



Improving service engagement and experience for people with intellectual disability from ethnic minority communities including new migrants

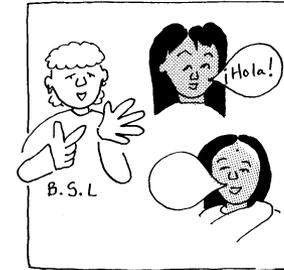


Findings from the “Here to Stay” research project



So do people with intellectual disability migrate?

- children born to migrants
- children brought by family
- adults brought by family
- trafficked adults
- adults who travelled on their own





What is our research about?

- the origins of the title: *Here to Stay*
- research into the needs and service requirements of people with intellectual disability from ethnic minority communities, including new migrants, living in England
 - to explore **how many** people receive support
 - to explore **availability, quality** and **outcomes** of support
 - to explore **how support could be improved**





Definitions and why the research nearly failed

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

By ***ethnic minorities*** we mean groups other than white British.



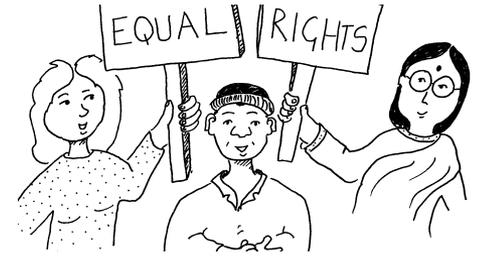
Why this research?



- *the Association for Real Change (ARC)*
- ***the perception:*** that migrants are not receiving care and support
- **the pilot project**
- ***the research questions***
 - are there migrants who are not receiving support they need?
 - are the services supporting them in the right way?
- funded by the *Big Lottery Fund*



What do we know?



Lower uptake of services by:

- people from ethnic minority communities
- people with intellectual disability



double jeopardy



Issues specific to migrants

Access to care depends on:

- legal rights of entry to the country
- dispersal and moving around
- prioritised issues (to survive)
- accessing informal support
- unusual pathways to services



Why? Policy context



- **The Equality Act 2010** - protects people against all forms of discrimination and requires the public bodies to prevent unlawful discrimination and to advance equality of opportunities
- **Human Rights Act 1998**
- **The Health and Social Care Act 2012** - promotes patient-centred care involving patients, carers, staff and local communities in improvement of the services
- **White Paper, our Health, Our Care, Our Say** (2006) (DoH) - a need for high quality information to help people choose and access services
- **The Children Act 2004** – services must ensure that every child have the support it needs
- **‘Valuing People’** (2001) (DoH) - needs of people from EMC are often overlooked (followed by DoH report *Learning Difficulties and Ethnicity*)
- **‘Valuing People Now’** (2009) (DoH) – EMC and NAC as groups of special concern, not listened to and excluded
- **‘Six Lives Progress Review’** (2010) (DoH) – need for improvements in access to services for people from EMC
- **‘National Charter for Inclusion’** (2011) (ARC, BILD and Mencap) - information should be provided in a way that people from EMC understand it and have support to use it well
- **‘Learning difficulties and ethnicity: updating framework for action’** (2012) (FPLD) - need to engage more with people from EMC and NMC and to identify their health and social care needs



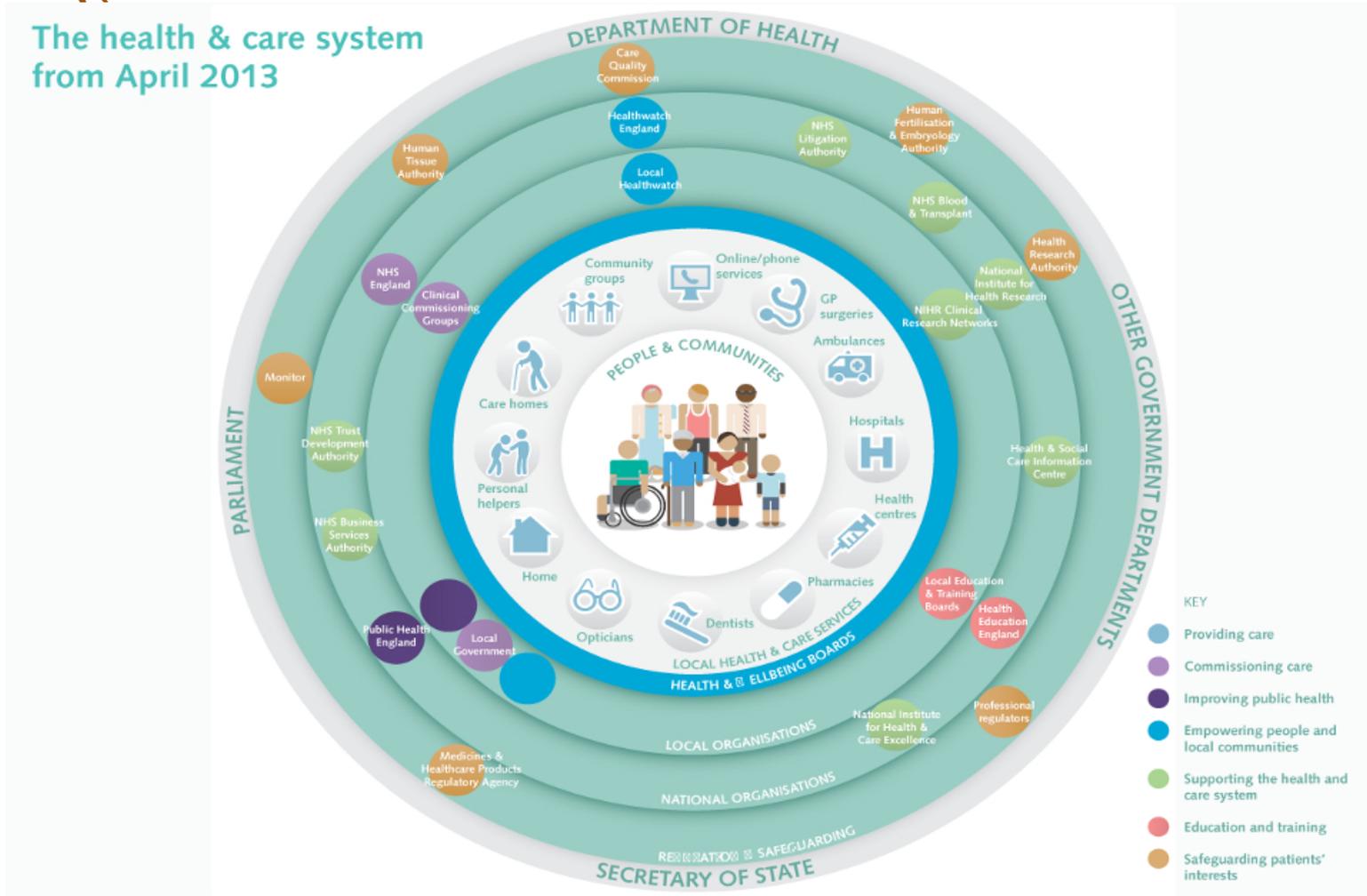
Why? NHS values

- **working together for all patients**
- respect and dignity
- commitment to quality of care
- compassion
- improving lives
- **everyone counts**

Department of Health (2013) The NHS Constitution for England



Complexity of access to care





Building New Evidence

The Structure

the
evidence

consensus
building events

the Delphi
study

the quality standard statements - the recommendations to help service providers, commissioners and policy makers in addressing needs of people with intellectual disability from ethnic minority communities including new migrants



Building New Evidence

inquiring about numbers of people using services

- to record **prevalence of intellectual disability** in this population - consultations with:
 - health
 - social care
 - education
 - Government, policy makers, regulators
 - organisations working with migrants and people with intellectual disabilities
 - organisations working with people with intellectual disabilities
- scope: England, West Midlands, Black Country (Wolverhampton, Dudley, Sandwell, Walsall)



Intellectual disability predictions

Learning disability predictions based on the Census 2011

	England	Wolverhampton	Dudley	Sandwell	Walsall
population (local authority)	53,012,456	249,470	312,925	308,063	269,323
ld prediction (2%)	1,060,249	4,989	6,258	6,161	5,386
Ethnicity – non White British	20.8% 220,531	35.5% 1771	11.45% 716	20.8% 1281	23.1% 1249
Country of birth (not born in the UK)	13.8% 146,314	16.3% 813	5.3% 331	15.9% 979	9.9% 533

Source: ONS, neighbourhood statistics (data for local authorities)



Data from the BC local authorities

Adults and children with learning disabilities on local authority registers

Area	Source	Overall number of people with LD	White-British with LD	Other than White British with LD	Unknown ethnicity	Difference in SEN and SNR for other than White-British (difference in number)
Wolverhampton	SNR	593	458 (77%)	135 (23%)	0	458
	SEN	1746	1136 (65%)	603 (34,6%)	7 (0.4%)	
Dudley	SNR	1165	1042 (89%)	112 (10%)	11 (1%)	362
	SEN	2661	2162 (81%)	474 (18%)	25 (1%)	
Sandwell	SNR	734	633 (86%)	96 (13%)	5 (1%)	116
	SEN	612	343 (56%)	212 (35%)	57 (9%)	
Walsall	SNR	760	640 (84%)	89 (12%)	31 (4%)	294
	SEN	1635	1238 (76%)	383 (23%)	14 (1%)	

SNR – Special Needs Register (Local Authority register of adults)

SEN – Special Educational Needs (the School Census data)



Building New Evidence consulting key stakeholders

- practitioners, commissioners, policy makers, regulators (612)
 - online survey with practitioners
 - online Delphi study
 - interviews with 126 practitioners
- service users (73)
 - online survey
 - interviews
 - people with learning disability
 - 22 young people with learning disability in college
- consensus building conference
- community engagement event – about 100 service providers and visitors
- local conference – about 100 participants



Definitions

What is Learning Disability?

Valuing people (UK Government):

‘Learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information in learning new skills (impaired intelligence), with:
- A reduced ability to cope independently (impaired social functioning),
- Which started before adulthood, with a lasting effect on development’

ICD-10:

‘...a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities.’



Findings – understanding LD

online survey

Table 5. In your experience, do you think in general people from ethnic minority communities and new migrants understand learning disability the way as we have described it in this survey?

option	frequency	percentage
no	218	62%
yes	111	31%
no answer	25	7%
total	354	100%





Findings – availability of services

online survey

Table 6.	From your experience, is the support that you provide available to people with learning disability from ethnic minority communities ?		From your experience, is this support available to new migrants with learning disability?	
option	frequency	percentage	frequency	percentage
always	216	61%	101	29%
very often	66	19%	49	14%
sometimes	49	14%	105	30%
rarely	16	5%	57	16%
never	1	0.3%	9	3%
no answer	6	2%	33	9%
total	354	100%	354	100%



Findings – accessibility of services

online survey

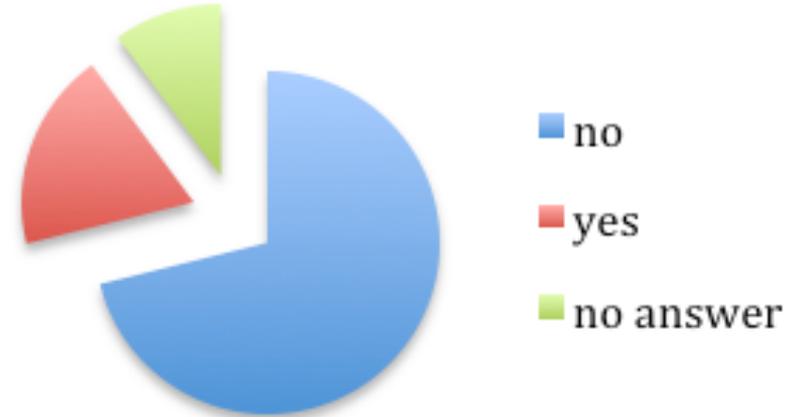
Table 7.	On the whole, do people from ethnic minority communities access all support they need?		On the whole, do new migrants access all the support they need?	
	option	frequency	percentage	frequency
always	17	5%	14	4%
very often	62	17%	33	9%
sometimes	193	54%	156	44%
rarely	69	19%	98	28%
never	3	1%	8	2%
no answer	10	3%	45	13%
total	354	100%	354	100%



Findings – timely access

online survey

Table 8. Do you think that people from ethnic minority communities and new migrants receive this support as soon as they need it?		
option	frequency	percentage
no	252	71%
yes	66	19%
no answer	36	10%
total	354	100%





Building the evidence

engaging with service users

- Interviews with service users to explore their **experiences** through their journey of using intellectual disability services
- 44 cases + 22 young people with intellectual disabilities





Tomek's journey through countries and services

a nine-and-a-half-year-old boy from Poland

Age 0-8 Poland	
Diagnosis	
Mainstream primary school	
No additional support to address the child's education needs	
	Age 9 Arrival to England
	*A GP did not know how to support the family
	No access to education
	No social worker attached to the family



How it was in Poland:

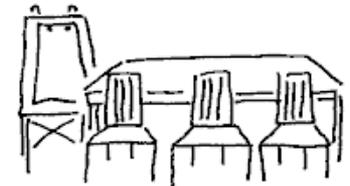
'The worst thing was at school in Poland because the teacher would have him come up to the blackboard, get him to write, add two and one or something like that in Form I. He couldn't do that so the others laughed, so he felt discouraged. He even started saying himself that he's stupid, he doesn't know things, that he can't learn.'



Expectations and professional ‘response’

- Expectations

‘I imagined things would be a bit different because I was convinced that if the English system... in general, special education is of a higher level here... that’s what I thought personally... and that there’s more help, let’s say, from the council here or some bigger city that will indicate to a parent where to send this kind of child, to a place that will help the child with learning, amongst others, also the English language and will educate him so that he can manage in life by carrying out the simplest form of work by using the language that’s spoken here... and that access to these schools will be easier.



- Response

The doctor told the mother that she was ‘a bit irresponsible and crazy coming over to a foreign country with a child with these problems’.



Analysis of current practice

High Impact Findings from online survey and interviews

- Services are not always
 - **proactive** (engagement and promotion on community and individual level)
 - **responsive** (awareness and information)
 - **integrated** (all needs including social care needs, locally and nationally)enough to address the needs of people from migrant communities effectively
- Outcome:
 - missing people out
 - late diagnosis
 - interrupted service
 - confusion, misunderstood and mistrust



Building New Evidence

consensus building events





Building New Evidence

The Delphi study

- Measuring agreement of stakeholders on what is important and what should be prioritised when providing service
 - recording information on service users
 - identifying people in communities
 - visibility of services
 - organisation of support
 - advocacy services
 - children's services
 - commissioning
 - monitoring
 - quality of staff
 - communication
- practice quality standards agreed with the key people – consensus on 24 out of 40 statements



Findings – the quality standard statements

I. Identifying people with learning disability from ethnic minority and new migrant communities

Very high consensus

Health and social care practitioners coming in contact with migrant population should be trained in awareness of and recognising signs of learning disability and should be able to signpost people to appropriate services.

Organisations working with migrant population (e.g. Citizens Advice Bureaus, Refugee Centres, Detention Centres) should play a bigger role in identifying and signposting people with learning disability.

Identifying people with learning disability is critical within the ethnic minority and new migrant communities.

General Practitioners should be more proactive in identifying learning disability in migrants.

Low consensus

Receptionists in health services coming in contact with migrant population (e.g. receptionists in GP surgeries) should be trained in awareness of and recognising signs of learning disability.



II. Recording information about people with learning disability from ethnic minority and new migrant communities

Very high consensus

Collection of demographic information about people with learning disability must include ethnicity, country of birth and language.

High consensus

Demographic information about service users with learning disability should be taken into consideration during process of evaluating services.

Collection of demographic information about service users with learning disability is necessary for equality monitoring in services.



III. Visibility of services
<i>Very high consensus</i>
Services should be more proactive in engaging minority communities to ensure that they meet their needs.
Statutory services should work closely with organisations based in communities to build effective networks to access communities.
Awareness raising campaigns should be increased to ensure people from the minority and new migrant communities understand what learning disability means in the UK context.
Services designed to meet the needs of people with learning disability should promote themselves in places accessed by members of communities, including GP surgeries, libraries, community centres, and schools.
<i>High consensus</i>
Services should provide information in languages spoken in communities and in accessible formats.
<i>Moderate consensus</i>
More targeted projects focusing on increasing access and utility of services from ethnic minority and new migrant communities should be commissioned.



IV. Organisation of support
<i>Very high consensus</i>
Increased efforts should be made to personalise support for people with learning disability.
Increased efforts should be made to co-ordinate support for people moving between services within the country.
Increased efforts should be made to co-ordinate support for people with learning disability when assessing their needs and planning for services.
Statutory services should work with organisations based in communities to increase engagement and uptake of services.
Services should exchange information to avoid duplication of procedures (e.g. assessment).
<i>High consensus</i>
There should be more investment in the services to increase staff numbers, direct engagement with communities, timely assessment, and appropriate support for people.
Each service user should have a key worker/a lead practitioner to coordinate assessments of needs and provision of support.
More services should be provided locally in order to increase the support available to people; particularly those whose legal status is yet to be decided or without a permanent abode.
<i>Moderate consensus</i>
To increase continuity and effectiveness of support the same practitioner should be kept on the same case for as long as possible.
A key worker/a lead professional should not only coordinate care but act as an advocate, provide information and involve the individual in all decisions.



IX. Quality of staff in services

Very high consensus

Practitioners should have training in diversity (cultural), equality and legal issues, and in skills for responsive engagement with service users and their communities.

Appropriately qualified and skilled staff should be involved in the organisation of delivery of support.

High consensus

Services should use staff resources meaningfully without simply resorting to ethnicity/language/culture matching.

Low consensus

Composition of staff employed in services should reflect the communities they serve.



X. Communication between practitioners and service users

Very high consensus

It is important for follow up when providing information, advice or support

Practitioners should ensure service users understand processes they engage in by explaining these processes thoroughly.

Practitioners should engage service users in dialogue and take into account their understanding of learning disability, acceptable support etc.

Signposting of service users should involve linking service users with practitioners and not only providing them with information.

High consensus

More interpreters should be used and their training should be accredited to assure minimum standards, quality and cultural sensitivity of their interpreting.



Implementing New Evidence

Walsall community engagement event

What to do when you need help and have a learning disability?



What to do when you need help and have a learning disability?

Please come to our event if...

- your child or relative finds it hard to learn new life skills, like
 - learning new things
 - looking after themselves
 - communicating
 - managing money
 - reading
 - writing
- you are a migrant or belong to an ethnic minority community
- you don't know where to look for help
- you need advice
- you would like to share your experiences with others
- you would like to tell us how to improve services

16 June 2015 (Tuesday)
10am-3pm

Forest Arts Centre
Hawbush Road Leamore Walsall WS3 1AG



FREE Car Park

FREE



Advice for you and your family



Refreshments



Health checks



Lunch



And some fun with art!

All are welcome

Interpreter will be available





Follow up on the community engagement event

- A story of a woman with mild intellectual disability
 - Born to Indian parents in Kenya
 - Migrated to the UK in childhood
 - Problems at school (language?)
 - Diagnosis of depression
 - Suspected dementia
 - Diagnosis of intellectual disability
 - Isolation, loneliness, close family support



Answering the key questions

- How many migrants with intellectual disability receive support?
 - accurate forecast is impossible because of missing cases
- Do migrants access services they need?
 - their experience vary
- Do services engage with them enough?
 - the practice is not consistent
- How to improve this engagement?
 - the developed *practice quality standards*



Final report

- To receive a summary please write to contact.us@arcuk.org.uk

