

CULTURE MATTERS

**HOW DOES CULTURE IMPACT PARENTS WITH A CHILD WHO IS
AUTISTIC AND OR HAS LEARNING DISABILITIES?**

**A PROJECT WORKING WITH ETHNIC MINORITY FAMILIES
AND REFUGEE/ASYLUM SEEKING FAMILIES LIVING IN WEST
YORKSHIRE**



NOVEMBER 2023

AN INTRODUCTION

For 10 years, Bringing Us Together has worked closely with disabled people, family members and organisations who share our values of inclusion, compassion, connecting people and a commitment to working together to effect positive change.

We are a grass roots organisation based in Halifax, with a team of staff from across the country with expertise and lived experience of disability, education, health and the social care system. We are well-known with families and disabled-led organisations for our co-production, proactive approach and we offer a wide, much-needed range of courses and workshops.

As an organisation, we know from experience that our training and focus groups are better when they are co-produced - including different people with different skills, lived-experience and points of view. Our large networks allow us to draw on people with a wide range of insight on different issues. Our approach is based on a conscious cultivation of humility, letting go of the 'expert based' need to inform others and instead drawing on the achievements of everyone, respecting their perspective, experience and knowledge as unique and valid.

Our team at Bringing Us Together are experts at creating trusted safe spaces for parents to speak up and be heard, whilst allowing people to feel valued in day-to-day situations in bringing up their disabled children. We know that small steps are important in creating an environment where people can grow in confidence, sharing their stories and lived experience without being judged. This way of working gives parents peer support to overcome isolation and build up their resilience, creating opportunities through connections and local networks and amplifying joint voices.

Recently, we have worked closely with Yorkshire and Humberside and delivered a range of courses including a co-produced Parent Advocacy

Course and a course for new Key Workers. These have been very well received with plenty of positive feedback.

We were pleased to be able to receive funding through a grant from the West Yorkshire Key Worker Barnardo's Service to deliver a piece of work to hear the voices of parents from refugee communities and ethnic minority groups with autistic children, and/or learning and physical disabilities.

We brought together a steering group and invited Hannah Otoo from London to join the team. We have worked with Hannah for many years and been impressed by her deep understanding of cultural barriers facing parents from a wide range of backgrounds and ethnicity. We also worked closely with two local Calderdale leaders, Florence Kahuro from St Augustine's refugee centre and Samina Arshad from the local Muslim community.

We spent a long time reflecting and using our insight to co-develop a workshop with Hannah that was sensitive and empowering and that would give ample opportunity for discussion and dialogue.

We organised two workshops in venues at the heart of the local Calderdale community and invited our local parent forum, NHS England and local leaders from the area to attend.

These were held in early October 2023, with over 30 parents in attendance. The sessions were delivered by Hannah and supported by Jenny, Tony and Katie from Bringing Us Together. For some of the parents attending this was the first time they had the opportunity to "open-up" and tell their stories. We discussed the themes below highlighted by Hannah who shared her own story.

The dialogue with parents was rich and insightful and, since the sessions, we have continued to build our local Calderdale networks. We have also established a WhatsApp group, as there was an overwhelming commitment to keep meeting; and Bringing Us Together is hoping to run some informal coffee mornings to find out what we can

do together as our next steps. We are hoping that in the future we can work again with NHS England to consider the possibility of hearing more voices.

For more information on our work please get in touch with katie@bringingustogether.org.uk or sign up to our newsletter [here](#).

You can find our group at <https://www.facebook.com/bringingustogether>.

Thank you for taking the time to read this paper, please share this within your networks and contacts and we hope to meet you either in our facebook group or at one of our future on-line workshops.

THE PARTICIPANTS & CONTRIBUTORS

Our work began by meeting up with local community groups and community leaders to tell them about our plans and find out where we might be able to hold meetings. We found out that there is a lot of distrust of this kind of work as many people feel they have been let down too many times; perhaps they have told their stories before, but nothing has changed.

Katie Clarke, from Bringing Us Together, has participated in various previous community support work and is a very familiar face to many of the community groups and individuals. This local connection certainly made some of the difference in being able to build the rapport and trust necessary to convince people to give their time to meet with us.

This local connection also enabled us to find two locally based interpreters who attended both events, making our presentations and workshop activities accessible for those who need interpreters.

We had already met with two local parents who have shared their stories as detailed case studies with us and have met at least two more parents who have told us they want to share their stories too.

At our first event, a representative from the National Health Service Executive (NHSE) attended and was so impressed with it they have contacted us to talk about funding our group to create a health leaflet for ethnic minority communities.

THE WORKSHOPS

Hannah set the scene for the workshops by kindly and honestly sharing her own story, summarised as follows:

“I was born in Ghana, West Africa, where I grew up till my early twenties when I came to the UK. I am a mother of two and my son is Autistic and non-verbal. I grew up in an environment where disability was seen as a taboo and was not talked much about.”

“I experienced the stigma issues from family, friends and community as a whole. I always knew I had to overcome the stigma, accept my son’s diagnosis in a positive way so that I can start working with professionals.”

In this context, Hannah and the rest of the facilitating team then introduced the main activity and discussion topics for the workshops:

- **What is Culture?**
- **What difficulties do our families face?**
- **What help do families need?**
- **What Professionals should know!**
- **Solutions to some of the issues we face.**

THE EMERGING THEMES

Unsurprisingly, many of the emerging themes from family members were ones that were challenging, difficult and negative. Some of these issues are generic challenges experienced by parents and families with disabled children and young people; and it was noteworthy that one parent said it was reassuring that some of the challenges were universal; whereas she had previously held the belief that it was only her culture that discriminated against her child.

Many challenges are then exacerbated by cultural factors, ranging from beliefs in witchcraft and black magic, to ignorance about disability, particularly those that are hidden.

However, one person who sought advice from a religious leader found it really helpful. When this parent sought advice from a spiritual leader the message was that the child was a gift from God. She was advised that Islam specifically says to look after and respect the disabled and so Islamic communities can be supportive. This mother found that this was a useful way to challenge cultural stereotypes.

“Islam says to look after and respect the disabled.”

“It teaches to be helpful to other people.”

“The way you approach each other.”

“The way you respect each other.”

“You pray first and whoever you meet, you meet with nice manners.”

“Life still presents challenges.”

Isolation and Loneliness

Quite often the sense of isolation that parents and families can feel are connected to specific cultural beliefs about disability.

“Our Culture does not believe in the disability if it’s not visual.”

“I have cried for six months when I gave birth to my child with disability; I got no support from my culture.”

Lack of Understanding

Linked to the sense of isolation and loneliness that parents felt, was the lack of understanding. This, in turn, could then be impacted by cultural factors.

“Lack of understanding of Special Needs.”

“People asking too many questions about the child, even if they know the case.”

“Blaming the parents for their child’s behaviour; it’s not ‘normal’.”

“Culture and people making the disability worse because of their actions and words.”

Disability as Stigma

Again, linked to these feelings of being isolated and ostracised, some parents said that they came from cultures and communities in which disability was viewed negatively – for various reasons – and this stigmatised the family.

“Our Culture believes it is a punishment from God or the mother is to blame.”

“You’ve done something wrong because you’ve got a special needs child.”

Mental and Physical Health

Several participant parents both directly and indirectly referred to the added stress and practical challenges of raising a disabled child and young person. One parent had worked out a strategy. Other comments suggested that issues were more challenging and, unsurprisingly, mental well-being was probably the area raised most often – both directly and indirectly.

“We are mentally affected and stressed. We need more support and care from everyone.”

“Parents are suffering from depression and they have to carry on with no help or break”

“We need to be listened to and treated fairly.”

“Too much for parents to handle; support given correctly will help.”

“With my second child with SEND I knew I had to fight, be a warrior Mum. I learned to be a Special Needs Mum.”

“Negative opinions affect our mental health.”

“Feeling grief, sadness and sorrow because of people’s words and questions.”

“All aspects of daily living are difficult - the way we think, act and behave.”

“It’s a constant battle.”

“Special occasions are difficult, even days out can be very difficult.”

Gender Issues

Some Mothers talked about challenges and complexities around gender which could be exacerbated by cultural beliefs and values. Also, some called for a greater understanding of separated spaces and services for women and men, particularly within Muslim culture. And one mentioned the need for a separate men’s parent group and it is of note that, despite it being open to all parents, it was only women who participated in these workshops

“Husbands have an expectation (*that it’s the women who have*) to do raising of the children and household chores.”

“If the child is a girl, it is more difficult.”

“Dads struggle too.”

Lack of Empathy and Understanding from Professionals

“Professionals need to know that many parents take many years before asking for help.”

“Professionals need to be more empathetic and more sensitive to parents of children with Special Educational Needs.”

“We want professionals to understand different cultures.”

“Failure to accept and work around culture.”

“Failure to understand our culture by provision holders.”

“Stop judging us on our culture.”

Language Barrier

Given that some of the participants were from refugee and asylum-seeking communities, it is inevitable that language was raised as an issue and an adjunct to some of the cultural challenges.

“Language barrier”

“More interpreters”

“More support to overcome the language barriers because it leads to unnecessary and very serious problems. Services don't understand.”

“Need to know what services are available in our languages.”

Speed and Access to Culturally-Sensitive Services

Unsurprisingly, participants had a lot to say about services.

“Service providers need to remember Children with Disabilities during their services and to follow up with families and their needs.”

“A more integrated system; services working together.”

“Special needs people should have more services available that listen to us locally, in our area.”

Schools to look after Children with Disabilities more carefully and focus on their education and treatment.”

“Health visitors to visit more regularly.”

“GPs to follow-up families.”

“Listen to parents’ needs; be patient; respect our needs; always provide interpreters; provide good signposting; translated leaflets; more special needs schools.”

“Respite we can trust, where they understand our culture.”

One parent made the important observation that social care is life changing when provision is fully effective and genuinely caring.

Diagnosis and Service Pathways

As well as waiting lists and lack of information, there were also comments regarding the cumbersome way the non-joined-up services worked.

“Waiting time for assessments” (*are too long*)

“GPs don't know about my child so no 'right to choose' – not every person gets the choice.”

“Special needs ought to be fast-tracked in hospital.”
(*There needs to be*) “Effective sign posting.”

“Asian parents need more information on the help that is available.”

“Early Years – spending days completing EHC gathering evidence.”

“Help with form filling, phone calls, emails, PIP forms.”

“After Covid we were left in a very vulnerable situation.”

Housing, Education and Community Spaces

“Our houses not suitable for children with disabilities. It's too risky. No garden and unclean.”

“We need more spaces for children's activities, especially during the holidays.”

“More play groups for 0 – 5 years with special educational needs provision.”

SOLUTIONS

The themes and issues raised by participants above are linked to important needs, which, in turn, point the way to some clear solutions:

- Awareness for parent carers on how the system and processes work
- Support for parent carers to navigate the system
- Meeting other parents to share experiences and gain peer support
- Free training for parents and hot meals provided
- Resources for parents
- Cultural awareness and sensitivity among professionals to combat stigma
- Greater ethnic diversity within services
- Diversity in housing, education and community spaces
- Faster and more efficient processes around diagnosis and support
- Joined-up services
- Consistent links to interpreters and translation services to overcome language barriers
- Information in plain English

RECOMMENDATIONS

- Support the parents moving forward
 - Funding for an inclusive peer support group and interpreters
 - Making the group sustainable
 - Empowering parents in the group to know their rights
 - Creating resources to help the parents understand how the system works
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