

# Is information enough?

A report about the information,  
help and support families of people  
with a learning disability from  
Pakistani communities want

Easy  
read

This report was made by Mencap  
and the University of Central Lancashire

Alastair Roy and Jez Buffin with Oi Mei Li and Lucy Virgo



# Thank you

We would like to thank the parents and carers who helped us with this report. We would also like to thank

- Ehsas Carers, Dudley
- Reaching Out Group, Midland Mencap
- Sharing Caring Project, Sheffield Mencap and Gateway

# This report is about what people who come from Pakistani communities told us.



We had meetings and talked to lots of families of people with a learning disability from Pakistani communities.

## We wanted to find out



- what information people want
- what support and help they need
- how people want to get this information and support.



## What is in this report

Introduction

Some of the things people told us



What needs to be done to give families from Pakistani communities better information, help and support

# Introduction



Mencap wanted to find out the best ways to support families of people with a learning disability from

- black and minority ethnic communities
- migrant communities.

**Black and ethnic minority communities** is often shortened to BME communities.

It means people whose family came from a different country a long time ago and people who have just moved to this country.



Some examples of people from black and ethnic minority communities are people from

- India
- Pakistan
- Africa
- Jamaica
- China



**Migrant communities** are people who have come to this country to find a better life. They might have come to find work or because it is too dangerous for them to stay in the country they were born in.

# Some of the things people told us

## Finding out your child has a learning disability



A lot of people told us they wanted the way they were told about their child having a learning disability to be done in a better way.



They wanted more information about their child's learning disability.



They wanted more support to understand what having a learning disability would mean for their child and for their family.



Families told us that it could take a really long time before they were told their child had a learning disability.

Families wanted people who work in health like doctors, nurses and health visitors to understand their culture and family.

People told us they got really good support from some health people and social workers and it made a big difference to them.

## Communities do not understand about learning disability



Some parents told us that they found it hard to accept their child had a learning disability.

Other people told us that their family or their community did not understand learning disability.



This could mean that they did not treat them or their child in a good and fair way.

## Problems with behaviour



Some parents told us that their child could hurt them or hurt themselves.

This made it very difficult to go out or to let someone look after their child so they could have a break.



Parents understood that the behaviour could be because their child found it hard to communicate.



Parents wanted help to understand and communicate with their child. But they were not sure that they could really help their child with their behaviour.

## Planning for the future



Parents told us it was hard to plan for the future as they were so busy looking after their son or daughter.

Lots of parents were worried about what would happen as their child got older.

### They were worried about

- what would happen when they left school
- how they would cope with being a teenager and growing up
- who would look after their son or daughter when they got too old or sick to do it.



### It can be hard to stay together as a family

People told us that having someone in your family with a learning disability can affect everyone in the family.



Family members may all have different ideas about the best way to support the person with a learning disability.



There might be arguments and family members might fall out with each other.

## Rights and benefits

Lots of people told us that they did not know what benefits or services they could get.



They told us they only found out information about rights and benefits when they joined a support group for parents.



## How to get information

People told us that the best way for them to get information was to talk with someone.



They said that they could build up trust with the person giving them the information.

When they trusted someone they found it easier to ask questions.



Many people wanted to be able to talk to someone in the language they understood best which might not be English.



## What needs to be done to give families from Pakistani communities better information, help and support



Here are some things that could make a big difference to families.

### Information and understanding learning disability

Give families good information about things that may mean they are more likely to have a child with a learning disability.



Explain which people who work in health can help to decide if a child has a learning disability when the child is very young.

Explain about the different tests to see if a child has a learning disability.



Explain why sometimes it can be hard to work out if a child has a learning disability or what their learning disability is.

## Help and support



Give families better support

- as they go through finding out if their child has a learning disability
- to understand about learning disability
- to understand what having a child with a learning disability might be like for their family.



Help families to support their child's communication.



Help parents to understand why their child might have behaviour that is difficult.

Help families to find good ways to support their child with their behaviour.



## More about help and support

Support families to know what advice, support and services they can use where they live.

Pass on stories from other families about what support they have used and how it helped them.



Get parents to help with running learning disability awareness sessions for Pakistani communities.



Help families to think about what services they would like that are right for them and their child.

