition of this is vital if health services want to support young LGBTQ+ people. A lack of understanding of specific issues such as gender dysmorphia and the gender reassignment process were mentioned in particular, with poor communication around what the transitioning process will involve to transgender people in MK.

## Reluctance to access health services

This lack of knowledge within healthcare settings around LGBTQ+ specific needs and lack of cultural competency all add to the reluctance many LGBTQ+ people in MK have around accessing health services. Many LGBTQ+ people say they struggle to communicate with their GP for example, with some anecdotal evidence suggesting some GPs respond to gender identity issues inappropriately.

*"One young person we work with, biologically a boy, told us they confided in their GP that they were questioning their gender identity, and were told to, 'play more football, that will sort you out'..." - MK YiS - recorded via MK Data Tool*

*"We have had several young people come to us throughout the last year or so saying that their GP has been dismissive of their issues around gender identity. One young trans woman was told she should start playing more football and that would sort it out by her physician.." - MK YiS - recorded via MK Data Tool*

GPs can also assume a patient is heterosexual, and treat them as though they are in a male-female relationship, making some feel uncomfortable in correcting them. Many LGBTQ+ people are scared of accessing mainstream services for fear of LGBTQ+ phobic responses and Q:alliance feels the LGBTQ+ community don't access health support early enough. "Gender and transgender education for GP's" has been recorded on MK Community data tool as something that is very much needed.

*"In some cases LGBTQ+ people avoid interacting with GPs altogether because they fear the worst - lack of understanding or an LGBTQ+ phobic response..." - Q:alliance*



## **Health care relating to the transitioning process for transgender individuals can be stressful**

The issues facing people who are transgender, particularly around the transitioning process, was highlighted as a big concern. It has been reported that there is a lack of clarity and understanding following interaction with health services around what the transitioning process will involve, and what the timeframes are. This can be extremely stressful, confusing and isolating for transgender patients.

## **Mental Health**

Some of the most common health issues users of Q:alliance mention are anxiety and depression, so appropriate mental health counsellors are extremely important. However, Q:alliance have found that there are a lack of specialist counsellors with lived experience, or at least a good knowledge of the LGBTQ+ community and the specific mental health support they need (e.g. around gender dysmorphia, gender reassignment etc). This means mainstream mental health therapy does not meet the needs of some LGBTQ+ people.

## **Intersectionality**

Q:alliance told us they estimate around 30 - 40% of adults that attend their activities are neurodiverse, or are awaiting a diagnosis. Those with a diagnosis reported having to wait a long time to obtain it.

Health equality challenges are likely to be more keenly felt by LGBTQ+ people that are also part of the other communities of focus identified within the first phase of the Denny review. There are some particular complexities surrounding LGBTQ+ people from some ethnic minorities and faith communities (for example, according to Government research a large portion of the conversion therapy offered or administered to LGBTQ+ people originated from a faith group) and as mentioned above, a large proportion of Q:alliance activity users are neurodiverse.

## **Communication**

Q:alliance believe that most of their users know the NHS website and resources are reliable sources of information, but more training to the LGBTQ+ community about what information sources are not trustworthy would be beneficial. If there were strong enough NHS resources relating to LGBTQ+ health issues, they wouldn't need to seek information out elsewhere and potentially become misinformed.

## **Communicating lived experience, co-design and co-production**

Q:alliance told us that the only active route they feel they currently have to interact with the health sector, and communicate the lived experiences of MK LGBTQ+ people, is via the MK VCSE Alliance and the MK Mental Health Alliance. They find these groups really beneficial in terms of linking and working with a range of groups, and in making some headway in communicating the health needs of the MK LGBTQ+ community. A recent survey showed that 80% of MK LGBTQ+ respondents had never been part



of a steering group but that 73% would like to be. This shows there is an appetite for involvement in co-designing / co-producing services, and in expressing lived experiences to affect change, but few opportunities to do this in a focused way.

## Recommendations

### Adapting services and spaces to be culturally appropriate

- To overcome the fear and mistrust associated with mainstream services, health providers should consider working with an LGBTQ+ specific organisation to reach LGBTQ+ people, and support them to access healthcare. Such organisations are trusted by the community because (unlike mainstream services) they feel they will be understood and not discriminated against.
- Sometimes Q:alliance users speak about health issues (physical and mental) at Q:alliance's social activities, however this space isn't always appropriate. Opportunities for LGBTQ+ people to speak about health in a designated setting with specialist support would help.
- Particular activities or services that support LGBTQ+ people with intersecting vulnerabilities in terms of health inequalities, e.g. those that are neurodiverse. Long term and careful support for LGBTQ+ people from ethnic minority and faith communities may also be helpful.

### Training, education and increasing cultural awareness

- Training around LGBTQ+ cultural competency and specific healthcare issues. Q:alliance provides training around cultural competency, trans awareness and pronoun use for example, and this kind of training has been used by many organisations (including Thames Valley Police) in order to ensure staff have an appropriate level of knowledge and can therefore provide accessible, welcoming and useful services for LGBTQ+ people. Training to ensure healthcare providers have a good understanding of the experience of trans people and of how the transitioning process works would be beneficial.

### Communication / information

- Q:alliance would like to explore any opportunities to work with Healthwatch around supporting LGBTQ+ individuals to voice their experiences re health.
- Resources and communications regarding health and wellbeing being more 'fun' would be welcomed.

## Actions Taken So Far

- Q:alliance have teamed up with Talkback to create a safe space for LGBTQ+ people who are neurodiverse
- Q:alliance training MH alliance and other MH / health / wellbeing groups
- Q:alliance joint work with crisis cafe - suicide prevention.

- Q:alliance are engaged on projects to reduce health inequalities within the LGBTQ+ community, particularly focussing on mental health, working with The Crisis Cafe (a high proportion of attendees at the Crisis Cafe are transgender).

## Learning Difficulties - Detailed Report

Camphill Milton Keynes Communities provides support and a meaningful working life for adults with a wide range of learning difficulties. Their aim is to create a safe and stimulating environment, fully integrated into the surrounding community that allows individuals to develop in accordance with their own needs. They have a great deal of experience and specialist knowledge so were a natural choice when seeking input into this research.

### Common health issues

We were told that a common health issue within the LD community is weight loss, and weight gain leading to diabetes. There is a real challenge in ensuring diabetes is managed within the LD community, particularly for those living in the wider community, and more intense, ongoing support and monitoring is required. This could help bring community members back to a healthier weight and prevent long term diabetes - making it cost effective in the long run.

*“Successful interventions have been long term, supporting residents to understand the issues with follow ups, and involved training staff around diabetes management and weight management.” - Camphill Communities MK*

Poor diet and lack of healthy eating within the LD community is an issue, with marketing of unhealthy food, comfort eating and affordability of healthy food thought to contribute towards this. We were told that levels of knowledge about being healthy and knowing when to get help may be linear for people who are neurodiverse so their learning may go forwards and backwards. Therefore, during times of stress, a person who is neurodiverse, may use food as a coping mechanism. We heard that perhaps people who are neurodiverse are more vulnerable as a result of this.

*“It’s easier to buy food that is higher in calories - and that takes many people directly down the road towards weight gain and diabetes etc” - Camphill Communities MK*

We were also told that there are not many opportunities for people with LDs to exercise in MK, and that they would not be very welcome in mainstream gyms for example. Camphill provides exercise options for their beneficiaries, but more opportunities in the wider community are required.

We were told that people with LDs not living in supported accommodation like Camphill, but living in Social Care settings can hoard, and struggle to keep homes clean and sanitary. Often unsafe

environments are not picked up until they are in extreme situations and clean up teams need to be sent in.

Isolation is also a big issue within the LD community, and we were told that individuals that are isolated are often not picked up quickly enough. Isolation is particularly prevalent amongst those living in more deprived areas of MK.

*"Those living in social care settings can become extremely isolated - especially if neighbourhoods are intimidating.." - Camphill Communities MK*

Lack of accessible transport for people with learning difficulties can increase the chances of becoming isolated.

*"There are a number of services out there, some of them are working with us to tailor the programme of support so people get proper investment and proper information that is available and well communicated to them. Examples where people have set up initiatives around information about diabetes just before you get to that point of needing insulin and information that diet could actually manage it." - Camphill Communities MK*

We were told that people with a learning difficulty often need ongoing support, monitoring and feedback in order to make life changes.

*"Just having that information isn't enough. There needs to be an additional focus on monitoring and support in putting it into practice. To manage your lifestyle, manage your diet and improve your physical activity." - Camphill Communities MK*

## Communication

Advocacy is a big issue for people with learning disabilities in MK. If more advocacy was available people with Learning disabilities in the City could be supported to communicate to health professionals and be supported to understand what they are being told by health services. Lack of advocacy is an issue just to ensure some people with learning difficulties have their day to day needs catered for.

General needs advocacy is missing at the moment. Within MK, there is a lack of advocacy across a range of different topics from sexual health to understanding ones rights or even advocacy around disputes with family or carers. In general, there is a large gap for advocacy for people with learning disabilities if the subject in focus is not directly linked to an individual's capacity.

*"A lack of available advocates is an issue, other than the IMCA's\* that are a statutory*

*requirement - this referral is through the Local Authority and it's the Local Authority's responsibility to get one and involve them but they are few and far between." - **Camphill Communities MK***

*\*Independent Mental Capacity Advocates, are appointed to act on your behalf if you lack capacity to make certain decisions, and helps for example when an NHS body wants to provide serious medical treatment to you or when there are plans to give you long-term accommodation in hospital or in a care home.*

A regular contact within health services would be useful - to build trust and familiarity. Knowledge of an individual is required to really understand their needs and how best to communicate etc. A named contact for reviews etc within the Local Authority or other services was suggested as something that would be useful.

Many individuals with learning difficulties struggle with communication when accessing health services. Some may be non verbal, unable to write and written and online information may be inaccessible to some. Alternative formats of communication are required such as pictorial.

*"Whilst alternative forms of communication may be available when people ask, they're not always available at the right time in the right place and this is an issue" - **Camphill Communities MK***

We were told that when attending appointments, residents are often supported by staff that know them well to communicate on their behalf or to support them to make their needs known. GP's that care for these residents are therefore aware that they can ask questions of the supporter of the client. However, we were advised of concerns about people with disabilities living within the wider community's ability to communicate with and feel understood by health professionals if this support isn't available.

*"We would provide staff that know them (the resident) well, to communicate on their behalf or support them to make their needs known. For example, if the resident is non-verbal, staff would help them to communicate their needs and wishes effectively. This often requires a knowledge of whatever means of communication that person has and that's often not makaton or something like that. The staff member just knows it. Sometimes questions are asked using written word, many residents would struggle with reading and writing." - **Camphill Communities MK***

We were told that the most impactful way of accessing information about health care for residents of Camphill MK Communities is a programme of care where those who have a good level of knowledge, insight and communication skills are supporting residents to understand the concepts and processes

that follow on. And either providing Camphill MK staff with the skills to monitor and continue the programme or offer review meetings.

*(When discussing a diabetes management programme of care) “There was an initial set of training sessions where people first worked with Camphill to make sure the whole group was able to engage so we had people that were non verbal, people who were able to use written word and people who needed just further explanation of complex themes. A programme was delivered for a couple of weeks and participants were given homework where the staff were encouraged to engage with the residents. Then they came back and reviewed the progress and then again later to review the progress. That type of approach is quite intensive but if it allows people to be more independent or stops more significant conditions developing it is worthwhile investing.” - **Camphill Communities MK***

*“Experiential learning and supporting people in a process that doesn't just deliver information, it checks understanding and follows up on actions that people have taken as a result. And I think that's the key, it is all very well and good to provide information to our service users however, it is the actions that are important. Information from understanding that smoking is bad for example, to not smoking, isn't an obvious connection, if it isn't an obvious connection. [Smoking isn't particularly a big issue for my client group]”. - **Camphill Communities MK***

We were told that celebrities are often trusted sources of health information by LD community members.

*“Sources of health messages that the LD Community trust, aren't always what you might expect. Health messages from celebrities are often well received. For example, Joe Wicks” - **Camphill Communities MK***

It was explained that as people with LDs are living longer than they used to, consequently age related difficulties such as frailty, dementia, hearing loss, Alzheimers, vision impairment and physical disabilities are now more common. Therefore specialist support for older people with learning disabilities and these issues is required.

## **General barriers and issues**

Camphill Communities is able to provide support for their beneficiaries, but we were told that the wider community of people with learning disabilities with less support have a worse experience of healthcare. It was explained that people with learning disabilities that would be considered lower down the threshold find accessing health support more difficult, and that the Local Authority is struggling to case manage, especially the lower thresholds.

*"People with higher physical needs and more complex needs get a better service, those requiring 1:1 support, as opposed to people that are lower down on the scale. For example, perhaps people with a diagnosis of Down's syndrome living in the community, with visiting support - it's not as easy to identify when changes in symptomatology become apparent." - Camphill Communities MK*

We were also told it can be difficult to find social work involvement to support with reviews including annual reviews or reviews due to a change in need or presenting behaviour.

*"Reviews (generally held here in the supported living setting - the residents home) on occasions, [we] struggle to find any social work involvement, ideally we would want someone who knows the person and has developed a supportive and trusting relationship".*

*"It's important to have local authority oversight generally, but where changes in hours of support are requested this is needed to agree funding. Reviews have been rescheduled due to changes in personnel (social workers / SW assistants) or we have carried on without representation". - Camphill Communities MK*

Proper discharge planning is required for people with learning difficulties to feel better supported when leaving hospital. At present, there is only one learning disabilities discharge nurse specialist working at Milton Keynes University Hospital. Families can struggle to engage with professionals for appropriate support, with DNR (do not resuscitate) being suggested inappropriately.

*"Sometimes families even struggle with engaging in support, even things like DNR being put in place inappropriately or at least suggested and you kind of think what if that family member had not shouted long and hard about their loved one having a decent quality of life, perhaps they would have been put on DNR inappropriately? ." - Camphill Communities MK*

Transport to allow people with LDs to access health appointments or services was raised as a big issue and barrier to access. This transport needs to be accessible to the LD community members, and feel familiar and responsive.

*"When there are problems with transport, people then become isolated and those problems get worse as a result of this including later treatment, later identification of problems and generally a lack of access to treatment and support - on some occasions emergency support." - Camphill Communities MK*

Sexual health and sexuality are challenging topics to navigate within the LD community, and more specialist support around this would be beneficial.

The CEO of Camphill Communities MK is a Health and Wellbeing Board representative, so has the opportunity to feed information relating to his beneficiaries into the health system. However, Camphill can find communicating at a local level more challenging, for example, with GP surgeries. Often accessibility would be increased if services went out into the community, but we were told this can be challenging for GP surgeries as they do not see themselves as funded for this. Camphill CEO found that influencing this through the CCG was challenging.

*"It's harder to be heard when it comes to GP surgeries. For example, trying to speak to them about how to make vaccinations more accessible to learning disabled community members..."*

*"Some things that look old fashioned may be the best way to engage with people. E.g having a flu vaccination clinic in the community hall " - **Camphill Communities MK***

In terms of opportunities for individuals with LD to have their voices heard, we were told that community members have been involved in co-design generally, but have not had the opportunity to be involved in co-designing health services or interventions. Opportunities for individuals to directly express their lived experiences are also limited. Additionally, there have only been opportunities on occasion such as the consultation that started in 2016 that looked at the delivery of services to people for skills development and meaningful occupation of time during the week. As well as the Learning Difficulties Partnership Board. We were told that in regards to healthcare services and solutions to issues, access is the key for people with learning difficulties.

*"The Learning Difficulties Partnership Board used to provide an opportunity for service users to feed in their experiences and ideas directly, and was really valued, but this ceased during Covid and although Talkback have taken it on now it hasn't returned in the same way." - **Camphill Communities MK***

We were told that there are many initiatives that could co-produce with with ELFT and MK Social Services and VCSE organisations that would have multiple outputs that would be beneficial. But, in order to do this, it requires resources. For example, someone to get involved with VCSE and statutory organisations to know what they are doing and look for synergies. One area of collaboration could be the priorities of the Health and Wellbeing Board.

*"And I think the priorities around the Health and Wellbeing Board, e.g dealing with obesity, dealing with abuse, it would be relatively easy to put information out to local*



*providers and 'say what are you doing across these themes' to be able to make it (initiatives) more impactful and broader." - Camphill Communities MK*

## Recommendations

### Adapting services and spaces to be culturally appropriate

- Better access to advocacy or at least provide services that are focused on general needs advocacy. People with LDs need to be supported to communicate when accessing health services, and the communication needs and preferences will vary from person to person so a knowledge and relationship with the individual is vital.
- A more robust discharge plan for people with learning disabilities leaving hospital is required.
- More specialist LD nurses
- Greater capacity within the Local Authority and other health services to manage all the support for people with learning disabilities required in MK, especially those on a lower threshold that are currently falling through gaps. Social work support to help with reviews needs to be available.
- Agencies need to work together to support LD community
- Intense, ongoing support and monitoring is required to support LD community members with diabetes and weight management. Long term, preventative support is ideal, with training to people that support the LD community too.
- Specialist support for people with learning difficulties and dementia, Alzheimers, frailty and other age related issues is required
- Specialist support to the learning disabled community around sexual health and sexuality would be beneficial as this is a challenging area to navigate and mainstream services aren't appropriate.
- More opportunities for LD people to co-design health services and interventions, and routes for them to directly express their lived experiences.
- A named contact for reviews etc within the Local Authority and other health services so people with learning difficulties trust the individual and the individual has a better understanding of the health and communication needs of the service user.
- More opportunities for people with LDs in MK to exercise
- Better access to transport that is familiar and responsive or funding to support that transport - Transport that is accessible to residents
- Better monitoring of people with LDs living outside of supported communities like Camphill, especially to avoid isolation, hoarding and unsanitary homes and to spot if changes in their symptomatology occur. With appropriate funding there is potential for the VCSE and volunteers to support this.

### Training, education and increasing cultural awareness



- Training around LD to healthcare providers to avoid potential mistakes around care, eg. issues around DNR in hospitals being wrongly assigned etc.

### Communication / information

- Easier for people with LDs and their families to communicate to the hospital and other health providers (e.g. issues around DNR in hospitals).
- Use celebrities to convey health messages.
- Better communication routes for people with LDs and organisations that support them in the health sector in order to work together on increasing accessibility etc. Especially GP surgeries and ICS.

## Mental Health Conditions - Detailed Report

- We spoke with Jon MacPherson who has extensive experience of supporting and working with people with mental health conditions. Jon was previously the Service Manager at Rethink Mental Illness and has worked as a health trainer within Milton Keynes within areas of high deprivation with mixed population groups.

### Health professionals understanding of mental health conditions

We were told that health professionals such as GP's have a lack of understanding around mental health conditions and how they may affect a person's life. This lack of understanding can lead to what is known as shadowing - the proposition that a health professional will put ailments or illness down to a person's mental health condition and therefore, dismiss it. Additionally, GP's may not always have a great understanding of how a mental health condition can affect a person's ability to access and interact with healthcare services.

*"GP's not having a good understanding of how mental health affects people. The anxiety of waiting for a phone call or going to a GP practice. Also, because of mental health, some people cannot manage a diary or calendar. They will miss 3 appointments and then be under the threat of being discharged from the surgery." - Jon MacPherson*

### Communication

Poor communication was an issue highlighted during our discussion. We were told that in terms of communication, there is a lack of trying to meet personal needs in the way in which people want to speak with health professionals and receive information.

*"[a client] did not want to speak over the phone due to having family around and*

*requested to receive information by text or online but this was declined. " - Jon MacPherson*

We heard that one way to improve the experience of connecting with healthcare services could be by letting people know what services are available. There seems to be a communication barrier around the variety and availability of services.

### Common Health Issues

We learned that a poor diet is often experienced by people with mental health conditions and heard that one approach is to take a holistic view with the promotion of healthy diets being important. In terms of mental health, we were told that there is a difference in having self awareness and being able to recognise that you are becoming unwell. We also heard that older adults with diabetes can have difficulty managing their condition such as medication management due to their mental health.

### Accessing health information/services

Accessing health information online can be affected by one's income, willingness or ability to use the internet. Raising understanding about skill and confidence may reduce digital exclusion within communities. We also heard that current NHS services should provide outreach to existing groups. Unfortunately, this way of working seems to have declined significantly over the last few years but if implemented, would be beneficial.

*"[A mental health charity] had a nutritionist come into the service and people talking about diabetes. 'Rather than people being expected to go to the specific healthcare provider or service?' yes." - Jon MacPherson*

When accessing healthcare services, finding an advocate for a client with mental health conditions can be challenging. Historically, mental health charities would offer services whereby support workers could accompany clients with severe mental health conditions to appointments such as GP or benefits appointments. This service allowed clients who had reported having difficulty with understanding information the support of having someone else there with them. However, due to funding cuts, there is less 1:1 support available. Additionally, accessing prescription reordering services can be an issue and result in missed appointments such as support sessions. We heard that service users had to cancel support sessions due to needing to sort out issues related to repeat prescriptions. Not only did this result in missed appointments, it also heightens stress and anxiety.

*“Our support worker (Mind BLMK) would accompany them if need be, but the nature of the service has changed. So that sort of 1:1 support, as far as I understand, has greatly reduced. So having someone to advocate for you is quite difficult to find now.”*  
**- Jon MacPherson**

We also heard that there can be a considerable perception that if a person with a severe mental health condition asks for help as they are ‘struggling’, they could be forced to visit an acute mental health ward.

*“There is a considerable perception that if people ask for help and said i’m struggling, that they would get locked away in the acute ward in the Campbell Centre, which isn’t true. I mean we would say look it’s really difficult [to visit an acute mental health ward] but that prevented them quite often from saying what they were experiencing.”*  
**- Jon MacPherson**

Additionally, previous research looking into health inequalities around mental health and physical health highlighted the lack of involvement people with mental health conditions feel they have in their own care.

*“Rethink Mental Illness did a project two and half years ago looking at health inequalities around mental health as well as physical health. One of the themes that came out was that people didn’t feel involved in their own care, sometimes it’s done to people, without proper discussion of issues in treatments. Also, a lack of encouragement for people to be involved in their own care.”* **- Jon MacPherson**

We were told that there used to be opportunities to connect with health services such as when the partnership board introduced separate sessions for service users which then fed into a further meeting between professionals and the NHS. In essence, it was a forum for people to voice their needs. Healthwatch Milton Keynes supported this but unfortunately, it stopped. Additionally, we were told that people can be reticent about being involved in opportunities to directly feed their experiences to health services, and/or to co-produce services or solutions to issues, even with Patient Participant Groups (PPG’s). This reluctance can be due to a lack of confidence.

## **Recommendations:**

### **Adapting services and spaces to be appropriate and accessible**

- Non-mainstream ways to help people with mental health conditions manage their appointments e.g. send the appointment to the service user and a NOK

- Services to highlight services users can have accompaniment when accessing appointments e.g. GP receptionist to mention that a friend/family member can attend if the nature of the appointment is regarding mental health
- Allow free communal opportunities to access internet services in order to access online health information/services

### Communication / information

- Reinstate sessions for service users to voice their needs as part of the partnership board
- Requests for personalised communication to be better acted upon
- More education about healthy diets as part of mental health support
- Sharing information about available resources for mental health within Milton Keynes

### Training, education and increasing awareness

- GP surgeries/PCN's to explore patient experiences and views of Patient Participation Groups (PPG's) to understand how to better use them
- Further research around people with mental health conditions' perceptions of healthcare staff's understanding of mental health
- Education co-produced and co-delivered by mental health professionals and people with a mental health condition to staff working in mental healthcare including GP's
- More mental health education within GP training - "During their training, GP Specialty Trainees (GPSTs) spend 18 months in clinical placement posts, and a further 18 months in general practice. There is a single opportunity for GPSTs to do a mental health placement within this three years, which is through a placement in psychiatry" Mind (2018)
- Education around diabetes management during periods of worsened mental health
- Education around being able to recognise when you are becoming unwell
- Tailored computer training courses focused on accessing online healthcare systems/services run by VCSE organisations linked to specific GP surgeries/PCN's across Milton Keynes to reduce digital exclusion within communities
- Reach out to private companies to obtain donations to reduce digital exclusion e.g. computers, sim cards etc.

### Actions:

- CA: MK staff to liaise with ICB staff responsible for Patient Participation Groups (PPG's) to share insight
- CA: MK to liaise with VCSE organisations that offer computer training to tailor service to accessing online healthcare systems/services

## Migrants - Detailed Report

Welcome MK are the VCSE organisations that have been supporting refugees from Afghanistan in Milton Keynes. Afghan refugees have been living in hotels in the City since they came to the UK. The CA:MK Team has also worked with volunteers at Harben House, and The Wisdom Principle engages with migrants through their work.

### Communication

One of the biggest challenges in supporting refugees and migrants to access health services and stay healthy is communication.

*"For migrant communities, there isn't anywhere that fully explains how to access services and what their roles are. Knowing what is available is a challenge." - **The Wisdom Principle***

When arriving in England, refugees are given information about health services including education about 111, the emergency services and A&E. This information is provided by Welcome MK or MKCC. There are also medical posters within Harben House, a hotel where the Afghan refugees are living. These are all helpful, but just the start of the support needed.

The most obvious communication issue is the language barrier, and we learned this can cause miscommunication in all levels of care. Understanding what health services and information is available can be made easier by simply having a good level of interpretation.

*"[When discussing difficulties with communicating well and being understood when discussing health and care with staff in health and social care services] Language and appointments, understanding what is available, but if they had a good interpretation, then they would understand what is available and what different things mean." - **Welcome MK***

Simply booking appointments is difficult, as is trying to describe an ailment without misunderstandings causing misdiagnosis.

*"An Afghan lady ended up giving birth standing up with her child delivered on the floor due to miscommunication regarding her pregnancy" - **Welcome MK***

Using a telephonic translator can be uncomfortable when discussing personal medical problems. There is also the issue that translation can be complex as in Afghanistan, there are some languages that only some parts of Afghanistan speak and that other Afghans don't speak. This means that in some cases the lesser spoken language is translated by a family member or friend into the more common Afghan language to be translated into English. This causes concern that information regarding health will be misunderstood as there's more chance for it to 'get lost in translation'.

*"A double translation was required for a client and the NHS cancelled it because they were worried that it would be mistranslated. In the end it was reinstated but how can we ensure we support this moving forward? How can this translation be effectively facilitated in health services? I don't have the answer but we need one. Are there examples from other languages, areas, countries...?" - **Welcome MK***

In terms of supporting refugees to learn English, this can be more challenging for some. For example, some Afghan women have not been educated as they grew up under Taliban rule, so they have a very difficult starting point. Developing the knowledge and skills to learn a new language would require a lot of time and support.

*"Groups that Welcome MK provide are about empowering the ladies and increasing their mental wellbeing so that they can function independently." - **Welcome MK***

Vaccinations in the UK, once explained to Afghan refugees, have been well received. However, there have been issues in accessing medical records and information on what vaccinations have already been received and what they were for, for example by Afghan children.

Finding alternatives to medication refugees are already taking can be challenging, this is difficult if the GP cannot understand the medication packaging or medical notes. Equipment used can also be different and incompatible with UK items, adding another layer of challenges.

*"An individual required something for their diabetic machine but this couldn't be sourced. Therefore, the client then needed a new machine and had to learn how to use the new machine." - **Welcome MK***

The Health Centre closest to the hotel Afghan refugees are staying in has been helpful in setting up systems to support access and communication and has set up a dedicated phone number for refugees to call.

*"People's starting point is different. The key to anything is knowing where the person comes from and building from that - finding alternatives to what they would have accessed in their home country and trying to meet their needs." - **Welcome MK***

## Common Health Issues

### Dental Issues

Welcome MK told us they estimate common health problems are a 50/50 split between mental and physical health including high blood pressure and depression.

Dental health is a big problem for Afghan refugees with the majority having dental issues, and access to dental services has been difficult. People are advised to contact 111 but the closest emergency dentistry services are in Luton and Northampton, which is impractical as refugees will not be able to travel there. There is a lack of knowledge around dental hygiene (e.g. refugees needed to learn that toothbrushes are not disposable, single use items) and support to understand how the system in MK works in terms of GPs Vs Dentists. However, this education has been difficult with the dental services available to signpost to, as many are not accepting new clients.

### Mental Health and Trauma

Welcome MK told us there is a lack of mental health support, with MK Talking Therapies only having become involved in the last few months, when Afghan refugees have been in MK for 16-17 months. They told us that refugees came to MK having experienced severe trauma, some with gunshot wounds for example, so trauma teams and mental health support needed to have been in place from the start. We were also told that there has been no involvement from CAMHS.

*“Children were experiencing night terrors during November due to the fireworks” - Welcome MK*

It was expressed that the need for ongoing mental health support is a big need, with individuals having gone through so much and many having family and friends back home, so they are constantly worried and anxious about their safety.

There is a concern that some mental health conditions can come to be thought of as normal.

*“Some migrants are experiencing PTSD, but it goes unrecognised and is normalised” - The Wisdom Principle*

### Cultural differences

People living in Afghanistan are used to queuing for services and being seen that day, so the concept of waiting lists, or pre-booking and waiting for an appointment are unfamiliar. There has been a need to explain that this situation is not because they are refugees, but rather just how the system works in the UK.

Many Afghan refugees have large families (6-8 children for example), and in Afghanistan they would live with relatives so childcare was never an issue. However, as they have come to the UK without that support network, they struggle to access appointments as taking 8 children with them is impractical. If a father is working, there is often a fear that if they take some time off to support with childcare to enable wives or children to attend medical appointments, they will lose their jobs. More education is required around this, and there needs to be more childcare support for refugees with large families.

Female refugees being supported by male doctors can be an issue, especially when accessing support on specific issues.

Harben House have worked with refugees to ensure the food being provided is culturally appropriate, with one refugee having gained part time employment as an advisor as a result.

## Recommendations

### Training, education and increasing cultural awareness

- Programmes to support Afghan women, who may not have been educated previously, to develop skills and independence.
- Support to health providers around understanding current medication and medical records of refugees, and accessing alternatives.
- Education around dental health for Afghan refugees
- Afghan culture and health system / norms training for service providers, as well as similar education support to refugees around UK health system and cultural norms.
- Education for Afghan Refugees on rights to take time off work to support families access health care.

### Adapting services and spaces to be culturally appropriate

- More joint work with health providers, VCSE groups working with refugees / migrants and refugees / migrants themselves to make services more accessible and effective.
- Ensuring access to dentists is available to Afghan refugees.
- More and ongoing mental health support to refugees, adults and children including specific support relating to trauma.
- More support with childcare to allow Afghan Refugees to access to health care
- Access to female GPs if and when female refugees require this.

### Communication / information

- Research and development around appropriate solutions to translation issues. Including allowing refugees that don't speak English to access translation services that make them as comfortable as possible in sharing personal information, and around how to overcome the significant challenge of translating uncommon languages spoken in Afghanistan without mistranslation occurring through information being translated twice for example.



## Physical and General Disability - Detailed Report

MK Centre for Integrated Living (MK CIL) is an information centre which provides a very wide range of free and confidential information on any disability related issue for people with a disability, their families, carers, and anyone else with an interest in the field of disability.

The Disability Resource Centre supports disabled people and their families in a variety of ways via advice and services.

### Accessibility

The DRC told us that many of their service users struggle to get a GP appointment, with MK CIL explaining that people with disabilities in MK can often wait days before they can see a health professional after an issue or ailment arises. This is due to the lack of available appointments, and the fact that long waits at Walk-In Centres are impractical for some people with disabilities due to their conditions, as well as for some people who are mentally ill. This leads to issues not being addressed early enough and people slipping through the net.

*"People are dying because they aren't seeing their professionals soon enough - opportunities to prevent escalation of an issue or to get something early maybe aren't there as people are experiencing barriers." - MK CIL*

Although MK CIL advises clients to seek medical help for ailments or illnesses, due to the difficulties associated with accessing healthcare services such as GP appointments, this advice is often disregarded. We heard that there can be a reluctance to contact a GP surgery due to the problems associated with accessing an appointment. Additionally, waiting lists for specialist services are too long.

*"It is difficult. I speak to my clients and say you need to see your doctor and they just burst out laughing and say don't be silly." - MK CIL*

We also learned that some individuals are struggling to see their Social Workers when they need to, which leads to the individual going into crisis. We were also told that more support needs to be provided for people with disabilities that are homeless when being discharged from hospital. Due to the nature of homeless shelters, often residents are expected to vacate the shelter during the day. For someone that has a disability and has just been discharged from hospital, being expected to find a separate space during the day time can be challenging.

We were also told that sometimes people are advised to attend A&E, who tell them to go to the Walk-In Centre, who tell them to go back to A&E. All of this can be very difficult for people with disabilities, and potentially put them off attending at all.

*"If people were able to see GP's quicker and there was more availability to do so, they may get better quicker and then there wouldn't be the need to use other services like*

*the walk in centre or emergency department - there would be less pressure on these services." - MK CIL*

Transport is often an issue for people with disabilities in terms of accessing services. With the formation of the BLMK ICS there is a concern that residents living in Milton Keynes with a disability will be offered services/appointments in Bedfordshire and Luton, which is a long way to go for people with disabilities. Services need to think about how people with disabilities will get to their appointments if they are within Bedfordshire. It was suggested that to avoid this, specialists should be located within the geographical area in which the client lives.

*"Services need to think about how people will get to their appointments and know that people are worried about this. Specialists should be in the areas that clients live in." - MK CIL*

We were told that there is a lack of knowledge and consideration around disability within health services, and changes need to be made. For example, wheelchair users need to be able to access their own wheelchair (not a generic wheelchair) when they are using ambulances, in hospital or using other health services.

*"A client was taken into hospital and the paramedic advised they couldn't take her wheelchair in. She couldn't get out of bed until her friend brought her wheelchair in. There isn't enough understanding that people that have to use wheelchairs need to have it taken with them via ambulances. Not having their wheelchair with them is terrible and means they feel helpless and aren't getting moving again when they could stop them deteriorating" - MK CIL*

The DRC told us that there are not many accessible exercise and fitness options for people with disabilities, which makes it difficult to stay fit.

## Advocacy

MK CIL told us there is a large need for advocacy support with the people they work with, but the support is not available. As a result, MK CIL are having to fill the gaps and advocate on behalf of some of their users on a range of issues as there is a real need for support to help them communicate and be understood. MK CIL supports people with a range of disabilities which make communication using mainstream methods challenging (e.g. people who are deaf, people who are blind or people that are non-verbal). Healthcare services and staff need to be aware that mainstream services do not fit everyone's communication styles or abilities.

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

However, this can be difficult as sometimes it can take a long time to get through to MK Council to resolve certain issues, and clients cannot physically stay at MK CIL this long due to their disability.

*"CIL employees have difficulty speaking with Local Authorities - It can take 5 hours to get through to the Council, by this time, the client has returned home. However, at this point the Council staff member will state that they cannot talk to the CIL employee as the client is not present anymore" - MK CIL*

## Communication

We were told that reliable communication is very important for the people MK CIL work with, and those working with the DRC appreciate timely communication.

*"If you say you're going to get back to someone, get back to them. That's all people need - to know that people are still listening to them." - MK CIL*

Using alternative communication for different people was flagged as really important for many clients, for example using text or email for a person that is deaf, and relying less on written communication for people with dyslexia. The DRC told us that many of their service users would like access to interpreters and many would appreciate access to more hearing loops.

We were told that calling the GP at 8am is not suitable for everyone as some people with disabilities are physically not able to be up out of bed, and able to call at that time of the day.

GPs not processing prescriptions over the phone is an issue for some people we were told, as the alternatives of physically going into the GP surgery or using an online form isn't practical for people with certain disabilities (e.g. mobility disabilities and/or people that are blind or sight impaired). Systems with Chemists supporting people with reordering prescriptions has been helpful for some disabled clients.

Online services can also be difficult for people without internet access or dyslexia for example

*"If you have a mental health condition, the computer could become your enemy." - MK CIL*

However, post Covid, many services have moved online. Appointments that would have been in person can now be phone based, and we were told that not all people MK CIL work with want to or are able to talk on the phone. The DRC told us that the people they work with would value more time, longer appointments, attention, patience and to feel that they are listened to.

*"The NHS and health services need to be more accessible to people - like it was prior to covid." - MK CIL*

Due to the increased use of telephone appointments during the pandemic, MK CIL are often told that covid appears to be an excuse for the use of telephone as opposed to face to face appointments, even though restrictions have now relaxed.

*"Now that we are relaxing down, they (NHS services) are still using covid as an excuse. That's what everyone says to me. Here at CIL, for our disabled clients, they need that contact and we need that contact... And it's not just the NHS, it's across the board, DWP as well. They are still doing a lot of phone assessments so they can't see the clients and then they aren't putting them through as they say 'they sounded alright to me' but they don't see them." - MK CIL*

MK CIL told us that people with disabilities are experts in their own condition and know when to get help. But there are barriers in accessing that help. The DRC told us that feeling involved in decision making processes is very important for the people they work with when interacting with healthcare professionals. Additionally, we heard that Doctors do not appear to read notes prior to appointments and that a lot of newly trained Doctors are being trained to advise clients that they can only deal with 1 problem per appointment. However, due to the difficulty in obtaining appointments, you are left with the need to discuss more than 1 concern during your 1 appointment.

We were told that many people they work with would prefer to see a Doctor they know, and who knows them and their health issues. The DRC also advised that for the people they work with, working with healthcare professionals that understand their individual disability is very important.

*"Lack of coordination means that people often don't see Doctors that know them - this can lead to people feeling 'What's the point of seeing a doctor? They don't know me from Adam and don't read my notes'." - MK CIL*

The DRC told us that people with disabilities come to them as they build trust and a longer term, person centred relationship, which the people they work with really value.

*"Once clients have used DRC for guidance and support, they will then come back again for support. Our website use has grown over the last 3-6 months. A lot of people come to DRC prior to going to the local council - there is trust and people know DRC. A big part of it is time. DRC has less resources but can give time to the clients. DRC supports the paperwork aspect of it, not just 10 minutes. A more personalised service than the statutory sector". - DRC*

MK CIL told us that there is miscommunication happening that is leading to contradictory information being given to patients between GPs and the DWP. Patients are told by DWP that they need to approach GPs to obtain their medical records to use for benefit assessments, whereas some GPs are telling

patients the DWP needs to contact the Surgery directly. MK CIL reported that having help to access clients' medical notes would be very helpful. MK CIL currently has three staff members supporting medical forms and can do anything up to 10 forms a week. The bulk of their work for the past 2 years have been providing benefits support.

*“When it was DLA, disability living allowance, the onus was on the DWP and they went through the doctors. Now it's gone over to PIP, personal independence payment, the onus is on the client and if the client is going to the doctors and being told ‘no, no, no they (DWP) contact us’, they (DWP) don't always. So you are getting hit from the left hand side, hit from the right hand side, what do you do? The system isn't working. You really need to coordinate the doctors and the DWP to make it an equal world for people with disabilities.” - MK CIL*

There are also differences between Surgeries around the cost of obtaining medical records for benefits assessments (£30-£100). We were told that paying for medical records in order to process benefit assessments is very difficult if not impossible for some people with disabilities as they are applying for benefits as they are already struggling financially.

*“Paying for a medical letter/proof of condition can then mean that person does not have enough money for their weekly food” - MK CIL*

The DRC told us that many of their service users tell them that staff in GP surgeries and hospitals could be more helpful. We heard that some people MK CIL work with find Doctor's receptionists a barrier to accessing appointments or support, either due to receptionists being unwilling to give appointments or because clients feel uncomfortable discussing their health issues with anyone other than GP or other medical practitioner. This is thought to be a particular barrier to men, with many feeling uncomfortable disclosing personal /sensitive health information to reception staff.

In terms of opportunities for MK CIL to communicate and work with the health system, it was felt there is not an interest in this from health services.

*“CIL used to sit on a couple of JAG (Joint Action Group) Boards that were at the hospital but they went by the board years ago, we never knew if our participation was helpful or whether we were invited as the disabled person, where they could tick their list and say ‘well we have had a person with a disability on our board.’” - MK CIL*

We also heard that MK CIL used to be involved with other boards such as a police board but that involvement wasn't inclusive due to the amount of acronyms used. Although this was some years ago, this feeling of being invited as 'the token disabled person' still does happen nowadays. We also heard that feedback regarding input is only received due to explicitly asking.

MK CIL advised that they find that their involvement once they are on a board is helpful. CIL also work very closely with the Pain Management Service at Milton Keynes University Hospital, whereby the service refers clients to CIL.

The DRC told us that the people they work with are keen to be involved in shaping healthcare and services, and the DRC would like to work more with statutory organisations. Their Experts by Experience Team is popular, providing input to DRC re. their services and any others where input is sought, and they have 100 volunteers across BLMK.

## General Issues

We were told that **care at home** is an issue, with hospital beds being held up by people without provision at home that could otherwise be discharged. It was suggested that MK Local Authority do not utilise care services that they have access to, whereas Bedford Local Authority for example do. We were also told that there is variation in terms of availability of social workers across areas also. It was felt that these differences across areas are unfair and the system would be better if it was standardised and united across the country.

The DRC told us that the people they work with often experience a decline in mental health.

Assessments for people with disabilities can be stressful, and we were told that often DWP Assessors responsible for assessing a person's disability and entitlement to vital benefits often lack skills, knowledge and understanding to be able to make these judgements. We heard that it doesn't stop at the NHS, it goes further e.g. DWP. These factors all contribute to the health inequalities faced by people with disabilities.

*"I had one of the assessors ask my client, who is a below the knee amputee, 'will it grow back', she is supposed to be a fully trained nurse. Or you are getting mental health patients who have been seen by someone who has no idea on mental health and they are assessing them as 'perfectly normal', they've got no issues. They are not seeing them when their arms are gouged because they are self harming or the fact that they have attempted suicide 2 or 3 times. But they (assessors) say they are fine, they've got no issues. And then you get an assessor asking you, 'what's this condition all about' " - **MK CIL***

MK CIL explained how disabled people often feel relating to inequality and discrimination.

*"A lot of people deny being disabled or classing themselves as disabled. Some individuals do not like the stigma, if they say they have a disability, they won't be treated the same way." - **MK CIL***

Covid-19 has also affected MK CIL, resulting in many people coming to them for support due to the lack of volunteers within other voluntary organisations across Milton Keynes. We heard that Citizens Advice Milton Keynes had 400 employees including volunteering prior to covid, now this number is 1/10th. This then means there is less support from services such as CA for people with disabilities.

*"A lot of groups were lost because of covid - all sorts of groups including support groups. We are lucky as CIL, we are attempting to carry on as we did pre-covid because this was the thing that worked. People wanted to see us and come in and ask us for that help. They don't want someone to talk to over the phone. We had so many clients coming in because of the lack of volunteers in other voluntary groups around " - MK CIL*

MK CIL also highlighted that 111 is a very helpful service for the people they work with.

The DRC told us that in terms of partnership work, they are more likely / able to work with other charitable organisations than statutory organisations. Although they have some examples of developing effective joint work in the past with some pharmacists and some GPs.

Recommendations

### Adapting services and spaces to be culturally appropriate

- Make more GP appointments available the same day to relieve pressure on walk-in centres and to make care more accessible to disabled people, or people with mental illness that cannot wait hours in a walk-in centre. This will help catch issues before they escalate.
- Consider adjustments for people with disabilities in terms of reducing waiting times in Walk-In-Centres and A&E to disabled people that physically cannot wait that long, and for people with mental illnesses that make long waits impractical or impossible.
- Explore options to increase care at home to disabled people to enable hospital discharge when patients are ready to go home, rather than staying in hospital beds longer than necessary.
- Ensure that GPs and DWP communicate around access to medical notes so this process is straightforward for disabled people that need to access benefits. Standardise or remove the fee for this. Standardised and affordable price for medical notes across PCN's in Milton Keynes, or make them fee free.
- Improve coordination / communication between A&E and walk-In- centre so that people with disabilities are not pushed from one to the other and back again.
- Speedier access to Social Workers pre crisis.
- Find a way to ensure that people who use wheelchairs are able to have their wheelchair taken with them to hospital if they are taken there by ambulance as access to their own wheelchair is vital.
- Avoid out of area appointments for people with disabilities as transport can be an issue.
- More advocacy support for people with disabilities, and support to enable MK CIL and other advocates to communicate with service providers.
- Allow people with disabilities to regularly see the same Doctor so they understand their disability and needs.



- Consider ways to make ordering repeat prescriptions more accessible to people with disabilities.
- Opportunities for service users to co-produce services and solutions to issues.
- Less variation of services across areas - standardisation was called for.
- More support and funding to MK CIL due to the increased service they are providing

### Training, education and increasing cultural awareness

- Training to DWP assessors on disabilities to ensure understanding is sufficient to assess individuals.
- Education for healthcare staff and providers about disability awareness.

### Communication / information

- Can agreements be made whereby MK CIL clients send in an email or a form stating they consent for CIL to speak on their behalf even if not present at the time of particular phone calls to service providers e.g. MKCC
- Ensure that communication methods are appropriate for each person with disabilities so that they are able to use them, and that services are delivered in ways that are accessible to individuals depending on their disability and needs.
- Find ways to ensure people with disabilities don't avoid contact with GP due to concerns over communication with receptionists, and that appointments for people with disabilities that need attention are made by receptionists when requested.
- ICS to be clear how MK CIL can be involved in voicing the lived experiences of their users, how this information will make a difference and how MK CIL will receive regular feedback from health services.
- Communication around news ways of working and explanations as to why appointments are via the telephone as opposed to in person
- Make 'getting back to someone' business as usual for healthcare professionals and providers of services - can this be added to staff handbooks and roles and responsibilities?
- GP surgeries to provide an automated message when contacting the Doctor to advise that receptionists have been asked to ask about a person's reason for calling and stating that this isn't compulsory but could help the surgery help them, help the person
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### Actions

- CA:MK to flag the issue around confusion between DWP and GPs relating to accessing medical notes benefits assessments, and query the fee differences / need for a fee to people on low incomes.



