

Reaching out

**Making things better
for people with a learning
disability who come
from black and minority
ethnic communities**



Contents

What are black and minority ethnic communities?	2
What is this report about?	3
What we did	5
Why did we want to do this research?	7
Things that stop people getting the services they need	19
What Mencap will do	32
What Midland Mencap did to make things better	39

All photographs shown in this report are for illustration purpose only.



What are black and minority ethnic communities?



A community is a group of people who live near each other or have something in common.

People from black and minority ethnic communities are people whose families come from another part of the world.

Some examples of people that come from BME communities are



- **people from Africa**



- **people from Asia**



- **people from the Caribbean**

Sometimes in this booklet, instead of black and minority ethnic we have written BME to keep it short.

What is this report about?



Mencap tried to find out about the families and carers of people with a learning disability from BME communities.

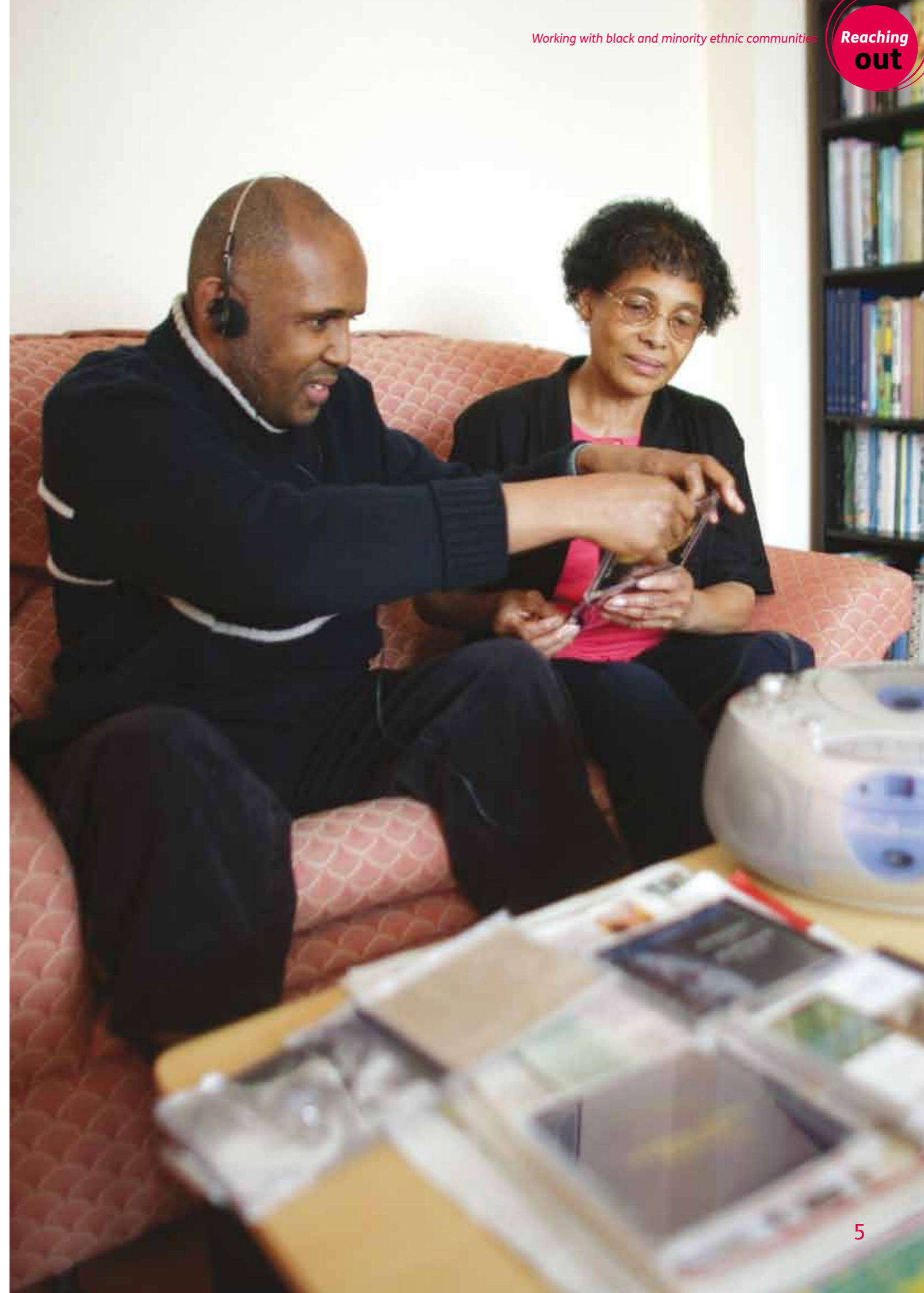
They wanted to know about the support and the services that they were getting.

This report tells you what they found out.

PERLENE'S STORY

Perlene has a son who is 41 years old. They have moved away from the place that her son grew up. Now he is at home all day and he gets bored. Sometimes Perlene takes her son on the bus or to church. She is worried because she doesn't know what to do for him.

Perlene thinks that her son would be more happy if he had a job and more things to do. Her other children do not live nearby, so she is worried about what will happen to her son if she gets ill. She does not know who would care for him.



What we did

We talked to 40 family carers from BME communities. A family carer is someone who looks after someone in their family.

We also talked to 20 **organisations**. An **organisation** is a group of people that work together.

We talked to lots of different types of organisations, they were:



- **social services, health services and other organisations that get money from the government**



- **groups of people who raise their own money to do their work**



- **other organisations that work with people from BME communities.**

Why did we want to do this research?



People with a learning disability from BME communities and their carers often do not get the same help and support as other people.

We wanted to understand

- **why this was happening**
- **what we can do to give them more support.**

Mark Goldring,
the chief executive of Mencap, says



“We want a world where everyone with a learning disability can make their own choices, gets the same chances as everyone else and the same respect.”

We want to make sure that people from BME communities are using the services and support we can offer. We will do all we can to work with them to make sure this happens.”

Things that stop people getting the services they need



Here are some of the main things we found out that can stop carers from BME communities getting the services that they need.

Carers do not have enough information that is easy for them to understand

The research found that carers often don't know about things like

- **what a learning disability is**
- **what services they could be getting**
- **how the services work**



There are a lot of people from BME communities who do not speak English. Most of the information about services is written in English so they cannot understand it.

It is not written in the languages that people from BME communities understand, for example Arabic or Urdu.

Some services do not work well with the carer's culture or religion

Culture is the way that people live their lives and the way they think about things.

Religion is when people believe in a god and the way that they do things and think about things to do with their belief in a god.

Sometimes the way that support is offered does not fit with people's culture or religion. For example, some Asian parents do not like their children staying away from the house during the night.



This means that some carers never get a rest from caring for someone because there are no services that can give them a rest during the day.

Some people have wrong ideas about people from BME communities



Some people do not know enough about people from BME communities.

This means they can have wrong ideas about them. For example some people think that

- **people from BME communities look after each other and do not need help from other people**
- **people from BME communities are all the same.**

These wrong ideas can stop people from BME communities getting the help they need.

Many carers from BME communities feel alone and they do not get enough help or support from other people



Carers may not get a lot of help and support from their own community because some people in their community may think bad things about learning disability.

This can make the carer feel very bad because they do not know how to help their child and are not getting enough support from other people.

One carer said

“I don’t know anyone else who has a child with a learning disability. I feel that I am not doing enough for her and I don’t know where to turn for help.”

Carers do not know enough about Mencap and our services



Not many carers knew much about Mencap or our services. Also groups that work with people from BME communities did not know much about Mencap.

Most people did not know what services they could get in their local area from local groups like Midland Mencap.

They did not know much about the services that Mencap runs that help with things like getting the right place to live, getting a job and learning new skills.



SOUBIA'S STORY

Soubia came to England to get married. Her husband has a learning disability and needs a lot of care. She did not know that he had a learning disability before she came to England.

Soubia lives with her husband's family. Her husband's mother makes all the rules about how they live and does not like Soubia talking to other people. She does not want Soubia to learn English.

Soubia says she would like to have someone to talk to about herself and her children. When she had her first child, she did not know that he had a learning disability, but when she found out from her doctor that he did, she got her son into a special school. Her son is happier now, but Soubia would still like to know more about how to help him and her daughter who also has a learning disability.

She would like to know more about learning disability and she would like the chance to learn English.

Problems with services from organisations that get money from the government

These are organisations like social services and health services.



Carers from BME communities say that they have problems getting the services they need from these organisations.

They find it hard to find out what services they can get and how they can get them. Many carers come from countries where services work in a different way.

There is not enough information in their own language to help them find out what services they could be getting and how to get them.

Many carers said that they don't get enough information from their social worker. The information they do get changes often.



Most of the information they get about services is from other people they know, or from their doctor or health worker.

Many carers said that social services did not understand their culture enough.



What Mencap will do

We will give information in the languages that BME communities speak and in ways that people find easy to understand.

- We can do this as part of our advice and information services.
- We will let more people know about our translation service. This service changes information from English into another language.
- We can give people information about things like what a learning disability is and where to get help and support.



We will tell carers from BME communities more about our services by working with people in their local area.

- We will get in contact with families through local BME groups and people who already work in the area.
- We make sure that social services, health services, schools and other groups have information about Mencap's work.
- We will work together with these groups to support families from BME communities
- We will encourage Mencap local groups to go to events in their community so they can tell people about what Mencap and Mencap local groups do.



We will make sure our staff know more about different cultures



- **We will give our staff equality and diversity training. This is training in how to understand about how to work well with people from different cultures and backgrounds.**
- **We want to increase the number of our staff who come from BME communities.**
- **We will have more staff who can speak community languages.**
- **We will find ways for staff who work in different areas to share their skills and the things they know about BME issues and communities.**
- **We will keep in contact with other organisations and learn about any new research.**



We will provide services and support that are right for people from BME communities



- **We will provide services that can work with people from many different cultures.**
- **We will continue to work with different communities in a local area. For example, working with carers in BME families in Ealing and Hounslow in London.**

We will make sure our campaigns include the things that happen to people from BME communities and the things that are important to them

- **We will tell local services and the people who are in charge of local services about the needs of BME communities.**

We will work together with other organisations

- We will learn from each other how to work well with BME communities and how to support people to get the services they need.
- We will share what we learn about what people need and what is important to them.
- We will make sure other organisations and professionals know about Mencap and what services and support we can provide to families.



What Midland Mencap did to make things better

Midland Mencap wanted to make sure that its services were working well for all the communities in Birmingham.

To do this, they made a job for a BME development worker. This is someone whose job is to find out more about what people from BME communities need and find out how to support them better.

This job was paid for by Birmingham City Council for 2 years. They spent a long time finding the right person for the job. Another local group, St Basil's, helped them to find the right person.

Some of the things that the development worker did to support local BME communities

- Worked with other community groups, social services, health services and special schools.
- Gave information about Midland Mencap's services in the languages used by local communities – Punjabi, Hindi, Chinese, Gujarati, Bangladeshi and Urdu.
- Started a parent and carers support group.
- Used advocacy and translation services to support the families of carers and young people. Advocacy is when someone speaks up for someone else to make sure they are being listened to. This is a big part of the development worker's job.
- Found parents and carers to be volunteers who could pass on information and find out what is important to each person.



September 2006 – *updated May 2009*

Mencap

123 Golden Lane
London EC1Y 0RT

Telephone: 020 7454 0454
Fax: 020 7608 3254
Email: information@mencap.org.uk

www.mencap.org.uk

Learning Disability Helpline 0808 808 1111

Midland Mencap

171 Alcester Road
Moseley
Birmingham B13 8JR

Telephone: 0121 442 2944
Email: info@midlandmencap.org.uk

www.midlandmencap.org.uk

You can also get this document from the Mencap website at
www.mencap.org.uk