



*'Talk to us...'
'We didn't have a voice'*

**Parent carers from BAME communities talk about health and social care
Brighton and Hove - March 2016**

1. Introduction

This report brings together findings from a project that Amaze and the Parent Carers Council (PaCC) carried out thanks to Community Spokes Funding Programme from Healthwatch Brighton and Hove (HW B&H). The aim of the project was to reach out to parent carers from BAME (Black, Asian & Minority Ethnic) communities, to listen to their stories and experiences and to find out how to better engage and include them in what Amaze, PaCC and HW B&H do.

1.1 Amaze, PaCC and Healthwatch Brighton and Hove

Amaze is an organisation that gives information, advice and support to parent and carers of children and young people with special educational needs and disabilities up to 25 years old.

The Parent Carers' Council or PaCC is a group of parents which represents parent carers which children and young people with additional needs and disabilities so to help improve services and support.

Healthwatch Brighton and Hove is the independent watchdog for health and social care services in the city. It helps local people and their communities influence the design, delivery and improvement of their local health and social care services.

Healthwatch Brighton and Hove:

- seeks the views and concerns from local people about local health and social care services;
- provides information about health and care services;
- makes recommendations about how health and social care services could or should be improved by identifying issues and trends, gathering evidence and holding commissioners and providers of services to account;
- influences local services based on the evidence it gathers and through its position on the Health and Wellbeing Board in the city.

The three organisations above worked in partnership to deliver this project and report.

1.2 BAME parent carers and access to health and social care in UK

As well as facing similar pressures of family life as other families, very often BAME families face additional stress due to poverty, poor housing, unemployment and low income, immigration issues, language difficulty, mental health issues or discrimination. Also because of their partial knowledge about the UK, BAME families may also lack awareness of, or access to, appropriate services which could help them. Children from BAME backgrounds may suffer other types of abuse such as racial

harassment, islamophobia and bullying which can harm them physically and emotionally (http://www.safenetwork.org.uk/training_and_awareness/Pages/black-and-minority-ethnic-bme-communities). Many factors are linked to people's cultural perspectives, including ethnicity and place of origin, education, religion, values, gender, age, family and social status. For refugees and asylum-seekers it may also include personal refugee experiences and length of stay both in the person's country of origin and in the UK (<http://www.engagetoolkit.org.uk/health-social-care/awareness>).

We know from anecdotal evidence that parents carers from BAME communities are more isolated and experience more complex needs than parent carers who are perhaps more confident about accessing services available in UK. BAME parent carers of children with additional needs very often experience different layers of difficulties, including cultural understanding of disability and/or additional need, additional added isolation due to their role as carers, long term unemployment, and so on.

1.3 BAME parent carers and access to health and social care in Brighton and Hove

Whilst we feel some of our services do reach some BAME communities, this project was set up in response to an increased awareness that some BAME parent carers were not accessing (enough) support and that they were disproportionately under-represented in some of our data, despite investing in some outreach work.

We wanted to explore the reasons we may not have been able to reach all communities – investigating factors such as cultural, religious, language, ignorance and so on. We also wanted to challenge some of the myths and misconceptions within some of these communities surrounding Special Education Needs (SEN) and disabilities so that support services can be accessed by these members together with their greater understanding of the conditions themselves.

First of all we looked at data held by Amaze and PaCC in relation to BAME parent carers knowing that approx. 20% of Brighton and Hove population are BAME. We found out that 16.9% of respondents to a questionnaire sent to parent carers who were supported by the Amaze DLA project were BAME, similar to the percentage of parent carers who are registered with the Compass Card. Similarly 20% of attendees to Amaze workshops and courses, which aim to increase parent carers' confidence and resilience, were BAME. However only 7% respondents to the last parent carer questionnaire sent by Amaze and 9% respondents to the Independent Advice Support (IAS) questionnaire were BAME. 18% of respondents to PaCC 2015 annual survey were non-British but only 4% BAME and finally 18% of respondents to one of our Brighton and Hove Clinical Commissioning Group (B&H CCG) consultation were non-British but only 4% BAME. It is important to note that where proportions above are 'respondents to surveys' these will always be lower from BAME populations as these have only ever been produced in English.

Clearly there are some Amaze and PaCC activities that have a better track record in terms of representing and engaging with BAME parent carers. We acknowledge that there are those within Amaze that have a better track record than others in reaching or representing BAME parent carers and understanding some of their issues.

An examination into the barriers of parents accessing our services was essential to see why this was the case and what could be done to remedy this. If an understanding could be made of this situation then steps could be put in place to bridge this inconsistency and to make our service

users truly representative of the city. For Amaze and PaCC to consider themselves truly demographically representative of the city we needed to understand what's going on and perhaps adjust the way we do things and also, to challenge misconceptions about SEN and disabilities.

2. Methodology

With this project we wanted to explore if there are any cultural and or community issues to do with recognising and supporting a child with Special Education Needs and Disabilities (SEND) and also what are the barriers to accessing information, advice and support around health and social care from Amaze or from any other information provider. We wanted to identify ways in which BAME parent carers could get more involved with provision of health and social care services in Brighton and Hove and finally what were the barriers to joining PaCC.

We aimed at exploring the above issues with BAME parent carers thorough a series of one-to-one semi-structured interviews and two focus groups. We thought that in that way we were able to first get personal experiences and suggestions and secondly, to have in-depth group conversations ([See Annex 1: "Notes on topics"](#))

We designed a flyer which we sent to those organisations, including community groups, which in some capacity or other work with or provide support and information to BAME ([See Annex 2: "Would you like to chat ...?"](#)). Some of the organisation managers and community group coordinators agreed to meet up with us and their ideas and suggestions are included on this report. Some provided parent carers' contacts. For a list of organisations and community groups which provided insights, ideas and suggestions see the 'acknowledgements' section at the end of this report.

Two weeks into our project it became clear that finding BAME parent carers who were happy to talk to us was going to be difficult. We eventually were able to carry out the planned 10 face-to-face semi-structured interviews but not the two focus groups. This highlighted one of the issues about our research: parent carers, and it is important to mention that not just BAME ones, find it difficult to talk about their experiences and/or problems in front of strangers or, as in this case, to people from their own cultural community.

All in all, we listened to and recorded parent carers' contributions from six different cultural backgrounds: Sudanese, Bengali, Chilean, Congolese, Rwandan and Jamaican.

From the interviews we were not looking for prescriptive nor predictable answers; the approach was very much that we were to learn from the participants' experiences what they were to tell us in their own words. Prompts aside ([See Annex 3: "Questions for focus groups and one-to-one interviews"](#)) we felt it was important for the authenticity of this project to hear from participants themselves, for them to place importance on those issues that mattered to them.

3. Findings

It was decided that in order to anonymise participants' contributions to this project we were not going to mention neither names nor country of origins. Fully written up notes from our interviews are available on request.

3.1 Awareness of Amaze, PaCC and Healthwatch Brighton and Hove.

Some parent carers we talked to didn't know about Amaze or PaCC or HW B&H. Two of those parent carers who arrived in Brighton as refugees were supported by The Carers Centre for Brighton and Hove because they had young adults with them. Some others knew a little bit about Amaze and HW B&H *"Something to do with your health?"* and PaCC *"any issues to do with education/transport/school. Bilingual workers there"*

One participant commented that: *"There were families who could be helped by Amaze but that they didn't want to look further into it. She knows about Amaze through the work of her sister and her nephew. She is grateful for the help Amaze is able to provide and gave anecdotes of those she knows in other places that are not so fortunate"* and another parent carer feedback: *"They do a wonderful job. Since my son was a toddler Lizzie has helped him with his DLA. I wouldn't apply for it in the first place. I felt guilty in the first place as I was a parent and should be able to do things"*

One participant knew about Amaze and Healthwatch B&H through her work with BAME people *"I know what they do and how they can help people - through my work with BAME communities and the work I do here in the city. Part of my job is actually to signpost people/clients to services in the city. I am happy to pass on information about those organisations. I didn't know about PaCC"*

Interestingly one of the parent carers we talked to knew about Healthwatch Brighton and Hove because someone from the organisation attended one of The Carers Centre for Brighton and Hove monthly meetings where people were asked if they wanted to receive the Healthwatch magazine and the parent carer signed to that *"I like the magazine very much, it contains cooking recipes but also news and updates"*

One of the parent carers who arrived in UK as a refugee was referred to The Carers Centre for Brighton and Hove where she received one to one support and advice including counselling, interpreters, support to access GP and so on ... *"My worker from the Carers Centre took me to a small community project where my English and my confidence flourished."*

One of the parent carers asked if any information could be provided. She wasn't aware of information made available in GP's waiting rooms which ideally should be in other languages.

A parent carer who came to Brighton as a refugee benefitted from signposting to other organisations and groups, e.g. Migrant English Project. The parent underlined the importance of having an organisation that acts like an advocate and that introduced her to lots of other support/help. In her country of origin there was nothing like a welfare system or Social Services and of course, the civil war shattered the little help and support that was available.

Another parent carer who is also a BAME project coordinator commented: *"As a project coordinator I was aware of Amaze and Healthwatch B&H. Personally I didn't feel the need to access them because I didn't consider my child disabled. He has special needs, he is not disabled."*

He has Robinow Syndrome, which is related to immune-deficiency. His spine was not straight, it was twisted. He is 3/4 years behind his age. He attended mainstream school, he went to secondary system and he did fine. Then he had an operation and he's now disabled."

3.2 Awareness of support, information and services

One parent we talked to didn't know of any services that could have supported her and suggested that: *"There should be more information available at schools and also staff at schools should be kept updated with services and groups."*

Another parent carer told us that she had no difficulties in accessing services, including what Amaze had to offer but that was because she is fluent in English, confident and able to navigate her way through services. She recognised that for others there is a definite communication barrier.

One participant who works in the voluntary sector stated that *"I think there is information. We got our support from the hospital when our child was there and then from the house visitor, we did receive quite a lot of information and support"*

A parent carer who came to Brighton as a refugee wouldn't have found out what was available in the city without The Carers Centre for Brighton and Hove which acted like a portal of information, providing contacts and with a representative sometimes accompanying her and her daughter to meet professionals and to attend appointments: *"Back in my country of origin there were not special schools or services. My daughter attended a mainstream school where she used to get lots of abuse from other children who used to taunt her and call her 'stupid'. Even the father wasn't really interested on getting involved because he saw her as 'useless', not important. As a result I was the only person who cared for her. The social attitude to disabled children and adults was awful and many people were trying to exploit my daughter at the point that I had to be with her all the time to make sure that no one would take advantage. Also people would think that a disabled child was God's punishment, a curse."* The same parent stated that she thought in Europe and in England there would be much better provision of services for her disabled daughter. She valued highly the provision of interpreters; her own interpreter gave her translated information about services, groups and other supports.

3.3 Barriers to support, information and services

Lack of information and what's on offer for the child and for the parents was mentioned by many parent carers. Many people didn't know they could access support, e.g. health care services and benefits, because in their respective cultures there aren't any. Instead, people looked for support from extended family members, if there are any, or from people within their community.

"I haven't experienced barriers in accessing health and social care services but it is difficult for those who can't access English." All participants highlighted the importance of language and how the lack of fluency can easily or understanding can become 'the' barrier some pointed out the importance of having money in relation to accessing opportunities like events and activities. Help with travel could really help in these cases, but also to be able to refer parent carers to organisations that could help with benefits, e.g. Money Advice Plus.

Some parents talked about the cultural non-acceptance of disability: *"I personally couldn't accept that my son was disabled, I found that quite difficult."* One participant talked about how people from her community feel shame about SEN especially with mental disability and consequently don't

access the services: *"The services in Brighton are brilliant. But my community don't like to talk about it. When my son was born an elder said it was due to the parents' sins! I couldn't talk to her. Such superstition. But it's genetic. Some families break down because of albinism/SEN/disability. Now my son is the apple of everyone's eye - he's loved in the community. It might have bounced off me because I'm liked but if it wasn't then I don't know how I'd feel. I'm pleased he's never been bullied. The behaviours of the older members of the community are old-fashioned - they sometimes feel he needs spiritual protection and want to put charms on him. This happens with other families especially if the disability is invisible."*

One parent pointed out that 'respite' can be a difficult word for some people, 'breaks' would probably be more accepted. A parent suggested that it would be better to focus on the child's behaviour and use language that reflects that instead of talking about 'disability'. A community worker suggested: *"BAME families don't like someone to come out and take care of the child. They would prefer to be offered breaks."*

A participant who is also a BAME project coordinator pointed out that services need to be culturally sensitive, for example provision of female GPs for mothers who are Muslim. Generally Social Services are seen as too intrusive, people feel they are judged: *"They tend to write everything down which in per se can be quite off putting. There is quite a bit of miscommunication going on, for example some cultures saw the soft slap an acceptable method to correct child's behaviour. Social Services see that as abuse and they observe parents!"*

3.4 What could Amaze, PaCC and Healthwatch Brighton and Hove do to help

A participant suggested that it would really help if Amaze, PaCC and Healthwatch B&H could make and maintain links with schools and also with communities and groups. That becomes apparent if we take into consideration that most parent carers belong or feel part of a community organisation which is also their first point of contact. A parent commented that: *"I can read and speak English - but due to my isolation wasn't able to engage."*

Most of the parent carers we talked to agreed that Amaze, PaCC and Healthwatch B&H need to provide easy to understand clear information which has to be translated for those people whose first language is not English. Some parents are happy to receive information by email including newsletters. One community project worker said she would like to receive information electronically or printed which she could then pass on to her clients.

Some parents suggested that schools should be more informed and involve the Ethnic Minority Achievement Service (EMAS) too. It would be good for health visitors to be informed and updated on Amaze, PaCC and Healthwatch B&H.

It was also suggested that interpreters be provided at events so that communication is facilitated and enhanced. A parent suggested: *"Reaching out to the community? Doing what you're doing. Outreach work. They won't go to you. Things like DLA, they won't know about Amaze. You need word of mouth and publicise Amaze's benefits"* A participant recommended that it would be good for Amaze, PaCC and Healthwatch B&H to outreach other organisations and visit them so people know about what they do and the support they can provide. That could also be a way to overcome the cultural acceptance, and perhaps stimulate families from different cultural background to recognise their children's difficulties and go out there to find a way to help.

A parent carer would like a more joined-up system: *"I think that services should work more with the whole family, different services should talk to each other so that everyone knows what's going on. Then decisions should be made, not the other way around."* Another participant commented that

help with forms for someone who doesn't speak the language or is not used to filling forms in have access to services or to receive support.

A parent carer supported the idea of more time for herself, and also for activities for parents like her or groups where she could meet people who are equally or more isolated. Another parent wished advocacy to be offered to the parents and another one commented: *"If I could have one thing it would be improved assistance when my son is travelling on public transport."*

4. Reflections

This project highlighted the need for further work with BAME parent carers. Difficulties on engaging with those parents were brought to light by the difficulties on actually finding people who would talk to us. However it is clear from our interviews that there is so much to talk about and BAME parent carers need a greater voice: they need to be heard; they need to be engaged and to be included.

The report 'Reaching Out - to people with learning disabilities and their families from Black and Minority Ethnic communities'

(<http://www.learningdisabilities.org.uk/content/assets/pdf/publications/reaching-out-report1.pdf?view=Standard>) nicely outlines some of the issues and ways forward for that to happen:

"Families are not "hard to reach" they simply have to be identified and contacted. Better partnership between schools and statutory health/ social care services is an essential requirement to prevent BAME families with young learning disabled people getting 'lost along the way'.

Local community organisations have a significant role to play in identifying and contacting local families supporting a learning disabled person. To work with community organisations in this way, statutory agencies need a joint strategy, an action plan, effective commissioning and monitoring.

More attention should be given to understanding the dynamics of families within the different BAME communities, especially the roles and responsibilities of their members, including siblings.

Specific attention should be given to ensuring that individuals and communities have relevant information on local services and how local decision making processes work.

The contribution of local community organisations should be properly identified and promoted, especially the networks and staff that may be vital. Such organisations and key staff (often volunteers) should then be protected and sustained by the statutory agencies"

5. Recommendations

Information:

- **Amaze, PaCC and HW B&H to involve BAME parent carers in developing websites and information** which reflects parent carers' needs and engage them in an appropriate way.
- **Amaze, PaCC and HW B&H to distribute leaflet/flyers and other information** about their services to GPs, health centres, children centres, schools.
- **Amaze, PaCC and HW B&H to attend BAME annual events** (e.g. Black History Month, Refugee Week).

Services:

- **Amaze, PaCC and HW B&H to provide services which are culturally sensitive.** Some services may need to adapt provision to meet the needs of particular communities, e.g. translations and interpreting, face to face as well as groups, bespoke info for each community.

Representation:

- **PaCC to consider how to attract more BAME parent carers to its PaCConnect focus groups**, possibly looking into translating promotion for these on social media and offering interpreters at the events.
- **PaCC to consider inviting a BAME parent carer to sit on Steering Group as a parent rep.**
- **Amaze to consider whether it can afford to translate some of its key parent carers surveys/questionnaires to improve feedback levels from BAME families.**

Partnership:

- **Amaze to provide training to professionals and volunteers who work with BAME parent carers** (training to explore diversity / working with different communities / how to deal with concerns regarding children / families from different background). Training could be run in collaboration with EMAS (Ethnic Minority Achievement Service).
- **Amaze, PaCC and Healthwatch B&H to work closely with EMAS.**
- **Amaze, PaCC and HW B&H to link with community leaders, advocates and/or community specific projects.**
- **Brighton and Hove Clinical Commissioning Group to fund annual consultation with BAME parent carers** organised by Amaze and The Carers Centre for Brighton and Hove.
- **Brighton and Hove Clinical Commissioning Group and HW B&H to direct some funds to BAME communities** (similar to the 'wellbeing' ones) to support their frontline work.
- **Amaze, PaCC and HW B&H to work with the Local Authority around monitoring of BAME parent carers.**

6. Annexes/Appendices

Annex 1: “Notes on topics”

Annex 2: “Would you like to chat ...?”

Annex 3: “Questions for focus groups and one-to-one interviews”

7. Acknowledgments

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Lucy Bryson, Community Safety Manager, Refugees & Migrants, Partnership Community Safety Team at Brighton & Hove City Council gave us an overview on issues faced by asylum seekers and refugees who may come into contact with services in the city.

A meeting with Sarah Berliner, Team leader at Ethnic Minority Achievement Services (EMAS) offered ideas and suggestions on why BAME parent carers could find difficult to engage with services and how to overcome those barriers.

Students and volunteers at Migrant English Project (MEP) offered their views on accessing services and talked about issues around stigma associated with disabilities. They also provided contacts to parent carers from their communities.

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The following organisations were contacted:

Amaze DLA and Compass, Brighton & Hove Refugee Forum, Brighton Housing Trust, Black and Minority Ethnic Partnership (BMECP), Ethnic Minority Achievement Services (EMAS), Euro-Mernet/Umit, Hangleton & Knoll Project, Parent Carers Forum Medway (London), Migrant English Project, MOSAIC, Mosques, Polish Church, Sussex Interpreting Services (SIS), Southdown Housing (Community Support), Trust for Developing Communities, Muslim Women Group, RYico, HOPE, Downs View School & Downs View Link College.