Autism in Black, Asian and Minority Ethnic Communities: A Report on The
First Autism Voice UK Symposium.

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Abstract

Little is known about the way autism is interpreted and accepted among the Black, Asian and Minority Ethnic (BAME) populations in the United Kingdom (UK). This report summarises a symposium on autism in the UK BAME community in 2018 organised by Autism Voice UK, Participatory Autism Research Collective (PARC) and the Critical Autism/Disabilities Studies Research Group (CADS) at London South Bank University (LSBU).

The stance a family or community take about a condition like autism is influenced by their cultural background. The aims of the symposium were to highlight different perspectives about autism in BAME communities and to preserve the cultural dignity of the community in supporting autistic members. Beliefs about autism, diagnosis, acceptance and support for autistic people from a specific cultural perspective of BAME communities must be cautiously interpreted by autism professionals because beliefs vary among different cultural groups.

Thematic analysis of feedback from participants yielded the following foci. Firstly, cultural, ethnic and religious sensitivities were important to participants who felt that these were often ignored by non-BAME professionals. Secondly, the need for collaboration to improve autism awareness within the community and understanding by professionals of the intersectionality between autism and identity in BAME families was prioritised. Thirdly, issues around feelings of stigma were common, but delegates felt that these were not well understood beyond people identifying as BAME. An action plan was created which highlighted raising public awareness through community engagement, improving access to information for parents, and culturally aware autism education for professionals and BAME communities.
Introduction

The authors acknowledge diversity within the BAME community. This paper only reflects the thinking of people who responded to the call to share their insights. The term BAME community used here reflects a particular body of literature and insights from a limited number of people. Mindful of the danger of over-generalisation from a small amount of information, the authors are cautious about these findings but feel that they make a useful contribution to the debate.

Although Autism Voice as an organisation has amassed knowledge and understanding through lived experience, research about how autism is experienced in the UK BAME community is slight (Munroe et al, 2016). Globally, many autistic children and adults live difficult lives. Access to education is often interrupted, employment opportunities are compromised, and support and acceptance may well be limited. These factors can prevent full participation in community life. In settings with low levels of autism education and awareness, cultural and religious beliefs, accompanied by stigma, can put individuals and families in intolerable and often dangerous situations (Nwokolo, 2010; Alqahtani et al, 2012). In other words, autistic people and their families can be harmed by the attitudes and behaviours of other people. If autism is conceptualised as a punishment from God, social exclusion is likely to follow. Autism Voice aims to address concerns of this nature through culturally sensitive education about autism delivered by community members who are themselves from BAME communities and by people who have lived personal or family experience of autism. Working under the umbrella of the Research Centre for Social Justice and Global Responsibility (CSJGR), (which incorporates LSBU CADS and ESJ Research Groups and
PARC) LSBU hosted the symposium for free as its aims were congruent with the organisation’s values as a civic university embedded in the community.

The main goal of the symposium was to raise awareness about autism within the BAME community with a view to promoting inclusion. The gathering enabled members of the public to share knowledge, discuss responsibilities and define important actions. An ongoing priority is to work with stakeholders to actualise the recommendations and action plan emanating from the work. The organisers are currently working with a group of autism experts via CADS, ESJ and PARC to ensure the actualisation of the recommendations in the action plan. This includes participating in an LSBU research project funded by The John and Lorna Wing Foundation which is concerned with the lived experience of older autistic adults who also have intellectual impairments.

**Review of current literature on autism in BAME community**

Findings from the few studies on autism in the BAME community suggest there is a substantial requirement for large-scale culturally sensitive training, research and awareness-raising programmes for families and professionals (Slade, 2014). The limitations of the research evidence base available indicate a pressing need for further academic study in this field. Autism Voice and LSBU favour research carried out by researchers with insider perspective, preferably of an intersectional nature. PARC includes autistic academics, but few PARC members are from BAME communities. Autism Voice includes participants who are currently taking research degrees at LSBU. The university is committed to supporting their endeavours and to collaborative work that is inclusive of researchers from minority backgrounds.
Cultural Perspectives of Autism

Culture is defined by Matsumoto (1996) as ‘the set of attitudes, values, beliefs, and behaviours shared by a group of people, but different for each individual, communicated from one generation to the next’ (p.16). Diagnostic assessment of autism in the United Kingdom is increasing but Slade (2014) suggests that cultural challenges prevent people from the different BAME populations from accepting, seeking or accessing diagnosis. The Slade (2014) study highlights some of the challenges that families in the BAME community face in getting diagnosis for their children.

These include limited knowledge about autism among family members, denial of autism due to religious beliefs that consider acceptance as an endorsement, and school authorities possibly having stereotypical views about behaviours of children from BAME backgrounds. Similar perspectives are expressed in Mandell and Novak (2005). The study discusses the role of culture in families’ treatment decisions for autistic children and concludes that culture may affect treatment decisions, and that culture is also partly responsible for differences in the use of non-traditional autism ‘treatment’ strategies. In another study by Ennis-Cole et al (2013), counsellors were encouraged to acknowledge the way culture impacts on perspectives about autism.

Religious Perspectives of Autism in BAME Communities

Religion and religious leaders play an important part in the cultural lives of many people from the BAME community. While religious beliefs may contribute to reluctance to seek diagnosis, religion could also provide a major source of help for families of autistic people, including emotional support, strength to carry on, accepting the diagnosis and living with the day-to-day challenges autism brings (Pitten, 2008). There are two major
religious denominations represented within Autism Voice: Christianity and Islam. While Christianity is mainly popular within the African-Caribbean community, most in the South-Asian community are followers of Islam. These belief systems can play a major role in the acceptance of a child’s autism. Faith, arguably, gives autistic parents the strength, hope and feeling of ‘all shall be well’ (Pitten, 2008). However, misconceptions about autism by people of faith could have negative consequences which can impact on the wellbeing of autistic people and their families. An extreme view is that autism is caused by demonic spirits or genies. Alarmingly, exorcism is not unheard of and this has been highlighted as a concern in research focussing on harmful cure focussed interventions. (https://network.autism.org.uk/content/westminster-committee-autism-reports-harmful-interventions). Accepting a diagnosis of autism can be very difficult for families faced with stigmatising views of what this might mean. Some religious leaders warn parents not to accept an autism diagnosis but rather to rely on the power of prayer. Attitudes in some places of worship associated with BAME populations limit the inclusion of autistic persons (Haack, 2017; Ault et al, 2013). PARC members, who are themselves autistic, strongly advocate engaging with adults on the spectrum in order to change harmful stereotypical thinking around autism.

Pitten (2008) concluded that a range of cultural variables impacted on family acceptance of an autism diagnosis. Family and cultural values shape our thoughts and perception of every new happening in our lives. The way families accept or deny autism could well significantly impact not only on the autistic child but also on parents, siblings and other family members. Inevitably the primary carer, who is usually the mother, is likely to be most directly affected. Slade’s (2014) survey shows that families within the BAME community can experience the pressure of isolation and alienation from their extended family and their community because of other people’s reactions to
their child’s autism. Myths about autism within the BAME community are common and unhelpful. Professionals involved in working with families need to be culturally sensitive to these factors. Those who consider themselves knowledgeable about autism may not appreciate the complexity of intersectionality.

**Myths, Misconception and Autism**

Wilder et al (2004) found that some of the myths associated with autism from the BAME community were gendered. The research is now fifteen years old, so caution is urged about assuming that the same applies today. One such myth identified by Wilder et al in 2004 was that girls speak earlier than boys. Holding this false belief may mean that parents put off taking their sons for diagnosis even when they experience delayed speech. Some families also relate aspects of their boys’ autistic characteristics to ordinary exuberant volatile male behaviour (Slade, 2014). Culturally, it is accepted within some BAME communities for boys to display ‘wild’ behaviour while girls are expected to be shy and quiet. Eye contact interpretation by different ethnicities can affect autism diagnosis. In the culture of many BAME communities, it is considered rude for a child to have direct eye contact with an adult. Cultural misunderstanding of eye contact could lead to a misdiagnosis of autism. These observations are built on a rather slight and outdated research base but there has not been a stampede of new researchers eager to engage with this agenda. Autism Voice hopes to do something to address this gap in collaboration with LSBU and PARC.

Papadopoulos’ (2016) more recent research findings partly attribute stigmatisation to collectivist cultures ‘which place priority on community interdependence and shared group norms and values’ (p.4). People who are perceived to ‘deviate from the norm’
in some way are more likely to be stigmatised as a result of subjection to ‘high surveillance levels’ (Papadopoulos, 2016, p.4) in which observers are on the lookout for difference. A major implication is that families who feel watched may decide to hide their autism circumstances from stigmatising community disapproval. Concealment in this way potentially leads to further isolation and loneliness.

People from BAME communities face poorer access to healthcare (Papadopoulos, 2016), including access to autism services (Slade, 2014). Reasons postulated range from apparent cultural misunderstanding by service providers, lack of rapport, discrepancies in conceptualization of autism between professionals and parents, and language barriers. Families may experience some behaviours from professionals as culturally insensitive and assume that they are on the receiving end of judgemental attitudes. This in turn may lead them to avoid particular services. The ability to self-advocate can be hampered by lack of knowledge of entitlement and availability of services and disjuncture in communication between families and professional. Language barriers will exacerbate already difficult situations and further limit access. Autism Voice is committed to the idea that knowledge is power and to empowering autistic people and their families with the necessary understanding of available services and how to access them.

**Employment of Autistic People in BAME Communities**

Intersectional factors between ethnicity and disability can limit employment opportunities for autistic adults. Carers who do not have satisfactory access to support services because of factors discussed earlier are also disadvantaged in the employment arena. The connection between poverty and unemployment hardly needs to be spelled out. Low income levels can further limit opportunities and exacerbate social exclusion.
Combining these factors will have an obvious effect on the wellbeing of autistic people and their families.

Previous studies (CIPD, 2017; EHRC, 2010; National Audit Office, 2008) have shown that people from BAME communities are less likely to be employed compared to their white counterparts. While 74% of white people at working age are able to find a job, only around 14% of people from BAME communities are in employment (CIPD, 2017). Despite the United Kingdom government’s pledge to increase the employment rate of disabled people from 47% to 64% by 2020, the situation still remains bleak, while the rate of employment for autistic adults is alarmingly low, as only about 16% are in full time work (ONS, 2016). Reliable current statistics on the employment rate of autistic people from the BAME community are not available. Cognisant of intersectional concerns, The Equality Act (2010) makes it clear that employers need to make reasonable adjustment to employ disabled people and must not discriminate on the grounds of disability and/or cultural or ethnic background. Disability by Association is also covered in the Act and is of relevance to parents and carers of autistic people who require ongoing support which may impact on the parent/ carer’s employment prospects.

Studies in America have shown that migrant communities could use their cultural resources impactfully to acknowledge, accept and support autistic people. Twoy and Novak (2007) emphasized that Asian-Americans were more likely to perceive their autistic child in a positive way in spiritual terms. In a study by Magana and Smith (2006), Hispanic contributors report ‘greater satisfaction’ for their autistic children than their neurotypical counterparts. Similarly, Ponde and Rousseau (2013) studied professional perspective versus parental opinion of autistic children in the migrant community. The study found 45% of parents mentioned positive views of their autistic child
and 16% mentioned only their children’s qualities. This endorses the notion that migrant communities can use their cultural resources (values and beliefs) to acknowledge, accept and support autistic people. These studies may well hold true for other communities. Autism Voice is of the opinion that with growing awareness by members of the BAME community championed by charities like Autism Voice, backed by the communal culture of BAME groups, perceptions are changing and acceptance and support for autistic people is gradually growing. Empirical evidence is necessary to support their hopeful assertion.

**Data Gathering**

**Process**

Demographic data was collected via anonymous evaluation forms. These included a range of open-ended questions designed to enable participants to express their ideas and share their knowledge and understanding of the topics under discussion and their wider concerns. In addition, the whiteboards were used to capture comments from the day. Four speakers presented on the symposium’s two themes: theme one covered diverse approaches to autism within the BAME community – cultural, religious and ethnic – and the second theme focussed on paving the way to future approaches. Participants were then divided into groups to discuss the themes from a practical and operational perspective. The groups generated action points, which were recorded on the whiteboard. The evaluation covered what participants found useful, what was missing, ideas for future events, suggestions for improvements and offers for future contributions.

**Results**
### Demographics

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<th>Additional impairment</th>
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Sixty-five participants from across England attended the symposium, having responded to publicity from CADS, PARC, Autism Voice and The Disability Equality Research Network (DERN), and all of them contributed to the discussion which was captured on the whiteboards. Among them, twenty-nine people responded to the evaluation form – twenty-one females and eight males. Seven were African-Caribbean, eight African, seven White British, one Asian (Pakistani), two White European and one mixed European and one Black.

Ten of the twenty-nine identified as disabled, sixteen as not disabled and three did not state their disability status. Four described themselves as autistic, one also said they had a mental health condition and five further autistic people said they had an additional impairment label (dyslexia, mental health, physical impairment, depression and anxiety, dyspraxia). Out of the sixteen non-disabled people, there were eight parents with one or more autistic children. One parent of an autistic child identified as autistic.

Attendees classified their work roles as: advocacy group leaders, family members, psychologists, teachers, social workers, nurses, early support practitioners, researchers, police officers, university lecturers, students, National Autistic Society staff and a councillor from a London borough. Eight people were not employed outside the home due to caring responsibilities.

**Symposium Themes and Discussions**

The two themes that provided a focus of the symposium were:

1. diverse approaches to autism: culture, religion and ethnicity;
2. paving the future for autism in BAME.
Culture, religion and ethnicity were discussed at the symposium. Commentary ranged from the various ways in which autism is approached by different cultures to how culture influences acceptance. Tincani et al. (2009) and Bernier et al. (2010) pointed out that labels such as autism may not exist in certain cultures. In Nicaragua and many south American cultures, autism and similar forms of impairment are not acknowledged and people are viewed as equal and embraced in society alongside non-disabled peers (Kim, 2012; Pitten, 2008). Many Nicaraguans within the Catholic faith are encouraged by their church to believe that a disabled child is a blessing from God. In Korea (Kim, 2012) and Ghana (Anthony, 2009) on the other hand, an impairment diagnosis brings shame and stigma to the family and is viewed as a curse. Findings from these studies suggest that culture plays an important role in how people view autism positively or negatively. The purpose of the first theme was to discuss good practice from different cultures and how to use them to support, accept and embrace autism in BAME.

The discussion on the second theme was centred on the need for autism stakeholders, working within the BAME community, to collaborate to raise autism awareness, improve autism professionals’ understanding of cultural values of the different populations within the BAME community and create common understandings and trust. Even though evidence shows that the prevalence of Autism Spectrum Condition (ASC) remains the same regardless of race or ethnicity, the condition is under-identified and/or diagnosed late in children from culturally diverse families (Montes and Halterman, 2011; Tek and Landa, 2012; Tincani et al., 2009). In the UK, the percentage of children identified as having special educational needs and disability (SEND) in state-funded primary schools without EHCP increased from 51.4% (2010) to 57.1% (2018), with 4.2% of black Caribbean pupils and 1.8% of Indian pupils having statement or EHCP
compared to 2.9% of pupils nationally (DOH, 2018). Reasons included low levels of autism awareness in BAME communities, lack of acceptance by families from BAME, and cultural misunderstanding by autism professionals working with BAME families. A critical requirement for success with autism is collaboration among stakeholders (Blair et al, 2010). Collaboration is essential for enhancing inclusion of people with autism within BAME communities and their families/carers at every level: from diagnosis, to getting an EHCP, to access to relevant services that will enhance their independence in adulthood. Service providers need to broaden the support menu from currently available services to include community integration for autistic people, a culturally sensitive approach to diagnosis, family-specific care and support services.

The main discussion topics which emerged from the presentations related to stigma, late or missed diagnosis, cultural misunderstanding by professionals and lack of trust of professionals from people from the communities. The need to address these concerns through collaboration among stakeholders and community engagement was emphasized.

Milton and Martin (2017) emphasise the role of autistic people as key stakeholders with huge reservoirs of relevant insider experience and expertise to bring to the table. Stakeholders may include, as well as autistic experts, service agencies, advocacy groups, parents, schools, family members and friends of families, religious and community heads, disabilities services offices, residential care workers, career services, the metropolitan police, customer services, and transport and prison services. Stakeholder involvement in disseminating autism awareness to communities was highlighted as the most important aspect of the action plan by symposium participants. It was suggested that the symposium itself could be used to build a network and a team of activists and agencies to advocate for families and people with autism in the BAME
community. The organisers were asked by the participants to prioritise work with schools in South London to develop autism awareness in the first instance.

Discussion on the day highlighted the lack of a comprehensive service for families and autistic people in BAME community. A particular issue which emerged was limited understanding of the cultural context of language and autism between professionals and families. Some participants suggested that there is no word for autism in many languages spoken within the BAME community. Participants shared that this linguistic disconnect, especially if coupled with stigma, often results in misunderstanding, negativity, fear and lack of trust for autism professionals.

All twenty-nine respondents asked for feedback said the symposium was useful. Eight rated the presentations most highly, and eight were particularly happy to learn about research into autism issues in the BAME community. One person commented positively about the diversity of audience, another described being delighted to learn more about Autism Voice UK. One person reported being impressed by personal stories of parents and another commented that they had taken away the message that it was okay to be autistic or have an autistic family member.

Respondents were asked whether the symposium covered their expectations and to make suggestions for improvements. Out of twenty-nine respondents, fifteen said their expectations were met and there was nothing else expected to be covered. In addition, they stated that the event was well organised with several useful aspects of autism covered. Three people noted that there could have been more time for questions and audience interaction. Others believe the symposium should have covered more related topics like sex education and autism, the positive sides of autism, more parents' experiences and information on the impacts of autism on siblings. Further education-
focussed suggestions included information on specific interventions, and the problem of exclusion of autistic children from schools. Participants expressed a wish to include people from broader BAME groups and to aim for a wider net of religious representation. Involving more adults on the spectrum and BAME autistic speakers was highlighted. Delegates were particularly focussed on practical solutions to issues affecting autistic people and their families from BAME communities.

Autism Voice is a charity and, although it was born out of the BAME community, it cannot and does not wish to restrict access solely to people with BAME heritage. The focus however, the symposium attendees felt, should coalesce around an understanding of autism and intersectionality with specific reference to issues impacting on the BAME community. People from non-BAME contexts continue to be welcome and Autism Voice is mindful of appealing to anyone involved with autism while retaining its particular focus.

**Recommendations**

*Make the symposium an annual event*

The feeling of the participants was that the symposium could be the beginning of a movement that could address stigma and limited access to appropriate resources through education aimed at autistic people and their families as well as service providers. There is also the need to follow up on the action plan, make reviews and further the discussion in other platforms. It was suggested that the event be made into a nationwide tour. A group within Autism Voice tasked with logistics and planning is developing a strategy to ensure that the discussion widens beyond people who attended the symposium.

*Consultative workshop*
A consultative workshop took place at LSBU three months after the original symposium. Its aim was to further the discussion and to set up a taskforce to ensure that the action plan is actualised. Follow up consultative workshops are planned. These will involve the organisers, autistic people, parents, autism professionals who attended the symposium and other stakeholders including community and faith leaders. The next meeting will start the process of implementing the action plan aiming for practical and policy changes.

*Community engagement*

Perceived lack of recognition and acceptance of autistic people in communal spaces in BAME has increased the level of vulnerability of autistic people and their families, and led to self-imposed ostracism, social isolation and loneliness. This is likely to have a negative effect on autistic people and their families including causing poor mental health. Recommendations for community awareness would involve a participatory approach, intensive community engagement involving faith leaders, other community groups and other ethnic groups within the BAME community. The aims would be to enhance positive acceptance and recognition and access to appropriate services, and to reduce stigma.

The essence of sharing perspectives and different strategies with other ethnic minority groups in the BAME community to learn from each other and improve on the existing campaign strategy was discussed. It was also recommended that Autism Voice UK work to strengthen awareness of autism and stigmatisation with community groups. Emphasis was placed on the importance of local councillors engaging in autism awareness through regular trainings and presentations in order to progress enabling autistic people from BAME backgrounds to be involved in the community engagement.
Schools

School engagement is also important to help bridge the gap between school authorities and families from BAME communities. Autism Voice asserts that education service providers, pupils and parents need a basic knowledge of autism in order to address the individual needs of affected children, develop positive attitudes, reduce bullying and boost acceptance by other children. Social model thinking should underpin any such activity which would ideally be delivered by people with insider perspective.

Contributions to future event

Participants were asked what they might be able to contribute to future event. Out of twenty-nine respondents, ten stated that they would like to be guest speakers, and four were interested in sharing their personal experiences. Research-orientated suggestions included presenting on individual autism research and plans for future autism research. Others offered to present information on the National Health Service, and charities in criminal and social justice contexts. Education-focused offers included presenting on Education Health and Care Plans and working with African parents. Further offers included perspectives on Somali culture and autism, the experiences of a Black psychologist, and mental health and autism.

Other offers of help from delegates included leading on media coverage, facilitating meetings/events in their London borough and helping with inviting autistic people, specific statutory organisations and local employers to participate. Thirteen out of twenty-eight respondents did not state what they would be able to contribute in the future but expressed an interest in continuing to be involved.
*What could we have done better?*

Twenty-one out of twenty-nine respondents answered the question. Only four rated the event organisation as excellent. Ten recommended a larger venue and better planning to cater for children. Having two rooms would have made the event more autism-friendly and some autistic participants found the children’s presence difficult. The LSBU organisers had not anticipated that children would be coming and can plan for this next time. Other recommendations included: starting earlier, encouraging people not to leave before the end, improved time management, and café-style seating to facilitate discussions. A brief opportunity for attendees to introduce themselves and say what they would like to take away from the event was recommended. Time management would be of the essence if this were to be built in. Two respondents commented that some speakers did not explain jargon and requested better microphone use. One recommended that presentations routinely end with strategies and solutions. Having a keynote by an autistic person from a BAME background was suggested. The organisers welcomed the constructive feedback and will build in the suggested improvements next time. Although not picked up in the feedback, LSBU and Autism Voice also wish to ensure that future activities are inclusive of people who cannot easily access verbal communication. Dr Sally Brett from the CADS research group has expertise she is willing to share to support this endeavour (Brett, 2017).

**Next step for Autism Voice UK**
School visits - The need for Autism Voice UK to visit schools in their neighbouring boroughs was emphasized. It is recommended that Autism Voice UK gathers statistics about the number of children with special education needs from minority backgrounds in local schools. Through these school visits, the organisation is expecting to inform parents about available services including those aimed at parents.

Autism awareness for social services - To reduce misunderstanding between autism professionals and families in the BAME community, it was recommended that Autism Voice UK makes contact with social services and offers training to help raise staff awareness about how the BAME community operates. Potentially, with suitable care arrangements, autistic children from BAME communities could be involved in this endeavour. An autistic speaker from a BAME background would be ideal and Autism Voice is prioritising finding someone suitable.

Parent support – Autism Voice UK should encourage parents with autistic children in BAME communities to volunteer in their children’s schools governing body if possible. (This comes with an understanding that social support might be required in order for it to be possible). The purpose would be to help influence decision making that will be in the best interest of children with autism from BAME communities.

Signposting – Autism Voice UK plans to conduct further research on organisations that offer specific services to parents and autistic people with a view to creating a service map. In addition, the organisation will help stakeholders to access helplines and advocacy. Families will also be supported on how to write letters of appeal or request for further support.
E-newsletter – Finally, it is recommended that Autism Voice UK should publish a monthly electronic newsletter to keep the public informed of the organisation’s activities.

Conclusion

The main outcomes of the symposium were collaborative efforts to ensure autism awareness, regular community engagement and advocacy networking to influence policy changes. There is a pressing need to increase awareness of autism in the BAME community. This awareness must be cultural, ethnic and religious sensitive.

Autism is still poorly understood by many people in the BAME community. While most may have come across autistic people, cultural and religious misconceptions about autism may blur their understanding. The symposium highlighted the need to end the stigma attached to autism as well as to foster recognition and acceptance of autistic people and their families in the BAME community. This initiative requires the support and firm commitment from autism stakeholders across different populations within the BAME community. Autistic experts have much to offer this endeavour.

Through collaboration with LSBU and PARC Autism Voice is better placed to realise some of the aspirations outlined in this report. The university views working closely with Autism Voice as a positive thing. This alliance is relevant to the role of LSBU in the community and the social justice agenda of the SJGR Research Centre. In addition, students at the university, particularly, but not exclusively, those studying on the MA Education /Autism benefit from exposure to the work of Autism Voice.
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