People with learning disabilities from ethnic minority communities including new migrants

Survey for family carers for the 'Here to Stay' project

The 'HERE TO STAY' project addresses the need to increase our knowledge about people with learning disabilities from ethnic minority and new migrant communities, living in England. We believe that better information about them and their needs will result in a better service delivery.

<u>If you are a family carer of a person with a learning disability, and the person is from an ethnic minority* or a new migrant community</u>, we would like to ask you to complete this survey. A family carer is a person who is not paid to have a personal, continuous relationship with a person with a learning disability.**

The survey will take about 20 minutes to complete.
No personal data will be collected unless you wish to stay in contact with us.
Our study has ethical approval.
If you are a volunteer, a support worker or a professional, please click <here> to complete another survey.

***By ethnic minority communities we mean groups other than White British.**
****By new migrants we mean people who are not British citizens but resident permanently or temporarily in England; this includes asylum seekers, refugees, seasonal workers and travellers, from all ethnic groups from within and outside of the European Union.**

If you prefer to have the questionnaire printed or translated into another language, please contact Ms Bridget Fisher: heretostay@arcuk.org.uk or 01246 555 043.

What do we mean by a *learning disability*?

A *learning disability* includes the presence of:

- **a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;**
- **a reduced ability to cope independently (impaired social functioning);**
- **which started before adulthood, with a lasting effect on development.**

(Valuing People Now, Department of Health, 2001)

A learning disability is caused by the way the brain develops. There are many different types and most develop before a baby is born, during birth or because of a serious illness in early childhood.

People with a learning disability find it harder than others to learn, understand and communicate.

A learning disability <u>is not</u> mental illness or dyslexia.

If you would like to watch a clip about lives of four people with learning disabilities, please click here

ABOUT YOU

How old are you?

What is your sex?

- ○ *female*
- ○ *male*

What is your nationality?

What country were you born in?

If you were not born in England, when did you come to live in England?

What language or dialect do you prefer to communicate in?

Do you need someone to help you to communicate in English?

- ☐ *yes*
- ☐ *no*

What is your religion?

- ☐ *Christianity*
- ☐ *Buddhism*
- ☐ *Hinduism*
- ☐ *Judaism*
- ☐ *Islam*
- ☐ *Sikhism*
- ☐ *Shinto*
- ☐ *Bahai*
- ☐ *Taoism*
- ☐ *No religion*

Any other religion, please write in:

Please state your ethnicity background:

A. White

- *British*
- *Irish*

Any other White background, please write in

B. Mixed

- *White and Black Caribbean*
- *White and Black African*
- *White and Asian*

Any other Mixed background, please write in

C. Asian or Asian British

- *Indian*
- *Pakistani*
- *Bangladeshi*

Any other Asian background, please write in

D. Black or Black British

- *Caribbean*
- *African*

Any other Black background, please write in

E. Chinese or other ethnic group

- *Chinese*

Any other ethnic group, please write in

ABOUT *THE PERSON WITH A LEARNING DISABILITY* THAT YOU CARE FOR

Is it your:

- ☐ *child*
- ☐ *sibling*
- ☐ *parent*
- ☐ *grandparent*
- ☐ *other member of your family*
- ☐ *friend*
- ☐ *neighbour*

If you care for anybody else, please write in:

Are you this person's main carer? Is it you who is mostly responsible for care of this person?

- ☐ *yes*
- ☐ *no*

For how long have you been caring for this person?

How old is this person?

What is this person's sex?

- ☐ *female*
- ☐ *male*

What is this person's nationality?

What country was this person born in?

If this person was not born in England, when did she or he come to live in England?

How does this person communicate?

- ☐ *speech*
- ☐ *sign language*
- ☐ *pictures/photgraphs/symbols*

If a person communicates in a different way, please write in:

What language or dialect does this person prefer to communicate in?

Does this person need someone to help to communicate in English?

- ☐ *yes*
- ☐ *no*

What is this person's religion?

- ☐ *Christianity*
- ☐ *Buddhism*
- ☐ *Hinduism*
- ☐ *Judaism*
- ☐ *Islam*
- ☐ *Sikhism*
- ☐ *Shinto*
- ☐ *Bahai*
- ☐ *Taoism*
- ☐ *No religion*

Any other religion, please write in:

Please state this person's ethnicity background:

A. White

- *British*
- *Irish*

Any other White background, please write in

B. Mixed

- *White and Black Caribbean*
- *White and Black African*
- *White and Asian*

Any other Mixed background, please write in

C. Asian or Asian British

- *Indian*
- *Pakistani*
- *Bangladeshi*

Any other Asian background, please write in

D. Black or Black British

- *Caribbean*
- *African*

Any other Black background, please write in

E. Chinese or other ethnic group

- *Chinese*

Any other ethnic group, please write in

ABOUT A *LEARNING DISABILITY*

We would like to know more about your understanding of a learning disability. Please read once again our definition of a learning disability.

A *learning disability* includes the presence of:
• a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
• a reduced ability to cope independently (impaired social functioning);
• which started before adulthood, with a lasting effect on development.
(Valuing People Now, Department of Health, 2001)

Do you understand a *learning disability* as we have described it?

- ○ *yes*
- ○ *no*

If you understand a learning disability in a different way, please tell us about it:

How did you find out that the person you care for has a learning disability?

How did you feel about the way you found out?

Is the person you care for able to cope independently or does she or he needs someone's help?

- ☐ *yes*
- ☐ *no*

If the person you care for needs help, what does she or he need support with?

Who is providing this support?

Is this support enough?

ACCESS TO SERVICES

We would like to ask you about the services used by the person you care for.

By *services* we mean any paid support that the person receives because of having a learning disability.

Is it easy to find the services needed?

- ○ *always*
- ○ *very often*
- ○ *sometimes*
- ○ *rarely*
- ○ *never*

Please tell us more about it:

Is it easy to use the services?

- ☐ *yes*
- ☐ *no*

Please tell us more about it:

Does the person you care for receive enough support from the services?

- ○ *yes*
- ○ *no*

Please tell us more about it:

Are you satisfied with the services that the person you care for receives?

- ☐ *yes*
- ☐ *no*

Please tell us more about what do you like and what you do not like about the services:

Do you have any other comments you would like to make?

If you feel upset after sharing your experiences with us please contact Ms Bridget Fisher for advice and guidance.
You can send an email to heretostay@arcuk.org.uk or ring 01246 555 043.

Following this survey, we will be developing national guidelines how to make the learning disability services more visible and accessible to people with learning disabilities from ethnic minority communities and new migrants. We will invite carers to participate in a consultation process. It will involve considering other experts' opinions and commenting on them with an opportunity to change your own opinion. This consultancy will give a chance of achieving a consensus. There will be no need to meet as we will contact you through electronic or mail post. We also guarantee anonymity in the process with an opportunity to be acknowledged in the end.

If you consider participating please leave your contact details below or contact Olga Kozlowska by writing to o.kozlowska@wlv.ac.uk or calling Olga on 01902 32 1742.

Your name

Your E-mail address

Your telephone number

If you would like us to send you a summary of our findings, please provide your full contact details below.

Your name

Your mailing address:

Your E-mail address:

**Thank you for sharing
your knowledge and experience
with us**