Reducing inequalities for children, young people and adults with learning disabilities from minoritised ethnic communities: CB-NSG workshop write-up

Gina Aujla (CBF Family Support Caseworker; sibling) and Gemma Harpum (CBF Family Support Lead) facilitated a discussion on the issues faced by children, young people, and adults with learning disabilities from minoritised ethnic communities and their families, and professionals. This discussion built both on lived experience and learning from the CBF's family support service, and on the literature review for the 'Building a Bridge' report, which identified that young people with learning disabilities from minoritised ethnic communities faced additional challenges during transition.

Learning from this workshop will be fed into the CBF's ongoing work, in particular the CB-NSG Transition Subgroup's future work on the experiences of young people with learning disabilities from minoritised ethnic communities and their families during transition.

Issues faced by children, young people, and adults with learning disabilities from minoritised ethnic communities and their families

Language and communication

Family carers who do not have English as their first language face barriers when communicating with professionals and/or seeking support for their relative. Examples were given of people who were unable to understand what professionals/practitioners were saying to them because of a language barrier (and failure to provide interpreters or other adjustments to overcome this). This also causes issues when filling out forms, e.g., to apply for support. In several cases, the failure to provide the family carer with an interpreter or other adjustment resulted in them and their relative missing out on essential support. Attendees highlighted that many languages can be spoken within a single local authority, e.g., Kent's 2025 Joint Strategic Needs Assessment shows that there are 98 languages spoken in Kent, 61 of which are spoken by less than 500 people. Medway had identified 21 different languages spoken by families, including where children spoke English but parents did not – this prevented families from contacting Medway as they did not speak the same language.

In some cases, there are not direct translations of particular words or terms in a language. An example was given of someone whose first language did not have a word for 'autism', which caused problems when trying to seek support for their relative, as they were unable to fill out forms or explain their relative's needs using the language professionals were looking for.

Actions that would address this issue:

- Offer a translation service – if there is a website, use country flags to help people choose the language they want to read the information in
- Work with people who are fluent in a particular language to create accessible translations when words do not have a direct translation
- Raise awareness about what support is available, and how to access this, in different languages

Cultural differences, stigma and prejudice

Cultural and religious differences

Examples were given of family carers from minoritised ethnic communities whose cultures place a heavy emphasis on providing support within the family, rather than seeking support externally. This can cause distress and difficulty in cases where it is not possible for the family to provide support. An example was given of a family carer who, because of the cultural norms of providing care within the family and for children to remain in the family home until marriage, found it very difficult to ask for help and did not do so until the situation had reached crisis – this had an impact both on his relative (who had experienced a crisis) and on him (due to burnout from not receiving help and from distress caused by not being able support his relative within the family home).

When cultural differences are misunderstood, this can result in people with learning disabilities and their families not receiving the right support. For example, one family with three adult children were living in a one-bedroom flat – due to cultural norms, the mother slept in the living room with her adult children so that she could provide care, while her husband slept alone in the bedroom. If the parents had slept together in the bedroom, the flat would not have met the criteria for 'severely over-crowded' - however, if the housing professionals had better understood the cultural and gender norms involved, the family may have been higher priority for a larger property that could better meet their needs. Examples were also given of religious practices being misunderstood and viewed under a safeguarding lens – in Islam the sunnah (practices of the prophet Muhammad that Muslims should follow) says that pubic hair should be shaved, but because this was not understood by staff, when a Muslim family wanted staff to help their son follow this practice, this was viewed as a safeguarding issue.

The concept of a social worker, i.e., a stranger coming into the home to ask personal questions about the family, is not common to all cultures/countries – an example was given of a family carer who was consequently suspicious of the social worker, which strained their relationship and made it more difficult for them to access support. If social

services had been more aware that the way social workers work is not common to all cultures and put effort into explaining this, it could have made it easier for the family to work with the social worker and receive support.

In some cases, people with a (mild or moderate) learning disability may hold racist or stereotypical views, which can make it difficult for people who they live with or who support them if they are from different ethnic or cultural backgrounds. An example was given of a provider helping people that they support to understand the cultures of the different people that they live with.

Stigma and prejudice

Examples were also given of family carers experiencing stigma within their communities as a result of their relative's disability, as well as talking about any issues they are having being deemed unacceptable. One attendee highlighted that it would be difficult to ask for practical or emotional support from wider family members because of stigma within their community.

On the other hand, people with learning disabilities from minoritised ethnic communities and their families also experience prejudice from services and White professionals/practitioners as a result of their ethnicity and/or religion. One example was a family carer who was continually talked over in meetings, which led to a lack of trust and a strained relationship between them and professionals/practitioners.

Actions that would address these issues:

- Anti-racism and cultural awareness training for professionals/practitioners
- Anti-racism and cultural awareness training for people with a learning disability
- Ensure that messaging is appropriate – e.g., ensure that cervical screening is framed as a preventative health measure, not a judgement on sexual activity

Action to be taken following meeting: CBF to explore whether cultural awareness can be embedded into 'Whole Family Approaches' training

<u>Access to formal and informal support</u>

People who are first-generation immigrants can face particular barriers to support if the social care system in the UK differs from the support available in the country that they moved from. One example was given of a family carer who had recently moved to the UK from a country which did not have a formal public social care system. This meant that she was unaware that the UK had a public social care system and did not know how to access this to get support for her relative.

When someone does not have the 'cultural capital' needed to navigate the complex social care system, particularly when combined with trying to navigate a system in a different language, they are unable to access support for eligible needs. People from minoritised ethnic communities with learning disabilities, or who are family carers, can also be more likely to experience poverty (e.g., Hatton et al., 2003; Butt and Mirza, 1996; Carers Trust, 2025). In some cases, this poverty and lack of financial support forces families to decide whether to pay for petrol to be able to bring their relatives to appointments, or to buy food. One local area had addressed this by setting up a foodbank to provide families with food, so that they would be able to afford travel to their relatives' appointments.

People with learning disabilities from ethnic minority backgrounds also face additional barriers to accessing healthcare, for example if they or their family do not understand the system or speak the language fluently. This contributes to significant health inequalities. Diagnostic tools also do not always work from people who are non-White. Attendees also raised that, if someone was diagnosed abroad, this diagnosis is not always accepted in the UK, which can be a barrier to accessing support (e.g., if needing to wait for diagnosis within the UK).

Although there is often a belief that people from e.g., Asian families have large familial support networks, this is not always the case. In particular, if someone is a first-generation immigrant, their family support network may be in a different country and unable to provide practical support. In some cases, the assumption that there is a large family that can provide informal support to someone with a learning disability and their family carers has meant that support has not been provided, but in actuality the person and their family are not able to access informal support from wider family due to either geographical distance or other reasons (also see 'stigma' section).

Actions that would address this issue:

- 'Community connectors' from the same country/cultural background that can act as 'buddies' for people who have recently moved to the UK, to help them understand the system and access support
- Equip health visiting services and family hubs with information for family carers of people with learning disabilities from minoritised ethnic communities on how to access services
- Identify how people with learning disabilities from minoritised ethnic communities/their families initially come into contact with 'the system', and whether there are steps that can be taken to make this a more supportive/easier process

- Require services (e.g., health, social care) to actively seek people out, rather than relying on the individual/their family to approach the service

Action to be taken following meeting: SCIE to share briefings around equity in care with CB-NSG members (via the CBF); this to feed into considerations of how to ensure development of neighbourhood health meets needs of people with learning disabilities from minoritised ethnic communities

Culturally-inappropriate support

When support is available, this does not always align with cultural needs. An example was given of someone with a learning disability whose support team were unfamiliar with their cultural background and what kinds of support were important because of this. This caused conflict with the person's family as they were not being supported in a culturally competent way. With support from the CBF Family Support Team, the person's family were empowered to talk with their relative's support team about the importance of their religion and culture, which meant that in future the support team supported their relative in a more culturally appropriate way. For example, the family shared recipes with the support team so that they would be able to recreate this food for their relative.

Actions that would address this issue:

- Training support staff in cultural competence and cultural awareness
- Work to build trust between the person, their family, and the provider
- Consider the intersection between the Mental Capacity Act and ethnicity for people with learning disabilities from minoritised ethnic communities