Equality, Diversity and Inclusion

Creating a strategy for West Yorkshire health and care services

July – August 2024

If you need this report in another format, please contact **Healthwatch Working Together in West Yorkshire** by calling 0113 898 0035 or email info@westyorkshirehealthwatch.co.uk

Information in this document can be copied or reproduced but please credit **Healthwatch Working Together in West Yorkshire.**

Contents

Summary

West Yorkshire Voice was asked to lead several focus groups to help West Yorkshire Integrated Care Board (WY ICB) develop its Equality, Diversity and Inclusion (EDI) Strategy. West Yorkshire Voice invited people to share their feedback and ideas about what should be included in the new strategy for health and care services across the region.

The focus groups were planned alongside other surveys and events led by the WY ICB: a 'Stakeholder Day' and two online surveys, one for the public and one for professionals. West Yorkshire Voice spoke to 46 people about their understanding of equality, diversity and inclusion, what they thought was working well, what wasn't and any suggestions they had for improvement.

Thank you

Thanks to everyone involved in this work for sharing their experiences and ideas.

> "The public are at the heart of the decisions made and it is vital for them to be part of the planning process - or any changes which are made will not be effective."

Key findings and what people want to see

Below is a summary of the key themes from the focus groups and what people want to see.

	Key Findings	What people want to see
1	**Accessible Communication:** Clear communication adapted to people's needs is vital to them having equal access and benefit from health and care services.	- The Accessible Information Standard (AIS) must be implemented by all health and care services. - More interpreters including different dialects and cultural backgrounds.
2	**Accessible, person centred and holistic care:** It is important for people that professionals understand them as a 'whole person' rather than their symptoms or diagnosis.	- Ensure that venues and facilities are accessible and reasonable adjustments are made for people with disabilities. - Ask people questions, involve them in decisions about their care and make sure that support is tailored around their needs.

	Key Findings	What people want to see
3	**Design and adapting services in line with community need:** There is often a disconnect between what professionals think people need and what they actually need.	• Services should be designed, delivered and evaluated with involvement of the people they aim to support and based on community need. • New projects and investments should use resources in existing communities and structures to help meet community need.
4	**Diversity in workforce and leadership:** People benefit from seeing and speaking to people like them in health and care services and would like to see diversity in leadership roles.	• There should be more alternative education and employment routes into the health and care sector as well as opportunities for people from diverse communities to develop into leadership roles. • People with lived experience should be part of recruitment panels.
5	**Make services welcoming:** People want to be able to go into a service without fear of judgement and feel safe.	• Physical spaces should be designed in a welcome and inclusive way that creates a sense of belonging. • Staff should be made aware of the importance and positive impact of making people feel welcome.

	Key Findings	What people want to see
6	**Compassionate and culturally competent care:** It is important to people that services are culturally sensitive, and that staff understand their background and culture.	• Staff should have meaningful training in cultural sensitivity to help them understand the needs and cultural contexts of specific communities. • We need to build a culture where staff can be confident to be curious, ask questions and recognise people's strengths.
7	**Early Intervention and preventative care:** Lack of early intervention can make things worse for people and exacerbate health inequalities.	• More investment in early intervention support and preventative care, particularly in mental health.
8	**Creating a strategy and accountability:** People want whatever is in the Equality, Diversity and Inclusion strategy to happen and for people to be accountable.	• Consider the impact of the strategy so that feedback from communities can be sought to measure it.
9	**Missing Voices:** There were still many voices missing from the conversation around the EDI strategy and we need to hear from these to get the strategy right.	• Go out to existing voice forums and community groups to hear from people whose voices haven't been heard. • Skill up professionals to help get more people involved in providing feedback and solutions.

Introduction

About the strategy:

West Yorkshire Integrated Care Board (WY ICB) want this Equality, Diversity and Inclusion (EDI) strategy to make a difference to the people who use healthcare services and the health and care workforce.

They want to have a clear strategy and plan in place to work towards:

- Equity, fairness and social justice.
- All communities can access the healthcare services they need.
- Valuing our diverse workforce.
- Inclusion and a sense of belonging for all.

They want this Equality, Diversity and Inclusion strategy to remove the barriers that exist and transform the lives of patients, staff and healthcare leaders.

About the focus groups:

The groups were advertised via the West Yorkshire Voice membership, local Healthwatch across West Yorkshire and the WY ICB. We were keen to hear from voices who are often not heard at larger events such as the Stakeholder Day and through surveys. We worked with organisations that are part of the West Yorkshire Voice network and engaged with local Healthwatch to help to bring a more diverse representation.

Seven focus groups were held throughout July across the different areas of West Yorkshire: two online, one in Leeds, two in Wakefield, one in Calderdale and one in Kirklees. There was no focus group held in Bradford as the Integrated Care Board ran a 'Stakeholder Day' in Bradford to support this work.

Focus groups were attended by between four and ten people in each session and ran for an hour and a half. Where people were unable to attend at the last minute, our West Yorkshire Voice coordinator offered one-to-one conversations over the phone or the opportunity to share perspectives via email. These perspectives have been included in this report.

Voices represented

We aimed to speak to a diverse range of people to gather different perspectives and to help strengthen the voice of those at risk of health inequalities. To understand the voices we heard from and who we were missing, we asked those who attended to tell us about their demographics. See Appendix 1: 'Who we spoke to' for a full breakdown and analysis of the voices represented.

In summary, 15 people attended in an individual capacity and 27 in a professional capacity. There was a strong neurodivergent voice throughout the sessions as well as lots of discussions around mental health, dementia and strokes. There was good representation from people with disabilities and people who identified as unpaid carers or had childcare responsibilities.

Although there was some diversity in terms of ethnicity, the sessions were predominantly attended by people who identified as White British. Representation was very limited in terms of the LGBTQIA+ community, with all participants who completed the survey identifying as cisgender and only one person who did not identify as heterosexual.

People also brought experiences of interacting with the social care system, trauma, coercive control and violence, poverty, speaking English as a second language, being a migrant and being a diabetes community champion.

"Things should never be done on behalf of people and that they should be involved throughout"

Definitions of EDI:

The West Yorkshire Integrated Care Board (WY ICB) wanted to know how people understand the terms equality, diversity and inclusion.

The focus groups were structured along the three themes of 'equality', 'diversity' and 'inclusion' but was also kept loose to allow for participants to bring what they felt was important into the discussion. We started each section by discussing what the individual term meant to us as individuals and in our organisations. This led us into further conversations about what this looks like in practice.

What does equality mean to you?

People told us that equality means having the same opportunities across different areas of life such as health, education and housing. These opportunities should be possible to access without experiencing any form of discrimination. To achieve equality, people told us it is important to recognise that certain support or services will be harder to access for some individuals and groups, due to many factors such as disability or race. People shared examples of where equality is not present such as when 'hierarchy' is present within services.

While some discussions used the word 'equal', several people shared that they prefer the term 'equity'. We heard that equity refers to everybody having equal value and needing an equal outcome but not necessarily having the same needs. People also described it as being treated 'fairly'.

People told us that creating equitable health and care would involve giving everyone an 'equal landing point' to access services, by removing barriers. This would look different for everyone because everyone is different. A good way of understanding this is exercises such as a 'privilege walk' where people step forwards and backwards based on their life experiences and the advantages and disadvantages that these can cause.

People also discussed different types of equality related to protected characteristics. People told us about the importance of 'race equality' and of recognising that treating individuals as 'disabled' prevents equality. This shows the importance of taking an 'intersectional' approach and understanding different elements of achieving equality and equity.

What does diversity mean to you?

We heard that people understand diversity as the differences between people and the range of characteristics an individual brings to any environment. People shared that it is important that others understand their background and individual experiences and that we should embrace and value the differences between us.

People told us that the staff and people using services should be representative of the population. People shared the importance of seeing someone like them when using a health and care service. Also, that there should be diversity at all levels of staffing within an organisation, including senior professionals and leadership structures to make sure decisions are being made in line with the priorities of local communities.

Diversity is also something that should be visible as this can support people to feel welcome, included and safe. It can help people to have the confidence to go into places like a hospital or doctors' surgery.

People talked about the importance of having meaningful diversity when hiring staff and supporting communities. Diversity should be celebrated for the value it brings and not be seen as a 'tick box' exercise. People suggested that better education in schools about diversity would help people understand it's importance within the wider health and care environment." People pointed out that diversity is not static and should adapt in line with a changing population.

What does inclusion mean to you?

Discussions around inclusion took a range of different directions but centred around making people feel a sense of belonging and welcomed within health and care services. People discussed the positives and negatives of labels and diagnoses for helping individuals to feel included. Lots of conversations centred around how to achieve better cultural inclusion as services and related to individual staff approaches. As with diversity, some people also told us that they feel included when they see people like themselves. For others, it was just important that a professional has cultural sensitivity and the ability to recognise and consider whether someone is from a particular community. There was also a recognition of the importance of health and care services including individuals in discussing and planning their own healthcare.

"Everyone requires different treatment to feel included and heard".

What does this look like in practice?

We asked people what equality, diversity and inclusion looked like in people's day-to-day lives and what could it look like if it was working as, it should be.

People were encouraged to imagine the year 2030 and consider what 'better' might look like. From the seven focus group discussions, follow up conversations and the 'Feedback and Findings' session run in August, the following themes emerged:

1. Accessible Communication
2. Accessible, person centred and holistic care
3. Designing and adapting services in line with community need
4. Diversity in workforce and leadership
5. Make services welcoming
6. Compassionate and culturally competent care
7. Early Intervention and preventative care:
8. Creating a strategy and accountability

Throughout these themes, we detail examples shared of where things have worked well where they haven't worked well, and suggestions for change.

"**Tendency to fix things when they have gone bad but lack of preventative care – health is wealth.**"

Accessible Communication

People shared the importance of being able to access their own medical information and interact with services comfortably and easily.

People told us examples of where things are working well:

- **Health passports:** Effective for those with long-term health conditions and disabilities to share communication and support needs with different services.
- **Clear communication**: People shared that information should be clear and easy to understand. A professional shared that an easy read version of their service information was most popular at a recent stall event, even for those without this access need.
- **Adapting communication**: Someone told us about taking their elderly parent to Accident and Emergency (A&E). When they did not understand the information about their treatment, the doctor took time to explain by drawing diagrams to adapt to their communication preferences.
- **Interpreting**: In Bradford, they have interpreters available at GP surgeries at set times during the week to help with access to appointments.
- **Access to records**: An autistic person told us that GPs sharing a copy of appointment notes helps them to process the information.
- **Learning disability health register**: we heard that the use of a learning disability health register at GP surgeries helps ensure reasonable adjustments can be made ahead of an appointment.

"Equality starts with accessibility"

People told us examples of where things are not working well:

Language and terminology:

- Too much jargon and medical terminology is used which can be difficult to understand.

Methods of communication:

- Many GP surgeries ask people to call for an appointment at 8am, which is a barrier for many.
- People with mental health difficulties and neurodivergent conditions told us that phone calls can cause a lot of anxiety.
- Professionals supporting people who are housebound and unconfident with digital technology, shared that they may be disadvantaged in terms of access to information about health and services.
- Not everyone is comfortable and able to use digital methods of technology to find health information or communicate with services.
- Professionals shared that literacy levels are often not considered when communicating with people.

Accessible Information Standard (AIS): The Accessible Information Standard (AIS) is often not met despite being a legal requirement.

- People who are visually impaired and have other disabilities continue to receive letters in a format that they cannot read or understand.
- People's records are not always being kept up to date with their communication needs or this information is not shared between colleagues supporting the same individuals.

Interpreting and translation:

- People shared examples of people interpreting for family members, due to lack of interpreting availability or assumptions that family will interpret, e.g. young children interpreting for their parents. This can feel intrusive and embarrassing and can also delay or prevent a person from accessing care.
- When booking interpreters, there is limited consideration of the use of different dialects. This affects the quality of translation and the person's experience of the appointment and care.
- People also told us that accessing an interpreter can take several weeks for some languages, including British Sign Language (BSL).

What people want to see:

People want to be able to understand the information they receive from health and care services and to communicate in a way that is comfortable and accessible to them. This helps people feel more accepted and listened to and ultimately get the health and care support they need.

- **Accessible Communication Standard (AIS)**: This should be adhered to in all services and there should be a process for how services are held accountable for implementing it.
- **Choice of modes of communication**: People should be able to choose how they receive information from and communicate with health and care providers.

"Being able to communicate without any struggles"

- **Recording**: Improve recording of communication preferences and needs. Ensure adjustments are in place without the need for repeated requests.
- **Person-centred**: Professionals adapting their communication style to an individual's needs and preferences.
- **Interpreting**: More availability of interpreters, considering different dialects and cultural backgrounds.
- **Diversity of workforce**: A greater number of medical professionals from different cultural backgrounds.

"Clear, compassionate communication that involves actively listening to patients' concerns and explaining medical information in an understandable way."

Accessible, person centred and holistic care

We heard that it is important for professionals to try and understand the whole context of a person, not just their symptoms and/ or diagnosis. It is important to ask questions and involve them in decisions about their care.

People told us examples of where it is working well:

- **Person-centred care**: When staff ask open questions, use active listening and hold space for a person to talk, it reduces assumptions, improves person-centred care and reduces re-traumatisation.
- **Adapting appointments**: An autistic individual told us they are offered one-hour appointments which supports them to explain their health difficulties in depth.
- **Involving carers**: Professionals working with people with dementia, shared good practice of involving and forming a partnership with carers and family in planning care.

" Need to be treated as 'me' and not as my diagnosis – should be about my whole identity"

People told us examples of what is not working well:

Reasonable adjustments: We heard that not having reasonable adjustments in place can have a huge impact on the quality of care received and the mental health of an individual.

- Neurodivergent individuals and unpaid carers shared experiences of not having reasonable adjustments met in other areas of life (e.g. employment), which discourages them from requesting adjustments in health and care services.
- Some people are not aware of the adjustments they can ask for or do not feel comfortable or confident asking for adjustments.

> **"The system is designed to treat 'illnesses' and 'disorders' in a standardised way rather than the people experiencing them"**

Universal approach and standardised care: People told us that while everyone's needs are different, people are often offered the same type of support, which is at odds with discussions around 'equity', and does not help people to achieve equal outcomes.

- People told us that short GP appointments mean it is hard to fully discuss health challenges, especially for those with multiple health conditions and wider risk factors.
- In mental health services, people told us that standard options of Cognitive Behavioural Therapy (CBT) and group work were not effective for them and very short term e.g. for those with complex trauma and there are limited alternative support options.
- A professional shared that stroke survivors are offered a standard six weeks of support before discharge, despite the variety in presentation and symptoms that people experience.

- Services are not flexible enough for people who are working or have caring responsibilities.
- Someone living in Kirklees told us that they had their wheelchair assessment done in a clinical setting rather than their home, resulting in their current wheelchair not being suitable.

Not involving people and their family/ carers:

- People also told us about experiences of professionals making decisions without consulting notes or involving family or carers who have knowledge about the person. One person gave an example where this led to them being incorrectly discharged without a care plan in place.

Inconsistency: People told us that it can be difficult seeing a range of medical professionals and having to retell their story multiple times.
- One person shared an example of their hormone medication being stopped after being 'passed around' several doctors.
- Someone shared how having to re-tell their story can cause re-traumatisation for people who have experienced trauma.

What people want to see:
- **Reasonable adjustments**: Offer people time and information to help discuss reasonable adjustments to support them to understand what is available and what they need. More effective recording on individual records to ensure adjustments are in place in advance.
- **Accessible venues and facilities**: Accessible buildings, toilets and other facilities that make it possible for people with all types of hidden and visible disabilities to access services.

- **Individualised support**: Support that is adapted to the needs of an individual e.g. length or type of appointment, treatment based on complexity, timings flexible that consider childcare and other caring responsibilities.
- **An intersectional approach**: Considers the whole person and their situation and not just symptoms or the condition being treated.
- **Understand barriers**: Services embodying the social model of disability by recognising that people are disabled by their environment and society.
- **Involve people in their care:** Staff to ask questions to better understand people. For example, one person shared the importance of staff taking time to understand their choice not to be sedated for procedures due to losing a friend who was sedated during a procedure.

> **"A welcoming and accessible environment where all patients, regardless of their physical abilities, feel comfortable and accommodated."**

Designing and adapting services in line with community need

We heard that there is often a disconnect between what professionals think people and communities need and what they do. Services should be designed, delivered and evaluated with involvement of the people they aim to support.

People told us examples of where it is working well:

- **Adapting to communities:** Professionals shared that it can be effective to use a variety of approaches to deliver health and care services to different communities. For some communities, drop-in and other outreach support works more effectively than individuals travelling to a health centre. Examples were given of successful outreach with Hindu and gypsy Roma traveller communities and delivering diabetes prevention in local supermarkets.
- **Cultural sensitivity and competency**: Good practice was shared around changing the menu at Leeds Teaching Hospitals Trust to include Halal and Kosher food.

People told us examples of what is not working well:
Not considering certain groups:

- People told us that often services feel like they have not been designed with neurodivergent people in mind.

- Someone shared that their family was unable to support and see a loved one in the way they wanted to during end-of-life care due to rules in place. This was at odds with their cultural practices as a family.
- People told us that services and professionals often do not consider ethnicity within their approaches to care. Someone shared that they had lost many friends from the Black community to hypertension, but that this health risk is not recognised by the health system.

Location of services:
- People shared that in rural areas of West Yorkshire, people must travel large distances to use health and care services. For example, Todmorden Health Centre is not used as much as it could be and instead people travel to larger areas such as Halifax, Huddersfield or Leeds for basic treatment that could be delivered locally.
- Many services are hosted in locations without nearby access to public toilets or that are a long distance from the train or bus station, impacting access for people with bladder or bowel problems.

Accessible transport:
- People told us that public transport and in particular taxis are often not wheelchair accessible, which can make it difficult to use health and care services.
- One person told us that they and other disabled colleagues do not qualify for patient transport to their GP despite experiencing barriers.

Consistency of services:
- We heard that regular reviews such as annual health checks often do not take place or vary in their quality.

Wider factors impacting health:

- There is a lack of accessible housing, such as single floor residencies, particularly for larger families. This can impact both the health of an individual (poor mental or physical health and isolation) and where a person can live.
- Financial support – Someone shared their challenges of accessing direct payments for their son to have a personal assistant once they turned 18. This is impacting their financial stability and access to care.

What people want to see:

- **Services designed around community need**: Equality, Diversity and Inclusion priorities should be based on 'what we are not doing' and 'what is missing', informed by speaking to communities at the earliest opportunity. Services should be delivered in a variety of ways for different communities with different needs.
- **Using existing structures**: New projects and investments should use existing communities and structures to help meet community need. e.g. could more community champion roles be funded?
- **Go to communities**: Deliver services in spaces where people already go and where communities feel comfortable e.g. physical spaces like community centres.

"**Minority communities like the Hindu and Sikh tend to get forgotten when programs like this take off, as allegedly or assumption is that they do not need any help and assistance as the noise isn't coming from them**"

Diversity in workforce and leadership

We heard that people benefit from seeing and speaking to people like them in health and care services and would like to see diversity in leadership roles.

People told us examples of what works well:

- **Seeing someone like you:** People told us that they have positive experiences when they see and receive care from people like them, e.g. a similar background and identity. This reduces the need to explain circumstances or preferences and often advocacy support was felt to be stronger when there is a shared experience. A professional told us about their Hindu community producing health information videos to be shared among community members.
- **Recruitment of people with lived experience**: Professionals shared examples of recruiting people with lived experience who are often marginalised by job application processes. E.g. Leeds GATE supports people using services into professional roles within their organisation.
- **Disability recruitment**: Recruitment processes can feel more manageable for disabled individuals when given automatic interviews through the 'disability confident' scheme.
- **Reasonable adjustments**: Good practice was shared from Airedale Hospital that uses an 'enable me' passport to help staff to communicate support needs related to any disability, health condition or broader factors such as being a carer and experiencing menopause.

- **Lived experience led approaches**: Airedale Hospital also have a staff disabilities network group that meets to try and improve things at the hospital for staff. This is led by people with lived experience.

People told us examples of what is not working well:

- **Not seeing someone like you**: Some communities and individuals told us they may struggle to engage with services where there is not an option to work with someone from a similar cultural or religious background.
- **Diversity in leadership**: People shared that professionals from ethnic minority and other diverse backgrounds often find it hard to progress into leadership opportunities.
- **Tokenism**: People shared that organisations have signed up to schemes such as 'Disability Confident' but do not implement enough support to staff and people using services.
- **Support for staff:** A disabled staff member told us they were not provided with nearby accessible accommodation to enable them to work on site. There are also no accessible toilets in their department.

Recruitment barriers: Recruitment processes can make it more difficult for people from certain backgrounds to get employment in the health and care sector:

- People who are neurodivergent may find it difficult to maintain eye contact during interviews.
- People shared difficulties with completing long application forms, saying they would prefer to send a CV.
- Scenario-based questions can be challenging for some learning styles.

- Professionals working with the Gypsy Roma Traveller community shared that many people they support struggle to gain roles in health and care because application processes are not accessible to those with lower literacy levels.
- Many health and care roles require a degree, which can exclude many for whom university was not accessible.
- It can be difficult for people to access adult education to progress into health and social care roles. One person shared being unable to enrol at Calderdale College which has impacted their ability to find work within health and social care, despite doing several voluntary roles within it.

HR systems: People told us that they do not feel supported and protected by Human Resource (HR) processes and systems.
- Examples were shared of incidences of racism that were not dealt with appropriately or effectively within an NHS team.
- People shared that they did not feel their HR teams represented the workforce or had any lived experience of discrimination.
- People talked about using the 'freedom to speak up' mechanism to raise concerns, but that it got stuck at board level with limited action taken.
- Some people turn to trade unions for support, but the financial costs of joining can be a barrier to access.

What do people want to see:
- **Senior leadership representation:** Greater diversity in senior leadership through offering more training and programmes to develop diverse leaders and close opportunity gaps.

- **Transparency of leadership**: Professionals want to know whether the Integrated Care Board are representative of the populations they serve. This information should be visible and accessible. They want to know what is being worked on internally to address Equality, Diversity and Inclusion for health and care workforces.
- **Learning from good practice:** Learn from communities where communities who face the greatest inequalities are supported into employment e.g. Leeds GATE.
- **Lived experience on panels**: People with lived experience relevant to the role should be part of recruitment panels.
- **Meaningful diversity and support**: It is important that commitments to schemes like 'Disability Confident Charter' are backed up by meaningful actions that support prospective and current staff.
- **More alternative education and employment routes**: Understand that many people miss out on education and traditional routes into health and care roles. Provide more flexible pathways into roles that include more hands-on learning.
- **Accountability**: Improve accountability structures (e.g. within HR processes) in health and care providers to protect staff from discrimination.

Make services welcoming

People want to be able to go into a service without fear of judgement and to feel safe.

People told us examples of where things are working well:

- **Inclusive physical spaces**: such as having gender neutral toilets available and having inclusive and positive signage e.g. 'LGBTQIA+ friendly'
- **Welcoming staff**: We also heard about the importance of the first interactions you have when you try to use a health or care service.

> "Small gestures that people show me makes me feel I'm welcomed and accepted to this society, community. For example, I went to the GP and the receptionist smiled at me."

People told us examples of what is not working well:

Representation of services: The imagery and language used can impact whether someone feels that a service is 'for them' or whether they are 'included'.

- Disability bus passes have an image of a wheelchair user, meaning people wrongly assume they are only for those with physical disabilities.
- Professionals from hospices shared that the term 'hospice' does not feel comfortable to certain communities and does not reflect the range of services that are provided beyond end-of-life care.

Physical spaces:

- People with sensory difficulties can feel overwhelmed by the lights and noise in A&E and there are no alternative spaces to wait.

"I would say from my experience people from lesser heard communities are not fully aware of what we do as a hospice and that leads to them not accessing us when they could be getting help."

What do people want to see:

- **Designing physical spaces** in a welcoming and inclusive way e.g. considering sensory overwhelm.
- **Creating a sense of belonging** for people when using healthcare services is important for patient satisfaction and continued engagement.

Compassionate and culturally competent care

People shared the importance of staff trying to understand their background and culture and wider services being designed with greater cultural sensitivity.

People told us examples of where things are working well:

- **Compassionate care**: someone shared that when receiving emergency treatment for cancer, a staff member treated them like an individual, held their hand and cared for them.
- **Labels and identity**: We heard that labels could be empowering and contribute to a sense of identity if it used in a kind and compassionate way. A label, for example, related to a diagnosis, can support someone to get the right kind of support and adjustments.
Diverse organisations: Organisations with a diverse workforce often have a better understanding of specific communities they serve. Some examples were shared around ethnicity and gender-friendly doctors working in a Gender Identity Clinic.

People told us examples of what is not working well:

Staff not asking questions:
- An example was given of a visually impaired person who was being provided meals in hospital but was not told when the food had arrived. When they did not eat the food, the staff took it away, assuming they did not want to eat, without asking any questions.
- People suggested that in some instances staff may be too scared to ask questions.

"We are often driven so much by Key Performance Indicators (KPIs) and targets that we lose or forget the humanity."

Negative labels and stigma: Some people told us that some types of labelling can be distressing. They can create a feeling of 'exclusion' from society or create 'hierarchy' and can carry a lot of misconceptions and assumptions.

- Examples were given of labels for mental health conditions that use the word 'disorder', implying there is something 'wrong' with the individual, rather than something they experience.
- Some neurodivergent individuals shared that having a diagnosis or label can impact the way in which they are treated within a health and care setting or the treatment or support that is offered.
- People also shared negative experiences of 'othering' and individuals and communities being treated as 'backward'.
- People shared their challenges with the use of words such as 'vulnerable' and 'victim'. We heard that stroke survivors are often automatically classed as 'vulnerable to abuse' and that friends and family are often assumed to be a 'carer'.
- Professionals shared that staff often do not know how to interact with people with learning disabilities.
- People told us that labels can be difficult as it can result in everyone with that that label being treated as the same. It is important for example to consider the cultural differences among 'carers' in how they see their role and the language they use to describe this.

"A label can create feeling of being treated like a victim, which is degrading for some people as not everyone in society is necessarily vulnerable if they have a mental health condition"

Professionals making assumptions or judgements: Someone shared that when accessing health services as an LGBTQIA+ person, there had been assumptions made about their sexuality and family make up e.g. being married and heterosexual because they had children.

- Someone shared that they have often been assumed to be taking drugs due to talking quickly which results from their ADHD.
- Sometimes staff think that only family members can be carers.
- Individual staff approaches and assumptions also may be affected by the political context of any time, e.g. there has been a lot of negative media around transgender people recently.

Cultural competence and understanding: People shared examples of services needing greater cultural competence when providing care.

- An example was shared by someone of Bengali heritage who cooked for the family from a young age. A professional expressed that this was not normal and did not take the time to understand this person's cultural norms.
- Someone shared that there is a harmful misconception, rooted in racial discrimination, that the Black community has a higher pain threshold[1], which can result in reduced care and missed diagnoses. They mentioned that their niece was rushed to the hospital multiple times but quickly discharged despite being in significant pain.

---

[1] https://pmc.ncbi.nlm.nih.gov/articles/PMC4843483/, Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites - PMC (nih.gov)

Not being believed:

- People told us about examples of not being believed or meeting criteria. This has required people to push and advocate for their own healthcare which can be difficult, especially for those facing the greatest healthcare inequalities.
- Someone shared being told their physical health symptoms were psychosomatic, which resulted in their physical health issues worsening significantly before they were diagnosed.
- Another shared that there is a lot of 'victim blaming' that people experience in the adult social care system.
- Someone shared that before their father passed away, he was not confident to challenge anything around his care.

What people want to see:

- **Reframe language**: Reframe and design terminology with people experiencing health challenges. Ask people how they like to refer to their health.
- **Recognise people's strengths**: It is important to recognise that people experiencing disabilities and health challenges also have great abilities and ideas. We should not treat them as 'incapable'.
- **Training**: Greater levels of meaningful training, led by lived experience, that adapts in line with changing population. This should include thorough inductions.
- **Understanding needs of specific communities**: For example, people told us that there is a need for greater understanding of Autism and ADHD.
- **Understanding cultural context**: Recognise the historical and cultural context behind how communities may feel towards services and asking for help. For example, there is often fear of judgement, shame or blame for example around discussing mental health in certain communities.

- **Build staff confidence to be curious**: We need to increase staff confidence to ask questions to understand how individuals want to engage and interact with services.
- **Accountability culture**: It is important that we create a culture where staff can confidently and comfortably challenge each other around approaches and language use.
- **Understanding systemic element**: While training and learning can make a difference, it is important to recognise that assumptions and staff approaches are largely systemic and there is more to do for tackling this.
- **More use of care needs assessments**: People suggested a greater use of care needs assessments to understand individual needs.
- **Fund diverse organisations**: Invest in supporting diverse organisations who are already well placed to deliver support to communities with whom they have trust.
- **Look at how we can better support staff wellbeing**: 'Compassion fatigue' can impact people's quality of care. Whose role is it to monitor and support this in services?

Early Intervention and preventative care

People told us that when things are not dealt with at an early stage, this can result in unplanned self-management and individuals having to advocate for themselves. This disproportionately affects individuals with health inequalities in terms of accessing care. Early intervention can improve Equality, Diversity and Inclusion across health and care services.

People told us examples of what is not working well:

- **Growing complexity**: People shared that when there has not been early intervention in mental or physical health, this has led to an increase in the complexity of their needs and developing further health conditions.
- **High threshold and criteria for support**: People told us that many metal health services do not treat people until they reach crisis point. This has led to long waiting lists and pressure on crisis services. One person shared their experience of being turned away from services due to their trauma being 'too complex to treat'.
- **Coordination between services**: Someone shared an example of disparity of support depending on diagnosis. They were rushed to be assessed for cancer but after a negative screening were discharged suddenly. Despite continuing to struggle with their symptoms, they were not offered follow up support.

What people want to see:

- People told us that they would like to see more investment in early intervention support and preventative care within mental health.

Creating a strategy and accountability

How do we prioritise?

People recognised that Equality, Diversity and Inclusion (EDI)is a vast topic and there are many things that need working on. People raised the question of, 'how do we prioritise and decide what to focus on?'.

Suggestions:

- **Involve** the voices of people we have not yet heard from.
- **Link** in with and enhance existing strategies and pieces of work e.g. 'women's strategy'. E.g. could we use an engagement calendar to help align actions with existing work taking place and awareness events.
- **Analyse** existing data to further understand needs of communities.
- **Be ambitious but realistic** with any goals set out in the strategy and be honest about what is achievable.

"Organisations often say we will 'weave EDI into everything we do' but this doesn't happen – what do you mean by this and how do we make it happen?"

How do we stay accountable?

Professionals shared that EDI work is incredibly important to them but were concerned that they have seen many similar strategies written and have not felt genuine impact from these. It was felt that despite recent progress, the pace and scale of change within EDI is not fast enough.

People want to see the West Yorkshire Integrated Care Board (WY ICB) design and share a process for checking that this strategy is followed and that those delivering on it are held accountable.

> **"When people are listened to, but nothing changes this breeds distrust from things not being delivered. How do we avoid tokenistic involvement?"**

What people want to see:

- **Make it meaningful**: Avoid this being a 'tick box exercise'.
- **Feeling impact:** Consider how people might 'feel' the impact of the strategy so that feedback from communities can be sought to measure it.
- **Involvement**: People should be involved throughout – things should be done with, and not on behalf of people.
- **Accessible communication**: The strategy should be written available in formats that are accessible for everyone e.g. easy read.
- **An open feedback culture:**
  - People would like access to the WY ICB decision making processes to scrutinise decisions made. Examples were shared of how involvement is done on police scrutiny panels.

o People want more development opportunities to build confidence to give feedback e.g. voluntary/leadership roles.

o Often feedback is taken personally rather than a positive opportunity for organisations to improve.

"Honesty, dialogue and uncomfortable conversations must be had if we are to make sure we can improve and help support."

How do we fund and finance the work?

People shared throughout the focus groups that there is always a worry around finances and funding. The ideas given by attendees were exciting and insightful, but people questioned how we carry this work out if we are already struggling as a system with regards to funding.

Professionals shared the challenges of funding and project working, particularly in the voluntary sector. Often funding is cut, and projects must end or are taken on by new providers. We heard that funding is often cut in places where there is a proven need and positive impact on marginalised communities and people felt this was often in the most deprived areas. E.g. in Birkby, there was a diabetes project ended despite identified need and proven impact.

Cuts to services have increased the health inequalities faced by people and access to private services by those who can afford them exacerbates this further. People who can afford private treatment get a better quality of care. For example, we heard that within the mental health system, it feels like there is a 'two-tiered' system of support. People who can afford to pay for private mental health support can get quicker support, access more options and use services for longer.

Suggestions:

- Fund services within existing communities who are often best placed to run things. Commission services to fill gaps.
- Recognise the role of the voluntary sector as equally important to statutory services.

"What are the processes for engagement and collation for this piece of work and how will it make a difference?"

Missing Voices and next steps

While the focus groups aimed to reach those who had not been reached through the 'Stakeholder Day' and survey, there were still many voices missing from the conversation (see Appendix 1 for more detail). There were some sessions that had more professionals than people sharing lived experience attending.

Engaging with missing voices:

- **Using existing forums**: People expressed the importance of using existing voice forums where people can share their views and experiences about processes such as these.
- **Going out to communities**: Professionals who attended recommended that this work should be carried out within community spaces and through community groups e.g. through connecting with religious leaders.
- **Using professionals as links**: Professionals asked to be given more information about how to share this work with their organisations and communities to get more people involved in providing feedback and solutions.
- **Explaining involvement:** People shared that there is more work to be done on how we support people to 'want' to be involved in giving feedback by for example, explaining how it will impact change.

"Being in the heart of the community and linking in with groups who are already holding events"

Other Recommendations:

- Continue to involve people with lived experience in this work.
- Create more ways in which people can feedback anonymously.

"I think a key question for you to consider is why ordinary and unpaid citizens should be interested in getting involved in all this strategy stuff and chatter. Do consider - What positive difference can it make for them in their lives?"

Appendix 1: Who we spoke to

We aimed to speak to a diverse range of people to help strengthen the voice of those at risk of inequalities.

To understand whose voices we had heard from and who we were missing, we asked those who attended to tell us about their gender, sexuality, caring responsibilities, disabilities, religion, ethnicity and employment status via a survey. 42 people attended the focus groups. 23 of these completed the demographics survey. This showed that 11 people attended to represent their own views and 12 were professionals. We spoke to a further 4 individuals outside of the focus groups via email, phone call or video call.

Of the 27 individuals who attended in a professional capacity, we had representation from the following organisations:

- Accessible Calderdale
- Alzheimer's Society
- Calderdale and Huddersfield NHS Foundation Trust
- Calderdale Council Coproduction
- Carers Count
- Cloverleaf Advocacy
- Community Links
- Different Strokes
- Evergreen Active
- Healthwatch Wakefield
- Locala
- NHS England
- One Ummah Community
- Spectrum CIC
- The Kirkwood
- Turning Point
- West Yorkshire Police
- West Yorkshire Sight Loss Council

Analysis

As not everyone completed the survey, there are limitations to our understanding of the demographics of everyone who attended. However, the 23 who did tell us more have allowed us to make some initial recommendations on who we still need to speak to.

Gender

- Everyone identified as cisgender, with over half (13) identifying as female and 8 as male.
- Of the professionals, 4 do specific work with men and 4 with women.
- There was no representation from non-binary or transgender individuals. 4 professionals stated they work with LGBTQIA+ communities, but this was not broken down into gender and sexuality.

Disabilities:

- Just under half (9) identified as having a disability, long-term illness or health condition.
  - 2 physical or mobility impairment, 1 hearing impairment, 2 sight impairment, 4 mental health conditions, 1 learning concentrating and memory, 2 neurodivergent, 3 long term condition, 4 other, 5 chose not to answer
- There was no representation directly from people with learning disabilities, but 3 professionals were in relevant support roles.
- Of the professionals: 2 supported people experiencing drug and alcohol dependence, 4 supported blind and partially sighted people, 3 supported deaf people, 7 supported people experiencing mental health difficulties and 5 supported those with physical and mobility conditions.

Sexuality:

- Only 1 person identified as LGBTQIA+.
- 2 people chose 'prefer not to say' and 2 people chose not to answer this question.
- 18 identified as straight/ heterosexual.
- 4 professionals shared that they work with individuals who are LGBTQIA+ within their work.

Age:

- Ages ranged between 24 and 69.
- Out of the professionals 1 works with children and young people and 4 work with older age adults.
- The voices of children and young people were missing throughout this work which was likely a result of the method of focus groups used.

Ethnicity:

- Around half (12) of attendees identified as White British, 2 people as Asian or British Asian – Indian, 2 people as Asian or British Asian – Pakistani, 2 people as Black or Black British Caribbean, 1 person as Mixed – White and Black African, 1 person as White Irish.
- Of the professionals 4 specifically support Black, Asian and Minority Ethnic groups in their work, 1 support the Gypsy Roma Traveller Community and 1 supports people seeking asylum.

Caring responsibilities:

- 8 people identified as unpaid carers with several people also having childcare responsibilities.
- Some people had multiple caring responsibilities.
- Of the professionals 3 shared that they work with unpaid carers.

Religion:

- 5 individuals stated that they had no religion.
- 8 identified as Christian, 4 identified as Muslim, 1 person identified as Jewish, 1 person identified as Hindu, and 1 person identified as Spiritual agnostic.
- We did not have any representation from Sikh or Buddhist communities.
- There was greater diversity in terms of religion among professionals who attended.
- 2 of the venues, in Kirklees and Calderdale were also venues that while were not attached to church buildings directly, are run by Christian faith communities which may have affected attendance from other religious groups.

Marital Status:

- The majority were married or in a civil partnership (10) with 6 single, 3 living with a partner
- 4 chose not to answer
- We did not have any representation from anyone who was widowed or divorced.

Employment status:

- A large proportion identified as being in some form of employment (12)
- 1 person was in receipt of benefits and 1 one not in employment, meaning we had limited representation from those who were potentially experiencing greater financial inequality.
- We did not speak to anyone who was currently completing an apprenticeship or training course or any students undertaking further education such as sixth form or college.

Representation across West Yorkshire:

- We had sessions across the different areas of West Yorkshire as well as online but did not hold one in Bradford due to the Stakeholder Day held in this area.
- The two Zoom sessions had 14 people attend in total from a range of areas.
- The in-person sessions were attended by 5 people in Leeds, 4 in Kirklees, 13 in Wakefield and 6 in Halifax.

Who we need to speak to:

- Gender-diverse individuals and the wider LGBTQIA+ community.
- More people from communities experience racial inequalities.
- Religious leaders and members of a wider range of religious communities.
- People with learning disabilities.
- More people who are Deaf or hard of hearing, with visual impairments and others who face various barriers to involvement due to inaccessible communication.
- People experiencing risk factors, such as poverty, violence and complex trauma, which make them most at risk of health inequalities: people experiencing homelessness, drug and alcohol dependence, people seeking asylum, Gypsy, Roma and Traveller communities, sex workers, people in contact with the criminal justice system and victims of modern slavery.

Appendix 2: Reflections on the process:

Following the focus groups, we gathered feedback from attendees via an online feedback form. This feedback is detailed below alongside our own reflections.

What went well:

- **Variety and diversity of voices**: While there are voices still missing, within the focus groups there was still a good range of voices and diversity present (see Appendix 1).
- **Transparency and feedback loop**: Following the focus groups, the discussions were collated, and notes were shared with the group to offer opportunities to comment. People shared that this was helpful and were able to make further comments.
- **Voices-led**: The structure of the sessions was designed to allow people to bring what they wanted to share on the topic of equality, diversity and inclusion. People told us they felt comfortable that the conversation was allowed to go off topic in line with what they wanted to discuss.
- **Facilitation:** People shared that they felt listened to, the atmosphere was open, and it was a safe environment. People felt their opinions and lived experience were heard and recorded and that it was run respectfully. People told us that the facilitator and group was friendly, and the session was laid back and relaxed.

- **Online option**: The online focus groups were very popular, and both were oversubscribed. This made it manageable for people to attend and these sessions had more attendance from people with lived experience.
- **Evening session:** Running an evening session made it possible for certain people to be involved in the discussions.
- **Professionals coming together**: People shared that it was good to get professionals together to highlight the areas that need addressing to enable better working with marginalised communities. For some this was a positive learning experience as expertise from others was informative.
- **Group size**: People shared that the group size felt manageable and comfortable with a maximum of 8-10 people.

What could be better:
- **Definitions of EDI**: people shared that discussion of the definitions of 'equality', 'diversity' and 'inclusion' was not productive and felt like a repeat of discussions they have had before.
- **Timing of sessions**: People shared that in some of the sessions they ran out of time.
- **Low attendance at some sessions:** Some focus groups had lower attendance of 4-5 people which limited the diversity of experience in the room.

"Participants need to know at the start where the session fits into a wider process."

- **Dominant experiences or themes**: Some focus groups had groups of individuals who attended together and therefore shared similar experiences. While our West Yorkshire Voice Coordinator attempted to bring all voices into the room equally, there were conversations that were led by certain themes due to shared experiences e.g. neurodiversity and dementia.
- **Venues**: Two of the venues were also run by local churches which could have affected attendance from certain groups.
- **Understanding impact and process**: People shared that it would have been helpful to understand from the ICB where these discussions fitted into a wider process and what impact they might have. Some felt that a draft strategy would have been helpful for the discussions.
- **Focus groups as a method**: People shared that while focus groups can be a useful method of hearing from people, they are not always suitable for engaging everyone. E.g. People may be anxious to share with people they do not know in an unfamiliar location.
- **Advertising**: Someone shared that people who do not speak English were unlikely to hear about or attend these kind of involvement opportunities. It is important to consider inclusive and accessible advertising of opportunities.

"Spending time trying to define Equality, Diversity and Inclusion felt like reinventing the wheel, as all present had discussed these concepts many times"

Appendix 3: What we heard from other community engagements

West Yorkshire Voice does regular engagement work to hear from communities about how they are experiencing health and care services, what could be better and what is important to them. We have shared some additional insights that came through from engagements between December 2023 and August 2024 that we wanted to highlight in addition to the focus group work:

Accessible Communication:

We heard:

- **People who are deaf or hard of hearing** are frequently being asked to make phone calls to book appointments which is not accessible. There are often not enough interpreters available and there are situations where interpreters have not been provided such as optician appointments and A&E. Some people had been offered video interpreting which they did not find accessible.
- **People who are visually impaired** frequently receive letters in a format they cannot read and requests for the correct format can often take a long time.
- **People with learning disabilities** shared that often services do not offer Easy Read options for people with learning disabilities. Booking appointments online and using other digital services can be difficult.

- **People experiencing homelessness** struggle to 'opt in' to appointments by phoning, which is required in letters sent by Pinderfields hospital. This is not accessible for those without access to a phone or credit. We also heard that people struggle to ring up at 8am for an appointment due to often not having slept through the night.

Accessible, individualised and holistic care:

We heard:

- **People experiencing homelessness** find having multiple services in one place is helpful, including having a hot meal.
- **People with learning disabilities** may prefer face-to-face appointments as it can be difficult to explain things over the phone. It is important to speak to them directly rather than their family member or carer.

Designing and adapting services in line with community need

Examples of where things are not working well:

- **People with learning disabilities** have found that annual health checks are different depending on the area they live. Some have been done on the phone where they should have been done face-to-face.
- **Autistic individuals** shared that Cognitive Behavioural Therapy is not suitable for their style of thinking but there are limited alternatives for neurodivergent people.

Early Intervention and preventative care:

Examples of where things are not working well:

- **People experiencing mental health difficulties** shared examples of indirect exclusion from services, due to being unable to support eating disorders, anger challenges and addiction alongside mental health.

West Yorkshire Voice

t: 0113 898 0035

m: 07496 403 341

e: info@westyorkshirehealthwatch.co.uk

W: https://www.wypartnership.co.uk/get-involved/west-yorkshire-voice