

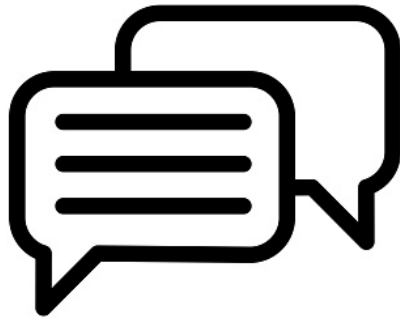
# Equal Treatment

Challenging Racism and Health inequalities  
through Strengthening  
Self-advocacy, Peer & community support

## Learning Session



# Housekeeping



# Today's Agenda

- Project overview
- Self-advocacy Strand – Changing Our Lives
- Families Strand – Contact
- Communities Strand – Include Me Too
- Summary of learning
  
- 10 minute break
  
- Questions for speakers
- Breakout room activity



# Menti

We are going to use menti in the breakout rooms

It's a way of everyone sharing together

<https://www.menti.com/myx885n877>

**Code: 73 88 67 5**





# Background to Equal Treatment



2020 project into health inequalities

Literature review

Focus groups and interviews with people and families



- Current ways of collecting data don't necessarily allow us to understand peoples experiences
- Self-advocates shared stories about when they were told to ignore racism
- Families shared how there young people were treated the same as others
- Role of networks

# Background to Equal Treatment



- From this we wanted to strengthen advocacy and community groups responses to racism and health inequalities
- Funding from NHSE for a short term project
- 3 strands of work
  1. Strengthening inclusive Self-Advocacy
  2. Strengthening family led or parent peer support
  3. Strengthening local community responses on tackling health inequalities and unfair treatment

# Equal Treatment Aims

The project aims to



- Strengthen existing self-advocacy & family carer organisations' work with people from minority ethnic communities
- Empower and support self-advocacy or family led groups to overcome barriers and taboos about
  - speaking up about racism
  - and its impact on access to preventative healthcare and treatment.
- Increase the confidence of local organisations led by people from minority ethnic communities in working with people with learning disabilities as part of their work on tackling health inequalities.





*“The Black Dolls in your nursery are not going to come alive and do the anti-racist work for you.”*



Liz Pemberton, theblacknurserymanager, @lizpemtbnm

# What we did and why

- Self-advocacy groups
- Self-advocacy organisations
- Geographical locations
- Anti-racist programme
- Coproduction
- Action planning towards anti-racist practice

# What was it really like and so what?

- Peter Gay, Interim Director, Disability Advice Service Lambeth (DASL)

# What other people said

“The team created a safe space for us all to speak openly and feel comfortable to ask questions and discuss.”

“I feel more confident in making changes within my organisation to be more anti-racist, both internally and when we speak out publicly.”

“All of the facilitators were excellent and provided a huge amount of knowledge and understanding.”

“I’m not going to pretend that these strategic meetings are not challenging, but that is precisely what I hoped they’d be.”

“The use of materials was excellent, especially audio and video.”

“We are at the beginning of a journey here - I have recently joined my organisation and been tasked with putting Equal Treatment at the core of what we do, from recruitment, to training, to having honest discussions about this with our self-advocates.”



# Our thoughts

- **Little or no space created for conversations around racism and what it means to be anti-racist.** *“Thank you for making me feel like I can ask questions I have never felt able to ask before.”*
- **Knowledge was very limited, but there is an appetite to learn, take action and be accountable.** *“Racism is not just a problem for ethnic minorities - it’s a problem for all of us.” “The session is engrossing and emotive, we need this.”*
- **Sometimes we felt there was a lack of empathy in the room reflecting the racism that exists in strategic structures.** *“I understand this because...” “We don’t have many Black people in this area.”*
- **People are not politicised, despite working in an environment that tackles oppression and social injustice.**

- **The world of self-advocacy is still siloed in its thinking, only focussing on learning disability. Not thinking more widely and struggling to understand intersectionality. *“I worry it will mean that people with learning disabilities get forgotten about.”***
- **Despite issues of racism and health inequality having been in the media a lot over recent years, the self-advocacy movement hasn't responded.**
- **In some cases there is still a power dynamic within self-advocacy. *“The gentleman.”***
- **There appears to be a lack of understanding of the basic principles of coproduction. *“What would we do, would we go to them?”***
- **The unintentional day to day racism or microaggressions are core to people's learning and realisation that racism is everywhere, everyday and it includes them.**

# The challenge

“But people can be racist to white people too, it doesn’t just happen to Black people or Asian people.”

“Those figures shocked me - that is a big difference. We talk a lot about health inequalities for people with a learning disability - we need to think about health inequalities for people from different ethnic groups too.”

“I don’t have any racial experiences so I’m struggling with this.”

# The take-home

“Thank you for these sessions. If there is any take away for you I hope it is that what you have delivered has been exactly the catalyst we needed.”

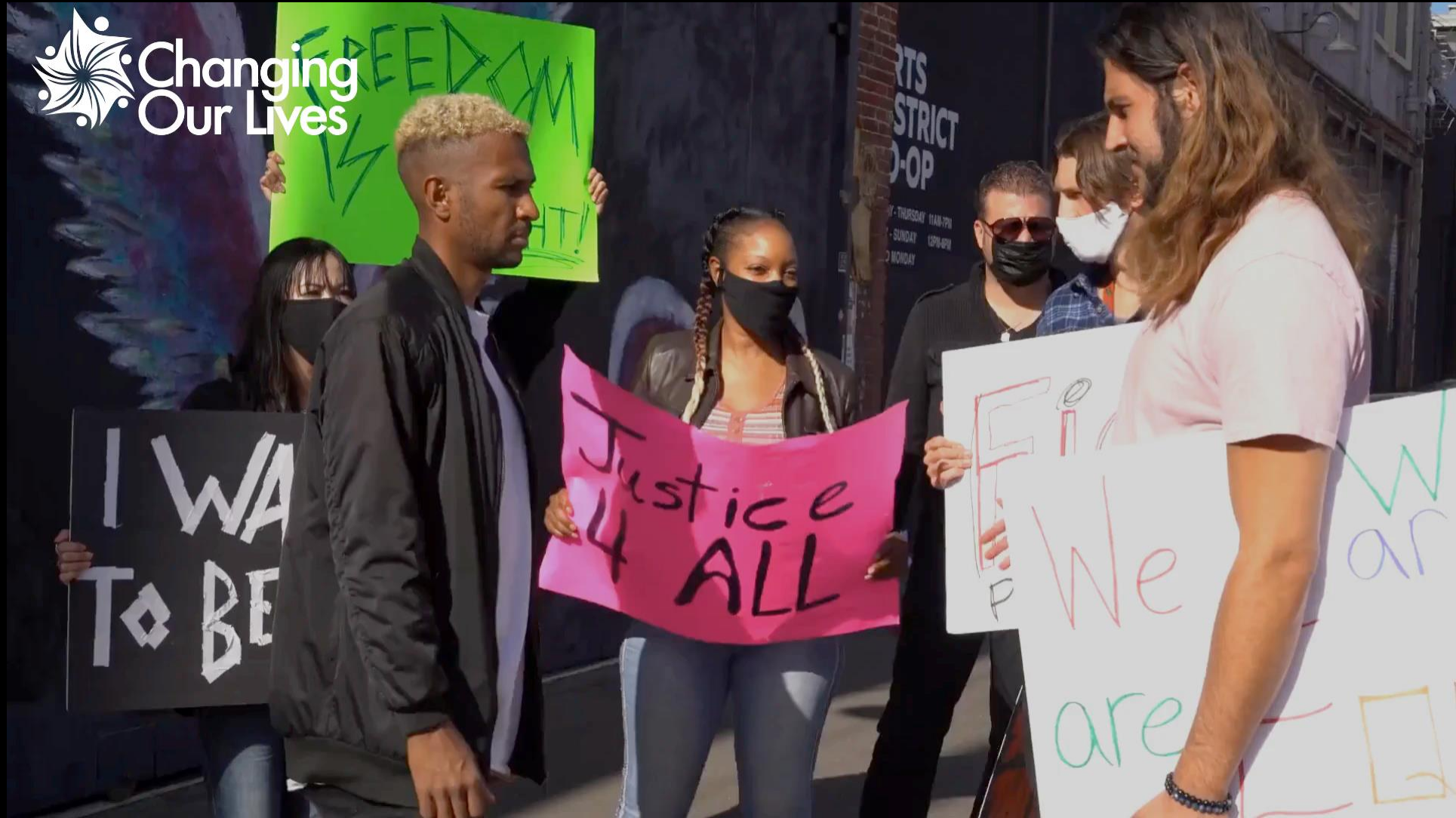
“Just because you are white and racism doesn’t happen to you, it doesn’t mean it doesn’t exist. You have to remember it’s still happening.”



# Resources

- Reporting racism
- What is an ally (easy read)
- Recommended reading list

# What is anti-racism



# What is racism



# Postcards



## Keys to anti-racism

Stop saying: "I'm not racist."

Being "not racist" is not enough.

Call it racism. **Take action.**

# Microaggressions



**Racism.  
It's an every day  
thing.**

**“You don't sound  
Black.”**

# Mobile phone diaries



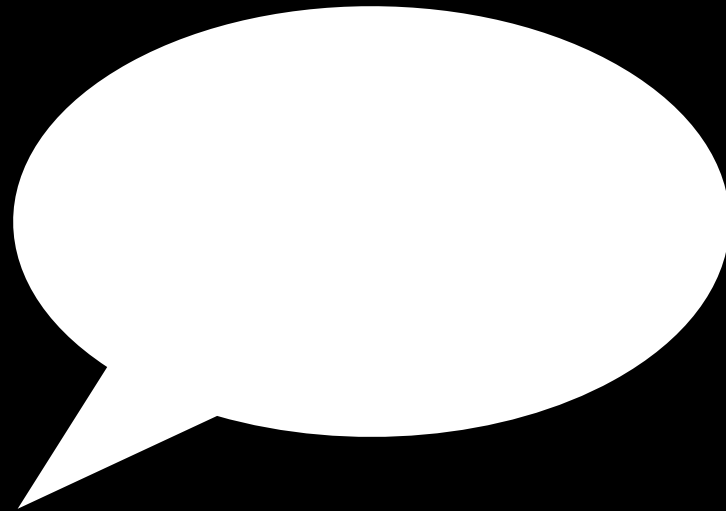
# The UGLY numbers



**Racism.  
It's an *every day*  
thing.**

In the UK, Black Caribbean children are 3.5 times more likely to be excluded from school than all other children at primary, secondary and SEN schools.  
(Barnardos, 2020)

# Questions or comments





# Equal Treatment Project

Challenging Racism and Health inequalities through  
Strengthening

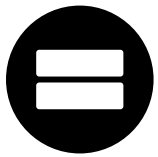
Self-advocacy, Peer & community support

LDE Learning session

Strand 2 – Contact

Jo Green & Mary Mulvey – Oates





# Equal Treatment - Challenging Racism and Health Inequalities Project



The LEADER (2020) report sadly evidenced unequal treatment and poorer outcomes for children with learning disabilities from Black and Asian & minority ethnic communities.

NHS England funded Learning Disability England to launch a new project about challenging racism and health inequalities.

"We know families with disabled children from Black, Asian and Minority Ethnic backgrounds often face a double disadvantage when accessing services... This project helps improve Parent Carer groups' confidence to challenge racism and barriers to equal treatment"

Jo Green, Project Lead.

## Diversity and Inclusion Toolkit

Building welcoming, inclusive community representation in parent carer forums



contact, MIND, The Diversity Trust

Contact had worked collaboratively to publish a Diversity and Inclusion Toolkit (funded by DFE)



contact For families with disabled children

# Equal Treatment – Challenging Racism & Health Inequalities Project

- Expression of Interest
- 15 Forums selected
- 1:1's
- Baseline Survey
- 3 Workshops
- Polls
- Lived Experience
- Action Planning
- Case Studies & Reflections

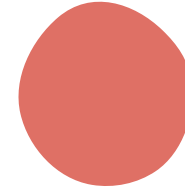


# Equal Treatment - Challenging Racism and Health Inequalities Project

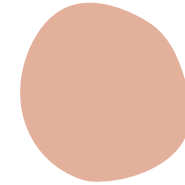
Developed and delivered 3 workshops

Topics included:

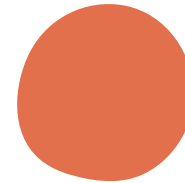
- Understanding representation and inclusion
- Intersectional disadvantage
- Identification of information gaps
- Action Planning



Worked collaboratively with 3 partner organisations:  
Learning Disability England, Include Me Too and Changing our Lives.



13 PCF's engaged in the Programme  
85% attended 2 or 3 workshops



Groups shared experiences, discussed and agreed action plans, including how Forums can reach out in their communities.

Overall, participants reported the Programme had strengthened their understanding around tackling racism and increased their confidence to talk to forum members about challenging racism and health inequalities.



# Challenging Racism & Health Inequalities – Workshops and Case Studies

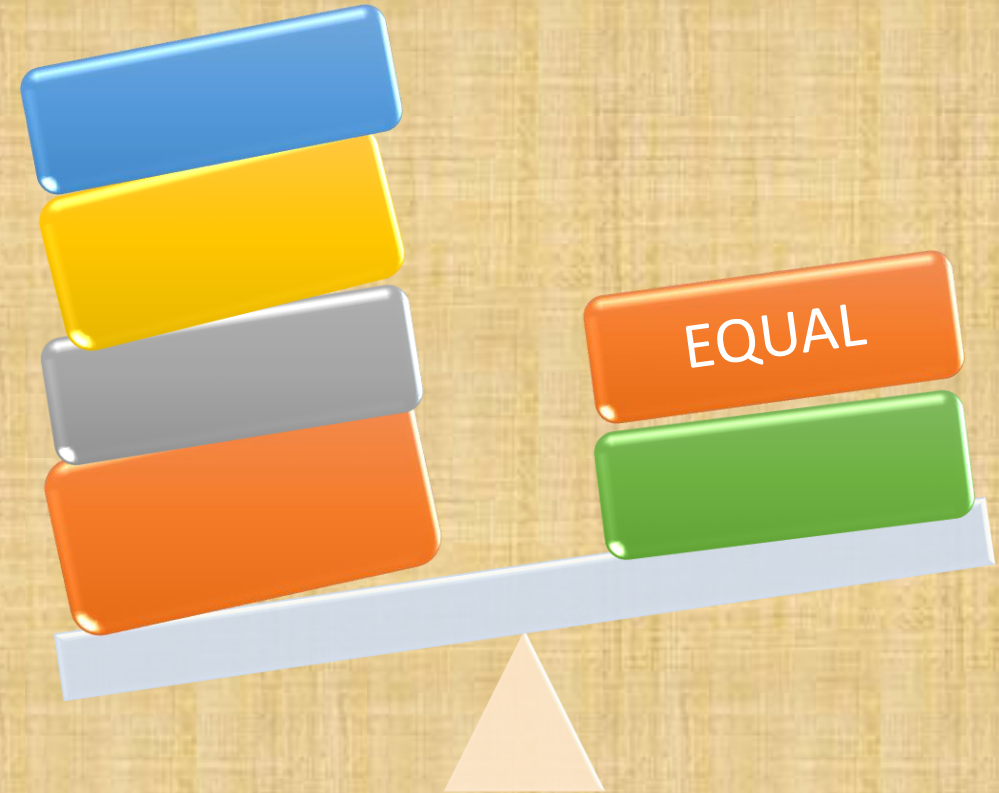
- CTO'S ( Care Treatment Orders)
- Exclusions
- MH – more likely to present in Crisis
- Annual Health Checks
- Late diagnosis /undiagnosed
- Higher risk of Secure care outcomes
- Poorer outcomes



Evidence of poorer health outcomes in minoritized groups (2021)

INEQUALITIES

OUTCOMES



## ETHNIC HEALTH INEQUALITIES IN THE UK



BLACK WOMEN ARE

**4x** MORE LIKELY  
THAN WHITE

women to **DIE** in **PREGNANCY** or  
childbirth in the UK.

Ref: <https://bit.ly/3ihDwcN>



SOUTH ASIAN & BLACK PEOPLE ARE

**2-4x** MORE LIKELY  
TO DEVELOP

Type 2 diabetes than white people.

Ref: <https://bit.ly/3ulDy88>



IN BRITAIN, SOUTH ASIANS HAVE A

**40%** HIGHER  
DEATH RATE

from **CHD** than the general  
population.

Ref: <https://bit.ly/3iifo9V>



IN THE UK,  
AFRICAN-CARIBBEAN  
MEN ARE UP TO **3x**  
more likely to **DEVELOP PROSTATE  
CANCER** than white men of the  
same age.

Ref: <https://bit.ly/39KWqEs>



ACROSS THE COUNTRY, FEWER THAN

**5%** OF BLOOD  
DONORS

are from **BLACK AND MINORITY  
ETHNIC** communities.

Ref: <https://bit.ly/3ulg17r>



BLACK AND  
MINORITY  
ETHNIC PEOPLE  
HAVE UP TO

**2x**

the mortality risk from **COVID-19** than  
people from a **WHITE BRITISH  
BACKGROUND**.

Ref: <https://bit.ly/3EzS2Qd>

# Discussion - Terms and Concepts

Racism

Bias

Micro-Aggressions

Anti-racism

Discrimination

Equity v Equality

Intersectionality

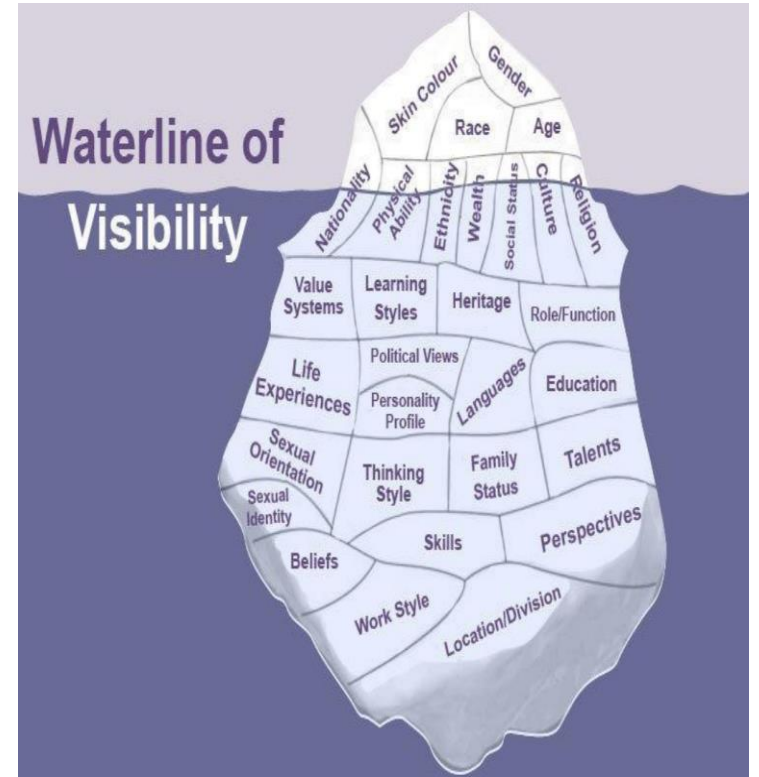
Allyship

Privileges

**BAME**

~~Hard to Reach/~~  
Seldom Heard

Stereotyping  
& Profiling



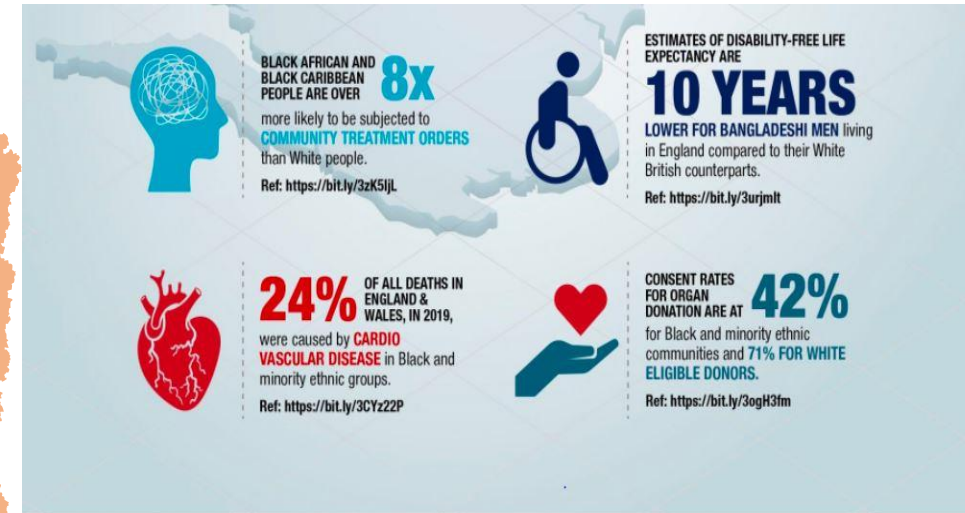
# Equal Treatment Project – Challenging Racism & Health Inequalities: Action Plans

Evidence & Lived Experience

Accessible and clear information

Working Together

Health Access & Annual Health checks



For more information and sources for above statistics please visit:

[www.nhsrho.org](http://www.nhsrho.org)

October 2021





## Equal Treatment Project Feedback: Participants' knowledge improved

We asked participants to rate themselves anonymously before and after on their:

- knowledge
- attitudes
- behaviours
- understanding of local demographics and data

On average, participants improved their understanding score on 7 terms or concepts after the programme, compared to before.

Terms with the largest improvement in knowledge or understanding were:

- micro-aggressions
- intersectionality
- unconscious bias
- anti-racism
- and allyship with Black and ethnic minority families





## Equal Treatment Project Feedback: Participants' confidence improved

We asked participants to score their own confidence on a set of actions, before and after the training.

The percentage of those with a *high* confidence\* was *higher* at follow-up than it was at baseline for each of the actions. This suggests that participants' confidence has improved.

Actions with the largest improvement in confidence were:

- talking about allyship
- challenging racial discrimination, harassment and bias

\*Self-scoring 4 or 5 out on a 5 point scale, where 5 is very confident.

### Actions:

- Talking about racism
- Talking about inclusion
- Talking about allyship
- Including diverse families in your forum
- Talking about over and under representation in your forum
- Identifying racial discrimination, harassment and bias
- Challenging racial discrimination, harassment and bias





## Equal Treatment Project Feedback: The programme had tangible impact

We asked participants to tell us more about the difference (if any) that the project has made to them or their forum?

10 participants responded with feedback, eg:

- Increased in confidence:
  - discuss issues
  - take action
- Clear on how to take action
- Useful to share with other forums
- Better understood the impact of racism
- Had ideas and information on how to increase diversity in forums

'Helped make a clear plan to increase representation and engagement'

'How to make sure everything the forum does takes into account needs from minoritised communities'

'I feel more confident in talking about racial bias and other issues'





# What have we learnt?



This work has potential to create improvements for families: eg

- Better access for families to information
- Increase knowledge and understanding around racism and Anti Racism
- Increasing the number of children from minoritised groups who access an annual health check.



Helping Forums to use the toolkit and resources means sharing more success stories to inspire more forums.

## Diversity and Inclusion Toolkit

Building welcoming, inclusive community representation in parent carer forums



THE DIVERSITY TRUST

‘Opened my eyes to the buzz words I had been hearing but not understood or discussed’



# Q & A ( Questions and answers)



Picture of red question mark

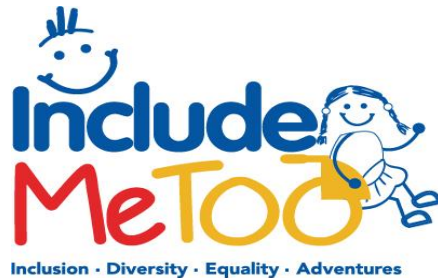


# #EqualTreatment Project – Learning Session

## Strand 3: Strengthening local community responses on tackling health inequalities and unfair treatment

*Challenging racism and addressing the health and social care inequalities experienced by children and adults with learning disabilities from our Black, Asian, Minoritised Ethnic Communities (B.A.M.E)*

**Parmi Dheensa**



**#EqualTreatment**

## AIM:

- ▶ Increase awareness of the health and social care inequalities and unfair treatment of B.A.M.E children and adults with learning disabilities
- ▶ Strengthening local community responses on tackling health inequalities and unfair treatment increasing awareness and action
- ▶ Increase the confidence of local organisations led by people from minority ethnic groups in working with people with learning disabilities and their families as part of their work on taking health inequalities
- ▶ Link the work being led by people with learning disabilities and their families into the wider work aimed at reducing premature mortality and health inequalities

## Two seminars and Five workshops

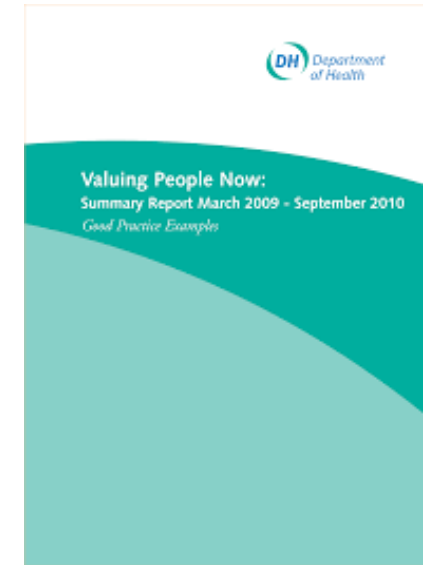
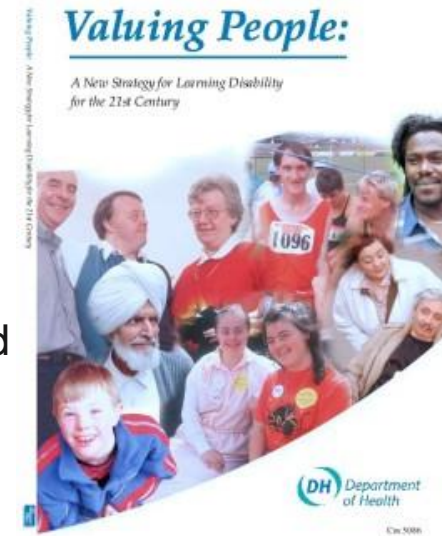
- 1: Understanding barriers and challenges through intersectional lens experiences of learning disabilities and race
- 2: Challenging racism and deconstructing systems which are failing B.A.M.E people with learning disabilities and their families
- 3: Discuss and identify solutions to reduce health inequalities, improve advocacy and support for B.A.M.E people with learning disabilities and their families.
- 4: Mapping local health initiatives and health projects, B.A.M.E led or supporting diverse communities and local self-advocacy and family support.
- 5: Explore the role and action faith/community/voluntary sector locally can take to reduce health and social care inequalities of our B.A.M.E learning disabilities communities and their families.
- 6: Share practices of empowerment and self-advocacy and family support for B.A.M.E people with learning disabilities and their families
- 7: Agree action, identify resources and change needed at local level and at strategic and policy level
- 8: Establish community champions/advocates

**Increase the confidence of local organisations led by people from minority ethnic groups in working with people with a learning disability and their families as part of their work on tackling health inequalities.**



# BACKGROUND:

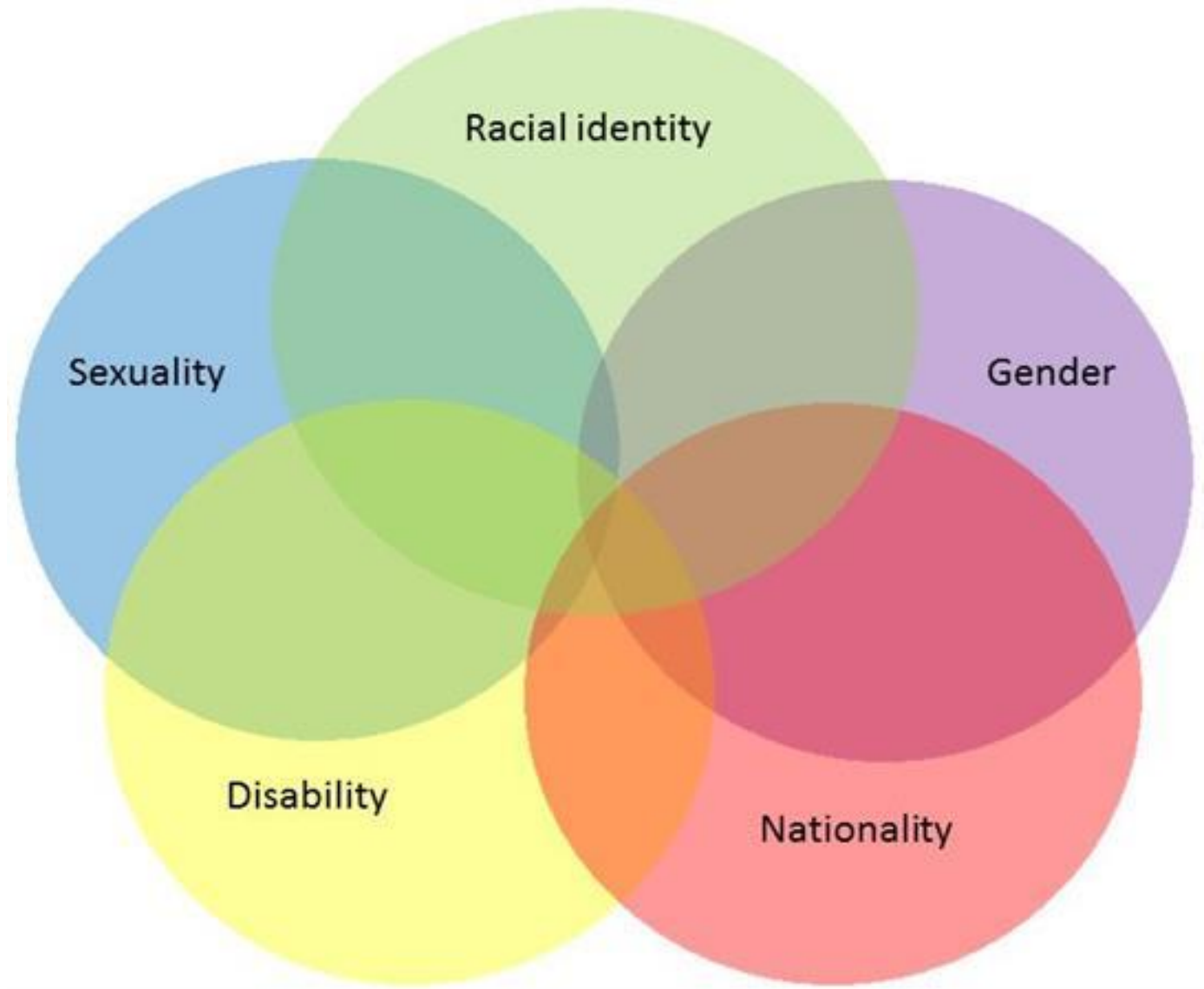
- ▶ The Transforming Care programme
- ▶ Intersection of Race and Disability
- ▶ B.A.M.E communities and families there is a lack of understanding and awareness of disabilities, rights and what support is available
- ▶ There is very limited information and data
- ▶ The LEDAR report 2020
- ▶ Valuing People in their Framework for Equality (2001)
- ▶ Valuing People Now (2009)
- ▶ FPLD in 2012 (Reaching Out to Families)
- ▶ COVID 19 and Do Not Resuscitate (DNR)
- ▶ The B.A.M.E charity sector



This information can be made available in formats such as easy read or large print and may be available in alternative languages, upon request.

# #EqualTreatment

# Intersectionality: what is it and why is it important?



**#EqualTreatment**

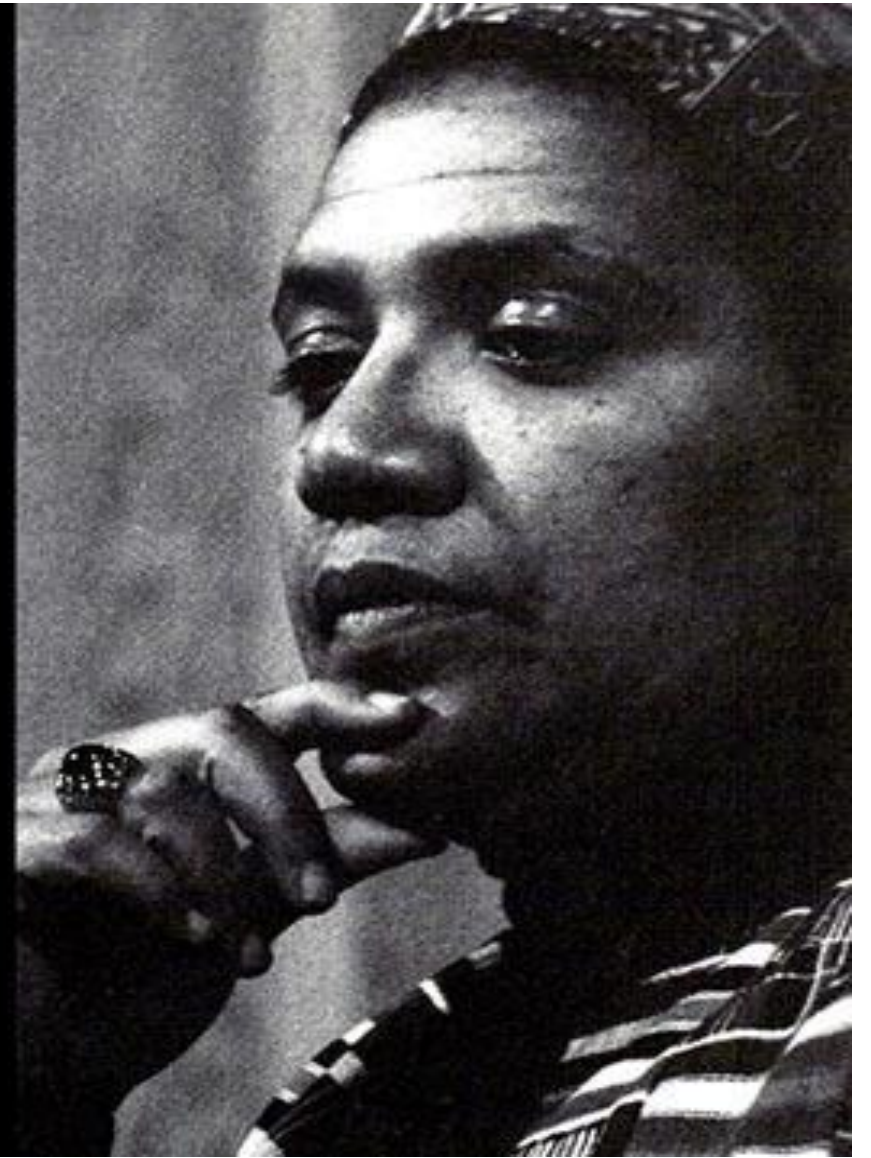
***‘In essence, intersectionality is a way of thinking about identity and its relationship to power.’ Kimberle Crenshaw***

## **Why does it matter?**

- ▶ Substantive equality that leaves no one behind
- ▶ More inclusive and responsive policy making and service delivery
- ▶ Better use of resources: improved stakeholder collaboration builds a better understanding of the context, solution and results in more tailored services

**There is no such thing  
as single-issue struggle  
because we do not live  
single-issue lives.**

**–Audre Lorde**



**#EqualTreatment**

***‘Intersectionality serves as a cautionary reminder not to speak for those who cannot, or ask others to share our agenda while they wait for their own’***

*Kathryn Henne*

# Human Rights Framework supporting and protecting the human rights of disabled children and young people

**United Nations Convention on the Rights of the Child (UNCRC)**

**United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**

**Applying Intersectional lens connecting to Human Rights approach**

- Human Rights Instruments
- People experiencing multiple forms of discrimination
- Substantive equality and equity
- Inclusion
- A sense of belonging
- Leaving No One behind

**‘Anti-racism is the active process of identifying and eliminating racism by changing systems, organisational structures, policies and practices and attitudes, so that power is redistributed and shared equitably.’**

What is Racism?

Racism = Racial Prejudice + Power

### ***Levels of Racism***

- **Internalized racism.**
- **Interpersonal racism**
- **Institutional racism**
- **Structural racism**
- **Cultural Racism**

**#EqualTreatment**

What is Anti-Racism?

**‘Anti-racism is the active process of identifying and eliminating racism by changing systems, organisational structures, policies and practices and attitudes, so that power is redistributed and shared equitably.’**

Becoming Anti Racist

***Antiracism isn't comfortable, just like racism isn't comfortable for Black, Brown and other Minoritised groups.***

**#EqualTreatment**



## **Key findings and testimonies were shared direct from families**

- 1. Unhelpful and hostile service provision that is more often unhelpful and unaccommodating to their families, which means low uptake of services, greater stress and poorer outcomes.**
- 2. Services that discriminate on the grounds of race, ethnicity and culture and are rarely culturally appropriate or holistic or accessible in meeting the needs of B.A.M.E. people with learning disabilities and their families.**
- 3. A lack of knowledge of their rights and entitlements to support their child, adult with learning disabilities and families, made worse by limited access to information and support and the persistence of language and communication barriers.**
- 4. Limited support to their advocacy for their families, especially when B.A.M.E. community sector providing vital specialist support and services is under- resourced.**
- 5. Families are driven from to crisis to crisis by services that are meant to help and support. The system does not work.**

**#EqualTreatment**

## #EqualTreatment Key Themes

The six key themes emerge from lived experiences shared:

One: The impact of race, ethnicity and disability-based discrimination on individual and families' health and wellbeing.

Two: The lack of appropriate access to the right support and effective accountability of professionals and service providers, planners and funders in meeting needs and their obligations.

Three: The impact of systems that perpetuate social injustice and cultural disadvantage through information, language, communication and cultural bias.

## #EqualTreatment Key Themes

The six key themes emerge from lived experiences shared:

- Four: The lack of disability awareness in diverse communities due to stigma, misconceptions, and limited provision and resources to further increase disability inclusion and understanding within communities.
- Five: The need for greater advocacy and empowerment amongst families with B.A.M.E. children, young people and adults with learning difficulties
- Six: B.A.M.E. children, young people and adults with learning difficulties their families and communities key actors to re- imagine and implement more equitable, innovative and responsive community-led approaches to improve life chances and better health and social care outcomes.

## Learning and action needed

- 1: Mapping local health initiatives and health projects, B.A.M.E led or supporting diverse communities and local self-advocacy and family support.
- 2: Opportunities and resources to mobilise and encourage potential role and action on the ground of faith/community/voluntary sector locally as recognised assets to combat the persistent health and social care inequalities of our B.A.M.E learning disabilities communities and their families.
- 3: It is vital to recognise the systemic and structural barriers that need to be addressed with real commitment to achieve improved health and social care outcomes, empowerment and self-advocacy for B.A.M.E people with learning disabilities and their families.
- 4: A commitment to an anti racist and intersectional approach with urgent action, resources to support much needed change at local level and at strategic and policy level
- 6: Work needs to be done building upon #Equal Treatment this is just the start and much overdue

**#EqualTreatment**

## **A rights based and intersectional approach**

**‘When we fail to incorporate intersectionality into our everyday practices and policies, we leave parts of our communities behind’**

- 1. ACKNOWLEDGE SYSTEMIC DISCRIMINATION**
- 2. INTERSECTING BARRIERS AND CHALLENGES**
- 3. RESPECT OUR VOICES AND EXPERIENCES**
- 4. INCLUSIVITY**
- 5. DISAGGREGATED DATA**
- 6. COLLABORATION**
- 7. HEALTH**
- 8. COMMUNITY**

**Building community and encouraging alliances, coalitions, and looking out for each other will help us solve problems.**

**‘Building trust and improving our experiences of health and social care for our children with learning disabilities, build that trust. That's been broken for such a long time. This isn't something that's going to get done overnight, you know, it's something that's gonna take a long time. Our communities that has been completely let down in the past and currently.’(Family N)**

**#EqualTreatment**



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# Key Learning from across the project



- Equal treatment has been a springboard
- People feel like they don't have the skills or knowledge to discuss or challenge racism well
- There often hasn't been time or space created to have conversations about racism



# Key Learning from across the project



- Local organisations often underfunded and overstretched.
- We need to start thinking about including people from minority ethnic groups in everything from the start and as a priority



- Opportunities to work together across the 3<sup>rd</sup> sector to ensure people are being prioritised
- Opportunities as social movements to stand in solidarity with other social movements

# Breakout rooms (15 minutes)

Think about

- What are your big take aways from today?
- What action can you and your organisations take to challenge racism and be more inclusive?
- What would you need to help you do this?







# Session Feedback



# Session Feedback

