Barriers to timely and accurate diagnosis – insights from family carers and practitioners

Here to Stay: People with learning disabilities from ethnic minority communities including new migrants

BPS Faculty for People with Intellectual Disabilities Annual Conference (Oxford, May 2015)

Introduction

It is unlikely that people with learning disabilities will be economic migrants travelling on their own. They are more likely to be forced to migration as a dependent member of a migrating family, refugees or asylum seekers [1].

Although there has been an improvement in addressing the needs of people from ethnic minority communities living in England, there are individuals in this population whose learning disability is not recognised and who neither receive support they need nor access the right services [2,3].

As a result, they are at increased risk of experiencing poor outcomes of health and social care and of developing preventable physical and mental health conditions [4,5].

There is a lack of information about what happens to people from these communities and what demands they place upon learning disability services. The **Here to Stay** research, examined necessity of increasing our knowledge of their needs. We found that better information would result in better service provision.

Objectives, design and methods

1. What is the current number of people from ethnic minority and new migrant communities who require support from learning disability services?
   - Data collection from health, social care and education services
2. How can the learning disability, voluntary sector and the wider community engage with the minority communities to promote their well-being and improve their life chances?
   - Focus groups, interviews and survey with people who provide services for people with learning disabilities about their understanding of the problem
   - Interviews with new migrants with learning disabilities and their family carers about their journey of using services
   - A consultation process with the stakeholders about actions needed to improve their situation

Emerging results and discussion

One of the reasons explaining the low uptake of the services is learning disability being under-diagnosed in these communities. It is estimated that **only 23%** of adults with learning disabilities were known to GPs in 2013 [6]. It is unknown how many were from the ethnic minority and new migrant communities.

Initial findings show that the context of migration adds to factors preventing or delaying diagnosis. The critical moments in the pathway to diagnosis are the point of access (if and what service people approach) and the point of assessment (if there is awareness and skills to recognise a learning disability in child/ young or adult migrants and its presentation across cultures).

Pathway to diagnosis and critical points

Entry to the country

Migrant status

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Initial identification of a learning disability

First contact point

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Assessment

Age, language, understanding of learning disability, other health conditions, behaviour, diagnostic overshadowing, aggression, race, ethnicity, attitudes, beliefs, national regulations, guidelines, organisational culture

Consensus on changes needed

Systematic approach in supporting this group and practitioners coming in contact with them is needed. The **national guideline**s on making the appropriate services more visible and responsive to this population and making this population more visible to services have potential to address the current patchy practice.

After consulting about 500 stakeholders on what should be done to allow for the appropriate support to happen, participants agreed that:

- Identifying people with learning disabilities is critical within the ethnic minority and new migrant communities.
- General Practitioners should be more proactive in identifying learning disabilities in migrants.
- 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 should play a bigger role in identifying and signposting people with learning disabilities.
- Schools should provide advice to parents and signpost them to services, if needed.
- Services should be more proactive in engaging minority communities to ensure that they meet their needs, e.g. awareness raising campaigns, services promoting themselves in places accessed by members of different communities, services working closely with organisations based in communities.

References

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People with learning disabilities from ethnic minority communities, including new migrants, living in England: improving access, experience and outcomes.

(Here to Stay research project)

Presented at the Faculty of Intellectual Disability Psychiatry Spring Conference (London, May 2015)

Introduction

Although there has been an improvement in addressing the needs of people from ethnic minority communities living in England, there are individuals in this population whose learning disability is not recognised and who neither receive support they need nor access the right services. As a result, they are at increased risk of experiencing poor outcomes of health and social care and of developing preventable physical and mental health conditions.

There is a lack of information about what happens to people from these communities and what demands they place upon learning disability services. The **Here to Stay** research, examined necessity of increasing our knowledge of their needs. We found that better information would result in better service provision.

Research Questions and Methods

1. What is the current number of people from ethnic minority and new migrant communities who require support from learning disability services?

- Data collection from health, social care and education services

2. How can the learning disability, voluntary sector and the wider community engage with the minority communities to promote their well-being and improve their life chances?

- Focus groups, interviews and survey with people who provide services for people with learning disabilities about their understanding of the problem
- Interviews with new migrants with learning disabilities and their family carers about their journey of using services
- A consultation process with the stakeholders about actions needed to improve their situation

Emerging results and discussion

Usually, family carers, community groups, practitioners and services are being blamed for the low uptake of the right services.

However, the blame culture does not allow for recognition of the support-seeking behaviours and embracing them to reach those in need. People seek support for health and social care needs and they use informal and formal resources to satisfy them and the response of the health and care system to them is critical.

One of the reasons explaining the low uptake of the services is learning disability being under-diagnosed in these communities. It is estimated that only **23%** of adults with learning disabilities were known to GPs in 2013. It is unknown how many were from the ethnic minority and new migrant communities.

Initial findings show that the context of migration adds to factors preventing or delaying diagnosis. The critical moments in the pathway to diagnosis are the point of access (if and what service people approach) and the point of assessment (if there is awareness and skills to recognise a learning disability in child/young or adult migrants and its presentation across cultures).

There is a need for a more proactive and integrated support working across sectors and services.

Next steps - Consensus on what needs to be done

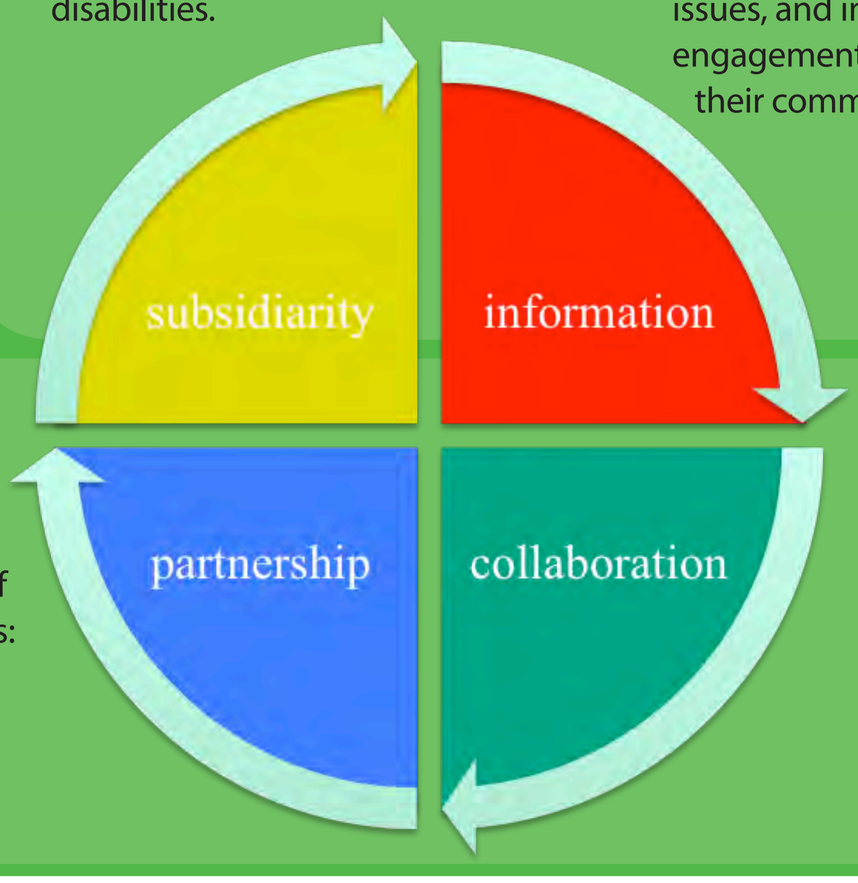
- Health and social care practitioners coming in contact with migrant population should be trained in awareness of and recognising signs of learning disability and should be able to signpost people to appropriate services.
- General Practitioners should be more proactive in identifying learning disabilities in migrants.
- Non-statutory organisations working with migrant population should play a bigger role in identifying and signposting people with learning disabilities.
- Schools should provide advice to parents and signpost them to services, if needed.
- Services should be more proactive in engaging minority communities to ensure that they meet their needs, e.g. awareness raising campaigns, services promoting themselves in places accessed by members of different communities, services working closely with organisations based in communities.
- Practitioners should have training in diversity (cultural), equality and legal issues, and in skills for responsive engagement with service users and their communities.

Model for engagement

Provision of services happens in the system of support recognising collaboration, partnership and subsidiarity of all its partners.

The model promotes:

- Increase in responsiveness of staff
- Building resilience in service users:
  - Information prescription
  - Raising awareness in community
  - Empowerment



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What's in a name? Critical discourse analysis of practitioners' perceptions of understandings of learning disability by people from migrant communities living in England, UK

Nordic Network on Disability Research
(Bergen, May 2015)

Did you know?

Research evidence shows that while progress is being made in addressing the needs of people with learning disabilities from ethnic minority communities, including new migrants, there are individuals in this population who still do not use available support or are not happy with the outcomes of support provided.

The **Here to Sta**y project is a response to the call to increase our knowledge of what happens to people from these communities and what could be done to improve their wellbeing and life chances.

Learning disability

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.

Department of Health, 2001

Answering the question

- individual and group interviews and online surveys with health, social care and education practitioners on their experiences of providing interventions to children, adolescence and adults from migrant communities
- critical discourse analysis was used to explore participants' constructions of the migrants' understandings of learning disability

What we found

Practitioners, although working in services endorsing culturally competent provision, do not always appreciate different understandings of learning disability across cultures and its differing presentation in the context of migration.

As a result, practitioners working with the 'official' definition of learning disability may involve themselves in practices different to those underpinned by a person centred approach.

As a result, there may be distrust, dissatisfaction and disengagement of people in need of support.

The burning issue

There is a need to explore the factors preventing access to services and effective engagement as timely recognition of needs and appropriate interventions could lead to positive outcomes.

The literature suggests that the barriers may be related to:

- people from migrant communities having a different understanding of a learning disability than the one officially accepted in England, but also
- practitioners making assumptions about the ways people from these communities conceptualise learning disability and what their needs are.

To understand the latter issue better, we need to determine the practitioners' perceptions.

What the participants told us

In your experience, do you think in general people from ethnic minority communities and new migrants understand learning disabilities as we have described it in this survey?

- Yes, they do
- No, they don't, because of:
  - different understanding (positive perception of learning disability)
  - different understanding (negative perception of learning disability)
  - no understanding of what a learning disability is

What is the impact of the understanding of a learning disability condition by people from ethnic minority and new migrant communities in accordance with the definition of the Department of Health or absence of that understanding on the support provided by you?

- access to care and its provision (cooperation, goals and expectations, communicating needs, criteria of access, the time of access, culture of care)
- community engagement into problems of people with learning disabilities
- practitioners' work organisation (needs for training, cooperation between services, time issues)

Impact on practice

The current definition impacts on how practitioners behave towards people with learning disability from different communities in terms of their access to support, experience of getting support and outcomes of support received.

There is consensus amongst the participants, that "practitioners should have training in diversity (cultural), equality and legal issues, and in skills for responsive engagement with service users and their communities" and that "practitioners should engage service users in dialogue and take into account their understanding of learning disability and acceptable support."

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