

# Small Margins

## Working with people with a learning disability and autistic people from minority ethnic communities

### Easy Read



Small Margins was a project by Changing Our Lives and Manchester Metropolitan University.

It was about people with learning disabilities and autistic people who come from minority ethnic communities.



There are many ways to talk about a person's ethnicity. In this report, we use **minority ethnic community** to mean when someone's ethnicity is not the biggest ethnic group in the country where they live.

In the UK, the biggest ethnic group is white British.



A person's ethnicity includes lots of things like their language, the country that they call home, their religion or the customs that they share with other people in their family or community.



A person's skin colour or how they look is one part of their ethnicity, but it is not the only part.

# What did we do?



We spoke to people with a learning disability and autistic people who are also



- **South Asian**
- **African Caribbean**
- **Black African**
- or **dual heritage** (this means when a person's parents have different ethnicities to each other.)



- Some of the people we spoke to live
- in their own home with support, sometimes called **supported living**
  - in **residential care**
  - **with family**



Some were **moving out of locked hospitals.**



We wanted to find out about the lives of people with a learning disability and autistic people from minority ethnic communities.



We wanted to know if people from minority ethnic communities get good support or if they find it difficult to get good support.



We wanted to find out if the professionals in their lives had the knowledge and skills they needed to support people from minority ethnicity communities.



We wanted to find out how this affects people with learning disabilities, autistic people and their families.



There has not been a lot of research done about the lives of people with learning disabilities and autistic people from minority ethnic communities.

We wanted to find out what areas may be important to look at in research in the future.



We wrote a report for

- commissioners
- care and support providers
- race equality organisations
- people with learning disabilities and autistic people
- the Care Quality Commission.



Small Margins was part of the 200 Lives research project. You can find out more about 200 Lives at the end of this report.

# How did we do this work?



For **part one** of this work we looked at some work we have done in the past.



## Quality checks

We looked at reviews we have done in the past to check if services are supporting people to live ordinary lives. Our team includes disabled and non-disabled staff.



You can read our Quality of Life standards here: <https://changingourlives.org/wp-content/uploads/2022/09/QOLStandardsandToolkitFeb2017.pdf>



## Colour between the lines

A history book we wrote about 7 disabled people from minority ethnic communities.

You can read the book here: <https://changingourlives.org/wp-content/uploads/2022/09/Colour-Between-the-Lines-100-high.pdf>



## Equal treatment

A training programme we did with Learning Disability England to teach self-advocacy groups about racism and how to challenge racism.

You can read about it here: <https://changingourlives.org/our-work/anti-racism-projects/>



For **part two** of this work **we spoke to 18 people** including people with learning disabilities, autistic people and their family members.



We spoke to some people on their own and some in groups.



We spoke to

- 7 people with a learning disability, 2 of these had the label of profound and multiple learning disabilities
- 4 autistic people without a learning disability
- 3 autistic people with a learning disability
- 4 people who are family members of the people above



We spoke to

- 7 men
- 11 women



We spoke to

- 4 Black Caribbean people
- 7 South Asian people
- 3 Black African people
- 3 dual heritage people



We spoke to

- 1 person in a residential care home
- 7 people who live in their own home with support, 4 of these had lived in locked hospitals in the past or had recently moved out
- 6 people who lived at home with their families



# What we found out in part one



## **No one is just disabled.**

Disability is one part of a person's identity.  
Disabled people have lots of different parts that make them who they are, just like everyone else does.



A disabled person could also be a woman or a man.  
They could be rich or poor.  
They could be gay or straight.  
They could have a religion or have no religion.  
Everyone is different. Everyone has their own identity.



People who run services or support people often see the disability first.  
They don't see all the different things that make a person who they are.  
They don't see a person's ethnicity as important.



Often people were seen as **either** a disabled person **or** a person from a minority ethnic community.



People whose disability is easier to see were mostly treated badly because of their disability.  
People whose disability was harder to see were mostly treated badly because of their ethnicity.



One person said "I haven't experienced much racism. People tend to look at me and see the chair first."



Another person said "I mainly experience racism, because people can't see that I'm autistic."



**Self-advocacy doesn't always include ethnicity.**  
Self-advocacy groups have done lots of good work.



But not many self-advocacy groups talk about racism or how to fight racism.  
Some self-advocacy groups felt that talking about racism would get in the way of talking about disability.



We know that disabled people from minority ethnic communities face challenges to do with their ethnicity and their disability.

We think self-advocacy groups need to talk about both ethnicity and disability.



### **Challenging myths about disability**

Some people told us about people in their communities who had hurtful beliefs about disability.



One person said "The elderly aunties and uncles have said to me 'Why don't you go to the Golden Temple to get healed?'"



We think that work should be done alongside disabled people to share real facts about disabled people and their rights.



### **Being anti-racist**

Most people do not want to be racist.



But being kind to people from other ethnicities is not enough to stop racism.



We all grew up in a world that has racism in it. This means that we all have thoughts and feelings that come from racist things we have been taught.



We need to learn how to spot when something is racist and challenge it.





We all need to learn about how racism has changed the world and made things unfair.  
For example, Black and Asian people with learning disabilities die younger than white people with learning disabilities.



We all need to work together to change this.



### **Quality checking**

Quality checking is when organisations like Changing Our Lives work alongside disabled people to check how services are supporting disabled people to live ordinary lives.



Changing Our Lives have done quality checks for 15 years. We have done work about quality checking across England and met lots of organisations who do quality checks.



We do not know of any quality checks in England that have focused on ethnicity.



This means not much is known about the support people with a learning disability and autistic people from minority ethnic communities are getting.

# What we found out in part two



We asked the 18 people in this project about the care and support they or their family member get. We also looked at what life is like for people we are supporting to get out of locked hospitals.



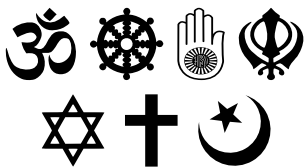
The Care Quality Commission (CQC) say that good care should include and celebrate a person's ethnicity. This means that supporters take an interest in a person's history, family, community, and customs. It means the person gets support to be themselves and do things to do with their ethnicity, history or religion.



They have written some examples of good care to do with a person's ethnicity.

You can read them here: <https://www.cqc.org.uk/guidance-providers/adult-social-care/culturally-appropriate-care>

We have used some of their headings in this report.



## Religion

Most people said that religion was an important part of their life.

Some people told us that they got support to do things to do with their religion.



Some people asked for their support to be at certain times to fit in with fasting and praying.

One person got support to go to Church.

While he was in a locked hospital his staff supported him to read the Bible.



One person had Muslim parents but she went to live with Christian foster parents. She said that she did not go to the Mosque when she was a child. She chose to go to the Mosque again when she grew up.



### **Food and drink**

Most people talked about cooking and eating. Some people said that their staff had learnt about making Halal food or understanding that the person sometimes ate with their fingers.



One person had a bad experience in a locked hospital. He did not eat some foods because of his sensory needs. He did not eat some foods because of his beliefs. He was not given any food that he could eat, so he went without food.



Many people had favourite foods from their community. Many people had good memories about cooking and eating with people they loved. Lots of people told us that they like foods that are seen as British, like chips, or Christmas pudding.



### **Healthcare**

Research tells us that disabled people from minority ethnic communities are more likely to have poor health than white disabled people.



Most people had bad experiences to do with health. Some illnesses are more likely for people from minority ethnic communities. People told us that doctors did not give them information about keeping healthy to do with their ethnicity.



Some people felt that health care should be done in a person's first language.

Some people said that they wanted to speak to health staff from their own community, especially if they were asking for help with their mental health.



We spoke to 4 people who had been in locked hospital for years.

3 of them had experienced racism in hospital.

They were seen as dangerous.



They were not helped to learn about their own history and community.



Some people told us about reasonable adjustments to do with their religion or ethnicity.

They said that doctors, hospital staff and advocates should understand a person's religion or ethnicity.



### **Clothes and the way I look**

The clothes we wear are part of our identity.

Some people choose to wear clothes related to their ethnicity or religion.



Lots of Black and dual heritage people use products to keep their hair and skin healthy.

People we spoke to had support with this.

One person told us that her support worker helps her to wash her hair and put oil in her hair to care for it.





One person said: "In Islam people shave their pubic and under arm hair. Staff need to speak to the person about how to support them to do this."



One person said: "I don't always wear traditional clothes but sometimes I love to as they make me feel great."



### **Relationships and community**

Relationships with other people are really important for our mental health.

We may say hello to our neighbours, we may visit friends, we may go to groups or clubs.



Some people were connected to their communities. They mainly spent time with family or with other disabled people.



People who didn't live with their family spent less time in their community.

Not many people we spoke to did things outside the home to do with their ethnicity.

Not many people did things outside the home with people from the same ethnicity as them.



One person said support staff should help people to make a community map to help them meet people in their local area.





## Learning about each other

Learning about someone's ethnicity, religion or history can be a way to get to know each other.  
It can help people to trust each other.  
It is a way of showing care and respect.



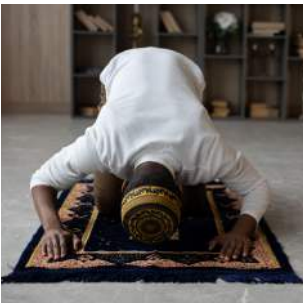
Some people spoke more than one language.  
Usually their support staff only spoke English.  
One person said it helps him if his staff speak Portuguese, especially if he is feeling stressed.



Two people told us about times when their staff have learnt about their language or their ethnicity.



Some people do not use words to communicate.  
Social stories can help them to communicate.  
Social stories should include people from minority ethnic communities doing things to do with their ethnicity.



## Support for our feelings

Many people were very proud of their ethnicity, their family history or the things they did to do with religion.



One person said she is teaching herself about Indian films and dance.  
One person loves to talk to his staff about his childhood in St Lucia.



One person had a Jamaican dad and a white British mum. She told us that a member of staff at her residential college taught her a lot about Jamaican heritage when she was a teenager.

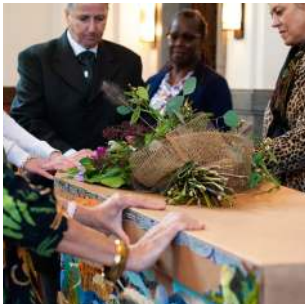


One person told us that he had been seen as naughty or aggressive because of his ethnicity.  
One person had a Pakistani name. She told us that her foster parents gave her a new name that sounded more English.



### **End of life support**

Some people have beliefs about death to do with their ethnicity or religion.



One person we worked with in a locked hospital made a funeral plan. This included things like what music should be played, who should be there and what people should wear.



### **Staff**

For people with learning disabilities and autistic people who use support, good support is important for a good quality of life.



Good support staff help a person to challenge racism. Some people we spoke to had care teams that were built around their ethnicity and background.



One person told us that families from minority ethnic communities can find it harder to get support.



They felt that if people speak up about things that are going wrong they are seen as trouble makers.



Speaking a different language can make it more difficult to get information.



Some people did not mind if they had support workers from different ethnicities to them.  
What was most important was if their support workers treated them with respect.

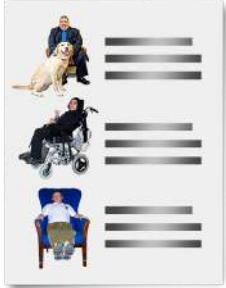


Two family members told us that they were caring for their adult sons at home because of racism.  
They could not be sure their sons would be safe if they were cared for by other people.



One family member of a young Black man told us that she made sure that he got to meet other young Black men.  
This was important for his identity.

# What changes do we think should be made?



## **Commissioners**

Commissioners need to understand ethnicity. They need to think about people's ethnicity when planning services or checking quality of services.



Commissioners should ask Quality Checkers to do quality checks about ethnicity. This will tell them more about the support that people from minority ethnic communities are getting.



Commissioners should ask short breaks providers to offer short breaks that reflect different ethnicities.



## **Support providers**

Support providers should see the whole person, including their ethnicity, when they are planning support or supporting a person.



Support staff should have anti-racist training and should challenge racism in their work.





A person's ethnicity should be included in the way that support staff are chosen, the way they are trained and the way they do their job.



### Care Quality Commission

The Care Quality Commission should do a themed inspection based on ethnicity and quality of care and support.



### Self-advocacy groups

Self-advocacy groups need to understand that fighting for disability rights goes along with fighting racism. Senior self-advocates and management in self-advocacy organisations should lead the way in fighting racism.



### Health

Disabled people from minority ethnic communities should be paid to create tools to make healthcare fairer.



Reasonable adjustments in health need to respect and include the person's ethnicity, religion or history.



Doctors should record a person's ethnicity and what this means for their health care.

They should know about the services in their area that meet the needs of minority ethnic communities.





Annual health checks should include a person's ethnicity and how this affects their health.



Care and Treatment reviews should include a person's ethnicity and how this affects their life.



### **Advocacy**

Advocacy organisations need to employ advocates from minority ethnic communities to meet the needs of people from different ethnicities.



### **Social stories**

Social stories should include people from lots of different ethnicities, religions and backgrounds.

# Who are Changing Our Lives?



Changing Our Lives is a rights based organisation.



We work with disabled people to fight for their rights.  
We know that no-one is too disabled to live an ordinary life with the right support.



We work in an anti-racist way.  
This means we challenge racism.  
We work with people from minority ethnic communities to fight for their rights.

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You can find information about 200 lives at: <https://www.ndti.org.uk/resources/research-project/resources-from-200-lives-project-evaluating-supported-living-and-residential-care-for-adults-with-learning-disabilities>