



## Here to Stay Project Summary

The Here To Stay project was carried out by the University of Wolverhampton and the Association for Real Change. It was a 5 year project funded with a Big Lottery Research grant.

We wanted to find out the numbers of people from ethnic minority communities, especially new migrant communities, who have a learning disability (intellectual disability).

We wanted to find out the best ways for them to receive the care and support that they need.

We have written a set of suggestions based on the questions we've asked to make things better. These are called 'Practice Quality Standards'.

We believe that if people who work in learning disability services use these ideas, life could be much better for people from migrant communities.

### **What we did**

We found out as much as we could by:

- Looking at any work already done about this (a literature review)
- Looking at any reports and other writing about this
- Talking to people who need services and their families
- Talking to people working in health, social care and education (services paid for with public money)
- Talking to people who work for community groups, charities and private companies
- Talking to other people who might meet people from new communities e.g. at immigration centres

## **We found out information in lots of ways**

- We had an advisory group of experts who gave help and suggestions to the project team.
- We did a study to make sure we were asking the right questions.
- We did interviews with people who work in learning disability services, people who make decisions, people who use services and family carers.
- Sometimes we talked to people in groups to hear their experiences and ideas.
- We had an online survey.
- We did 3 rounds of questions with key groups to check they agreed with our findings (Delphi study).
- We held 2 events to make sure there was agreement on our suggestions on what needed to be done (consensus events).
- We held a community engagement event in one area to highlight what needed to be improved.
- We talked at conferences and meetings nationally and internationally so people knew about Here To Stay.
- About 1000 people have been involved.

## **What we found out**

- We discovered that all existing systems for recording information are not reliable or completed fully.
- It is very important to have this information so services can understand a person's background and needs and also so we have effective equality monitoring.
- Service providers told us that there was a 'system wide' lack of reliable information on the needs of people from ethnic minority and new migrant communities.

It was therefore impossible to fully answer our first question on the numbers of people from minority communities needing services. We could estimate from the census results and research on numbers of people who may have learning disabilities that there could be about 220,000 people from ethnic minorities with an intellectual disability and about 146,000 would have been born abroad.

- In answering our second question - the best ways to offer people from minority communities care and support - we found that:
  - Many people working in services did not note any differences between established minority communities and new migrant communities.
  - 71% of people taking our survey felt that people from ethnic minority communities, including new migrants, do not receive the care and support they need in a timely fashion or quickly.
- There were many reasons for this including understanding intellectual disabilities, barriers to access, culturally insensitive services, people who use services not knowing what or how to ask for services, availability and quality of services, visibility of services, services not talking to communities, poor coordination of support, poor access to children's services, cutting down of services, workforce poorly trained and poor communication between service providers and service users.

### **What we are suggesting**

- Based on the research we have done and having looked at and listened to all the people involved we have written 40 statements that we believe would greatly improve the wellbeing and life chances of people with intellectual disabilities from ethnic minority communities and ensure new migrants with intellectual disabilities receive a high standard of support. We call these the 'Practice Quality Standards' and they are listed on the next page.

## Practice Quality Standards

Health and social care practitioners coming in contact with migrant population should be trained in awareness of and recognising signs of learning disability (intellectual 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 intellectual disability.
Identifying people with an intellectual disability is critical within the ethnic minority and new migrant communities.
General Practitioners should be more proactive in identifying intellectual disability in migrants.
Collection of demographic information about people with intellectual disability must include ethnicity, country of birth and language.
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 intellectual disability means in the UK context.
Services designed to meet the needs of people with intellectual disability should promote themselves in places accessed by members of communities, including GP surgeries, libraries, community centres, and schools.
Increased efforts should be made to personalise support for people with intellectual 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 intellectual 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).
There should be more advocacy services available and they should be made more aware of specific issues faced by people from ethnic minority and new migrant communities.

More holistic approach should be applied when supporting families - their physical, psychological and social needs should be considered.
Schools should provide advice to parents and signpost them to services, if needed.
Users' feedback should be sought, developed, and included into outcomes and used to evaluate service effectiveness.
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.
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 intellectual disability, acceptable support etc.
Signposting of service users should involve linking service users with practitioners and not only providing them with information.
Demographic information about service users with intellectual disability should be taken into consideration during process of evaluating services.
Collection of demographic information about service users with intellectual disability is necessary for equality monitoring in services.
Services should provide information in languages spoken in communities and in accessible formats.
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.
Commissioners should commission services on long-term basis to avoid interrupted service provision.
There should be more services addressing the needs of isolated communities (e.g. Gypsies).

Outcomes data (from service providers) should be collected and made available to commissioners to inform their commissioning decisions.
Services should use staff resources meaningfully without simply resorting to ethnicity/language/culture matching.
More interpreters should be used and their training should be accredited to assure minimum standards, quality and cultural sensitivity of their interpreting.
More targeted projects focusing on increasing access and utility of services from ethnic minority and new migrant communities should be commissioned.
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.
Key contact staff in health and social care services coming in contact with migrant population (e.g. receptionists in GP surgeries) should be trained in awareness, recognition of signs and making the necessary adjustments for their care.
Composition of staff employed in services should reflect the communities they serve.