Caring alone

Why Black, Asian and Minority Ethnic young carers continue to struggle to access support

Emma James
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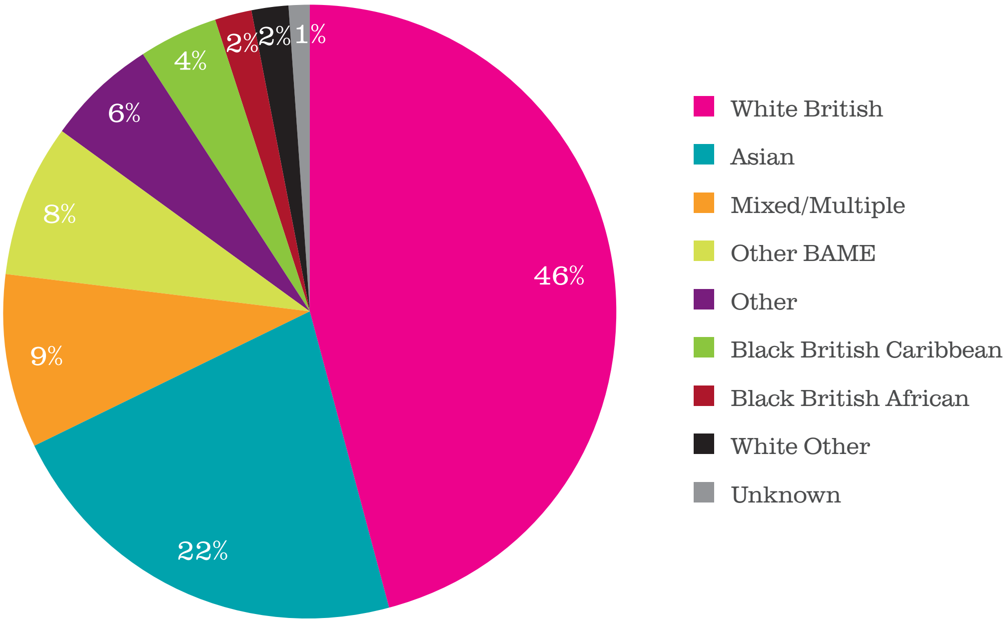
Believe in children
Barnardo's

Executive Summary

This briefing looks at Black, Asian and Minority Ethnic (BAME) young carers and their specific and unique needs. BAME young carers have long been recognised as particularly vulnerable. The term BAME is inclusive of those who may have vastly different issues and vulnerabilities including within their own communities. For example, there are differences within Black, Minority Ethnic and many Asian families and communities. Asian communities themselves vary drastically also depending on their country of origin and time spent in the UK. Much of our research is focused on issues within Asian communities, predominantly South Asian, as that is the highest BAME demographic within our young carers' services. The sheer breadth of different communities we work with is demonstrated in the chart below. Therefore, in this report the term BAME relates mostly to South Asian families.



Ethnicity of Young Carers referred in Leicester 2017-18

Many organisations over the last ten years have looked at how support is offered to BAME communities, why BAME young carers often have additional issues to deal with such as stigma and what impact cultural differences have. The National Black Carers and Carers Workers Network highlighted their inability to find a word which effectively translates to carer in the following languages: Gujarati, Urdu, Punjabi and Bengali.[1] This could be due to the fact that many of the countries where these languages are spoken have very different cultural traditions and expectations and therefore responsibility often falls to the younger members of the family. It is commonly expected that help for older or ill relatives remains within the family rather than relying on strangers from the health and social care system who may not understand the culture, family traditions or community and could be 'judgemental'.

Just under 20% of the total number of young carers we support have been identified as being from non-white communities. As part of our research into the needs and vulnerabilities of BAME young carers, we examined existing reports and information in addition to conducting interviews with Barnardo's young carer practitioners from our services across England. We

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[1] Carers at the heart of 21st century families and communities, HM Government, 2008

also undertook a short survey with our services to identify the key issues faced by young carers from BAME communities in accessing support services and to gain insight into what measures can be adopted to ensure that BAME young carers have better access to support.

The research found that:

- Young children were far too often being relied upon as interpreters often interpreting technical and deeply personal medical information between patients and doctors which could lead to misdiagnosis and exacerbate anxiety within families.
- The concept of a young carer is completely unfamiliar to many BAME communities as helping your family and extended family is something that is expected and often the impact on the child is not realised or understood.
- Often BAME families do not want agencies involved as there is a deep mistrust of social services or authorities and they are fearful of their families being split up.
- There is stigma within many BAME communities in acknowledging mental health and disability issues and in seeking support.
- BAME families are more likely than other families to be impacted by other inequalities and adversities such as mental health issues, poverty and domestic abuse which provides an additional strain on young carers within these households.

In the NHS's recently published 10 year plan, there is acknowledgement of the impact caring has on children and young people. The report states that up to 40% of young carers report mental health problems as a result of their experience of caring. The NHS will roll out 'top tips' (which have been developed by young carers) for general practice. These 'top tips' include access to preventative health and social prescribing as well as timely referral to local support services. According to the plan, up to 20,000 young carers are set to benefit from this approach by 23/24.

Whilst we welcome the acknowledgement of the needs and vulnerabilities of young carers, we are concerned at the lack of ambition and vague proposal. There are an estimated 800,000 young carers in England and therefore, a plan to benefit 20,000 of them just does not go far enough. There are also many other areas within the NHS plan that will impact on children and young people who are carers. Pledged investments in technology will result in an NHS with widespread digital access to services. When there are young carers within families, these changes will affect the way they support their parents and/or other family members. The NHS needs to monitor whether these technological advances in health support will help or make things more difficult for young carers.

It is important to remember that many young carers are extremely proud to care for their families and, despite the negative impact it can have on them and their outcomes, they are fiercely protective of their role. Sixty three per cent of young carers we surveyed in 2017 said they were proud and happy to help their families with caregiving. It is when the caring has a detrimental impact on the child's schooling, mental and/or physical health and future life chances that it becomes a concern.

Recommendations

Given our findings, Barnardo's is calling on policy makers to act soon to better support BAME young carers and we have made the following recommendations:

Recommendation 1 – The NHS 10 year plan needs to allocate more resources and go much further in its proposals for improving support for young carers identification and referrals for support of young carers from the NHS should be more frequent. Their current proposal will only benefit 2.5% of young carers in England and is insufficient in ambition and scope.

Recommendation 2 – Young carers will often be the members of the household navigating online medical systems on behalf of their families. Therefore, the NHS needs to take into account the impact the implementation of the proposals set out in their 10 year plan around the increased use of technology will have on children and young people that act as carers for their relatives.

Recommendation 3 – Clinical Commissioning Groups and local authorities should analyse the demographics of BAME communities within the health system and ensure that there are plans in place to use insights to support young carers within their local transformation, area plans and NHSE arrangements and that NHSE staff from those communities are employed as needed.[2] These demographics must be shared with local health surgeries like GP surgeries and health centres.

Recommendation 4 – The Department of Health and NHS England should seek to review the current guidance on the use of interpreters and translators within the NHS and look to ensure that it is being more widely implemented. There must be better oversight by the Quality Care Commission on implementation and provision. As well as this, the impact of not having access to interpreters is having on families and their treatment, particularly those with young carers, must be made clearer to GPs and hospital medical professionals and non-medical staff.

Recommendation 5 – NHS England and community outreach groups need do more within BAME communities to reduce the stigma of mental illness, special needs and disability in order to ensure that families access support that is available.

Recommendation 6 – Local authorities, NHS England and young carer services need to work to better engage BAME communities through targeted promotional work and should look to employ specific BAME outreach workers who understand the community they are working within.

Recommendation 7 – Services working with BAME families impacted by domestic abuse and other vulnerabilities need to be more joined up and work more closely together to ensure that young carers within these families are identified and referred for support.

Recommendation 8 – Local Authorities need to reassess funding structures to ensure that the focus and funding is not just on the identification and assessment of young carers but also on sustainable and worthwhile support.

Recommendation 9 – The Government should publish an update on their cross departmental Carers Action Plan to ensure that progress on all proposals can be examined.

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[2] For example, at the one of the London teaching Hospitals where there is a large Bangladeshi community there is reception with just Bengalis reception staff – male and female – who can also help with interpretation.

Section 1 – **Background**

‘Still Hidden, Still Ignored – Who cares for young carers?’

In December 2017 Barnardo’s published the in-depth report into the support and identification of young carers: ***Still hidden, still ignored – who cares for young carers.*** This was our first piece of research on young carers since 2006. Drawing on research conducted with our service practitioners, teachers and young carers themselves, we found that many young carers were still being failed by the numerous agencies they come into contact with. Some were not being identified and were not receiving the targeted and consistent support they so desperately need. It continues to be hit and miss as to whether schools are aware of the reality of their situation and whether they are equipped and putting safeguards in place to ensure there is a whole school approach to offering support.

The report found that:

- Agencies are missing opportunities to identify these children and young people. GPs are seeing parents regularly and are not asking the questions about who is supporting them in the home. Adult social services and mental health services working with parents are not seeing children as their responsibility or don’t know where to refer them for further support.
- Schools are failing a generation of children who are sacrificing their futures to care for sick or disabled family members. Teachers have been failing to identify and support children who are shouldering an extra burden as young carers by looking after their loved-ones.
- Forty per cent of teachers were not confident they would be able to identify a young carer in their class. More than a third of teachers surveyed thought there were young carers at their school who were not supported and a third said their school does not have any particular ways of supporting young carers. Nine-in-10 teachers thought caring responsibilities could impact negatively on young carers’ school lives as it could mean they are late or absent from school or have trouble keeping up with work.
- Some children and young people are carrying out more than 30 hours a week of caring responsibilities[3] – almost the equivalent of a full-time job –filling in the gaps left in adult social care. Young carers carry out tasks including cooking, cleaning and shopping, as well as providing intimate personal care, administering drugs and taking care of household finances.
- Cuts to local authority budgets have meant that more and more children are taking on more and more caring responsibilities and despite changes to legislation which have led to more young carers being identified, there are still children with caring responsibilities slipping under the radar.

Based on the evidence, we made a number of recommendations to Government, local authorities, the NHS and schools. What underpinned these recommendations was that the responsibility of effectively identifying and supporting young carers needs to be solidly ingrained in all agencies (both adults and children’s services) and clear pathways must set out to ensure that these children and young people do not continue to be failed and forgotten.

While we found that many young carers struggled to get the support they needed to live a normal childhood, Black, Asian and Minority Ethnic (BAME) young carers are even less likely to receive support both financially and practically, often as a result of the difficulty in accessing culturally appropriate information and a lack of engagement with these communities.[4] BAME young carers continue to be even more isolated and hidden from services. This is particularly worrying when,

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[3] Still hidden, Still ignored *Author: Emma James 2017*

[4] https://www.carersuk.org/images/Facts_about_Carers_2015.pdf

according to the 2011 census, young carers are 1.5 times more likely to be from these communities and twice as likely to not have English as their first language.

It is clear that to improve the lives of the most marginalised young carers, specific action and policies that address the particular needs of BAME young carers is needed. Barnardo's undertook this further review to help identify the approaches and policies that would make an impact.[5]

The Carers Action Plan

In our report on young carers, we called for a review into the legislation and the impact the focus on identification over support was having on young carers. In June 2018 the Government released their two year cross departmental Carers Action Plan which detailed actions around identification and support of young carers. Many of the actions respond to recommendations we made in our 2017 report. We were particularly pleased that young carers are now one of the vulnerable groups included in the 'Children in Need review' and are particularly encouraged that the Government have highlighted the need for more support and identification of especially hidden young carers – those from Black, Asian and Minority Ethnic families.

The Action Plan includes a call for evidence on identification but as our report made clear, the focus on identification by local authorities continues to the detriment of support provided. We still would like Local Authorities to reassess funding structures to ensure that the focus and funding is not just on the identification and assessment of young carers but also on sustainable and worthwhile support.

The Action Plan referenced the importance of group and participation work to young carers. We strongly welcome the plan to **'develop the capacity of young carers to participate in the planning and development of young carer friendly services.'** We would like this to go even further and encourage local authorities to include the creation and use of participation groups within their commissioning arrangements.

Whilst we are happy that the Government is committed to actions to improve support and the identification of young carers, we also want a commitment that Government departments will work together to reduce the amount of caring young people are doing. Children are currently filling in the gaps in the social care provision. When thresholds are raised and care packages cut for adults with disabilities, long term illnesses, mental health and drug and alcohol issues, it is children who are picking up the pieces. When children as young as eight are doing over 15 hours a week of caring[6], more work needs to be done with the family to understand why this is and what other support can be put into place.

Recommendation 8 – Local Authorities need to reassess funding structures to ensure that the focus and funding is not just on the identification and assessment of young carers but also on sustainable and worthwhile support.

Recommendation 9 – The Government should publish an update on their cross departmental Carers Action Plan to ensure that progress on all proposals can be examined.

Overview of Young Carers in England

Statutorily, a young carer is defined as a *'person under 18 who provides or intends to provide care to another person'*. This includes *'providing practical or emotional support'* which is *'not under or by virtue of a contract or of voluntary work'* (Children and Families Act, 2014). More broadly, a carer is *'somebody who provides support or who looks after a family member, partner or friend and who needs help because of their age, physical or mental illness or disability.'* (Care Act 2014)

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[5] Still Hidden, Still Ignored – Who Cares for Young Carers, Barnardo's, 2017

[6] Ibid

Their day to day responsibilities often include: cooking, cleaning, shopping, providing nursing and intimate personal care, giving emotional support, financial management and caring for siblings. The majority of respondents from our Young Carer's survey last year stated that as well as undertaking physical tasks they also provide emotional support to the person they care for. Other high responses included shopping, going to doctors' appointments and doing the cleaning and washing.

The legislative framework for young carers has changed substantially in the last ten years. The Children and Families Act 2014 and the Care Act 2014 place a statutory duty on local authorities to take 'reasonable steps' to identify young carers in order for them to have a needs assessment. This has often led to the focus being on identification rather than suitable support. Our practitioners tell us that referrals continue to rise but this can be at the expense of service provision.

The Children's Commissioner's 2016 report Young Carers – *The support provided to young carers in England*[7] requested referral data from all local authorities. The data gathered suggested that 'only a small proportion of young carers in England are identified and supported by their local authority'. The report also suggests that although local authorities may be focussing on their statutory duties to undertake a needs assessment, it is at the detriment of actually providing concrete and specialist support to them. So even though the right to a needs assessment is provided for in legislation, and 97% of those assessed were deemed to be in need of support, as many as 30% of those referred were not assessed. This equates to nearly 6,000 children.

In September 2018, the BBC released new research with the University of Nottingham revealing that 800,000 secondary aged young people in England are caring for a parent or sibling. These findings suggest that approximately seven percent of all young people have a significant caring role in the home for an ill or disabled relative[8].

Black, Asian and Minority Ethnic Young Carers

The Children's Society in their briefing *Young Carers of Black and Minority Ethnic families*[9] state that BAME groups as a whole are more likely not only to report ill health but also to experience it, in comparison to those who identify as white British. They go on to say that people from marginalised groups including BAME households are at greater risk of developing mental health problems.[10] Government statistics support this, indicating that a higher number of particular groups from the BAME community experience severe mental health issues when compared to those from non-BAME communities.[11] This finding is also reflected in the number of detentions made under the Mental Health Act. In the 2016-2017 period a far higher number of individuals from BAME communities were detained under the Mental Health Act. For example, for the Bangladeshi group there were 107.6 detentions (per 100,000 population). This is significantly higher than the number of detentions for those of the 'White British' group which had 64.3 detentions (per 100,000 population). The numbers for individuals from the 'Black Caribbean' group are even more alarming with 249.6 detentions (per 100,000 population). This is almost four times the number of detentions for the 'White British' group.[12]

Many of our practitioners were keen to point out that young carers across the board need more support and the very nature of being a young carer and what that entails leads

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[7] The Children's Commissioner's (2016) Young carers – *The support provided to young carers in England*

[8] https://www.bbc.co.uk/news/resources/idt-sh/Being_a_young_carer

[9] The Children's Society – *Young Carers of Black and Minority Ethnic families*

[10] Independent Mental Health Task Force (2016) – A five year forward view of mental health

[11] UK Government ethnicity facts and figures (2017) – Adults experiencing a psychotic disorder.

[12] UK Government ethnicity facts and figures (2017) – Detentions under the Mental Health Act.

to vulnerabilities for all children and young people. As well as this, it is clear that issues impacting on one BAME family may not always arise in another BAME family. Others reported that some BAME communities actually had better specialist local services in place than other communities although some said that these services did not always give the substantial and well-rounded support that young carers need. However, there were significant consistent trends that came up from practitioners when they discussed working with young carers from BAME communities. In our survey to young carer practitioners they cited language barriers and stigma as the two key reasons why Black, Asian and Minority Ethnic young carers and their families were less likely to access support than other young carers. Other issues such as a fear of social services and agency involvement in the family as well as an acceptance that a child should care for older relatives within the family were also seen as significant.

More needs to be done to ensure that BAME communities not only understand the term ‘young carer’ and the impact caring has on children and young people but equally, that they know what support is out there and how to access it. Many of our services reported that having a service worker from the community they support has proved crucial in engaging BAME families.

Section 2 – **Findings**

What are the specific issues facing young carers from BAME families?

1. Interpreters

Our services in Leicester and Bradford work with a large number of ethnic minority families. They reported that young children were frequently being taken to doctors and hospital appointments and were being relied upon to interpret between parents and medical professionals. This leads to a plethora of issues for the family. Parents often don't want to tell their children personal details about their medical issues particularly if they are mental health related. Children often don't understand, in detail, what is being discussed so significant issues can get lost in translation and medical issues are therefore being misdiagnosed or remain hidden. Children also had to miss school to attend these appointments. Our services reported their own struggles in finding accredited interpreters to support families particularly ones from outside of their immediate communities. One gave an example of a woman who found herself with an interpreter at a medical appointment who was a father from the school her children went to. This led to her not wanting to divulge too much detail about her condition and led to additional anxiety and worry.

Interpreting and translation in primary care

The NHS spends millions of pounds every year on interpreters and translators. According to the most recent census (2011), around 4.2 million people in England and Wales speak a 'main language' other than English or Welsh: this amounts to one in 13 people. Within this, there are 88 main languages; the most common is Polish (1% of the total population), followed by Punjabi, Urdu and other European languages. Indeed, this is also clustered in many urban areas. As an example, in Leicester, up to 9% of the population either does not speak English well, or does not speak it at all.[13]

NHS England has worked with professionals and the public to identify what good interpretation services look like. Focus groups took place in 2015 and the output of these discussions was a draft set of Principles for Interpreting and Translation Services. In 2016 and 2017 the draft principles were revised and incorporated into guidance for commissioners. Although written with primary medical care services (GP surgeries) in mind, the contents are applicable to other settings, such as other primary care settings or hospital sites.[14]

The guidance for commissioners highlights that: 'patients should be able to access primary care services in a way that ensures their language and communication requirements do not prevent them receiving the same quality of healthcare as others'. 'Interpretation and translation should be provided free at the point of delivery, be of a high quality, accessible and responsive to a patient's linguistic needs. Patients should not be asked to pay for interpreting services or to provide their own interpreter.'[15] Where the patient has an identified carer (i.e. someone who provides regular, unpaid care and support) then the carer should be able to access language support to understand the discussion between the medical practitioner and patient, with the patient's consent.[16]

Yet despite this guidance, many patients are relying on children to interpret their medical needs often leading to the children missing school and increasing their anxiety. Although the guidance states that the use of interpreters should not incur a cost, many of our young carer services told us that families have not been able to afford to get an interpreter and sometimes the cost has fallen to the young carers service itself.

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[13] The Royal College of Physicians quoting Census 2011 stats.

[14] Stephenson, S (September 2018) *Guidance Note: Commissioning Interpreting and Translation Services in Primary Care*, NHS England

[15] ibid

[16] ibid

Dr Teodora Manea Hauskeller, an academic from the University of Exeter who specialises in medical interpreting, was cited on the Royal College of Physicians website as saying 'Not everyone is aware of interpreting services, but even if someone comes with a family member to interpret for them, that is not sufficient – even if the family has the best of motives, there is a tendency for family members to filter information and even keep information from the patient; and there are also issues around privacy. And for paperwork and legal matters, an interpreter is compulsory.'[17]

It is clear that not having interpreters more regularly available to families within the NHS is a particular problem for parents whose children care for them. If the issue is not with the number of interpreters in the system, then families need to be made aware of their entitlements and how to request an interpreter well in advance of an appointment. General practitioners and hospital doctors and non-medical staff must be more aware of their patients language needs prior to appointments. Training in cultural competence and awareness of the demographics of the communities they are working in would help NHS staff consider these issues in their plans. Responsibility needs to lie with the practitioner and not the patient when it comes to employing fully trained medical translators.

Recommendation 3 – Clinical Commissioning Groups and local authorities should analyse the demographics of BAME communities within the health system and ensure that there are plans in place to use insights to support young carers within their local transformation, area plans and NHSE arrangements and that NHSE staff from those communities are employed as needed.[18] These demographics must be shared with local health surgeries like GP surgeries and health centres.

Recommendation 4 – The Department of Health and NHS England should seek to review the current guidance on the use of interpreters and translators within the NHS and look to ensure that it is being more widely implemented. There must be better oversight by the Quality Care Commission on implementation and provision. As well as this, the impact of not having access to interpreters is having on families and their treatment, particularly those with young carers, must be made clearer to GPs and hospital medical professionals and non-medical staff.

2. Stigma and fear

The majority of Barnardo's young carer services identified stigma as a key barrier to seeking help for minority communities' families with young carers. These families are often more concerned about perceptions from those within their communities and will often find it more difficult for them to seek help or admit there is a problem because of fears of being shunned within the community. This particularly applies to mental health issues or other hidden issues. Our service in Leicester told us that BAME families were much less likely to self-refer although this could be for a number of additional reasons such as difficulty in navigating the system which is examined later. However, our practitioners do see stigma as a key reason for the lack of self-referral. Our service in Bradford told us that mental health issues can be severely stigmatised with some South Asian families "rather than thinking it's a mental health issue they may think that someone has been cursed". Another service said that they work with BAME young carer families that, as a result of the cultural stigma attached to mental illness, do not accept the medical diagnoses of mental health illness. This observation is reflected in government statistics which present ethnic community access to mental health support. Despite the fact that a higher number of BAME community members have severe mental health issues (and far higher numbers of

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[17] Royal College of Physicians (2018) *Speaking in tongues: how do translation services work in the NHS?*

[18] For example, at the one of the London teaching Hospitals where there is a large Bangladeshi community there is reception with just Bengalis reception staff – male and female – who can also help with interpretation.

BAME community members are detained under the Mental Health Act) less individuals from BAME communities are receiving support for mental health issues.[19]

As well as this there is often a deep ingrained fear within communities of asking for help, particularly if social services are involved. Our service in Rotherham stated that 'trusting us can be difficult as there is a fear of authority that is often cultural.' Agencies and workers need to have a positive influence within the community which allows them to maintain trust with families. Barnardo's work hard within these communities to do just that but more needs to be done to engage and educate BAME families and help them access the support that is out there.

Specialist BAME community services need to work more closely with universal services to ensure that all communities know what support is out there for them. Universal services need to be mindful of cultural and religious issues, for example our Leicester young carers' service holds Saturday support groups for young carers because many children in that community attend mosque during the week.

The following case study is a good example of how a Bangladeshi family has overcome the stigma associated with their children's autism diagnosis and ensured that their daughter Safa, who is a young carer, has accessed support. Shila is a mum of four who lives in Bradford, with three children on the autistic spectrum, the family care work often falls on her daughter Safa

Case study

Ten-year-old Safa is supported by Barnardo's young carers' service in Bradford. She lives with her mum and dad, two brothers and sister. Safa's three siblings are all on the autistic spectrum. Safa helps care for her siblings – getting uniforms ready for school, helping prepare meals, cleaning up around the house. She is attentive to their needs providing invaluable support to them and emotional support to her mum. She instinctively knows what her siblings need and keeps them calm and entertained. Safa's grandfather came to the UK from Bangladesh in the 1960s to work in the textile industry and her grandmother, mum and aunty came in the 1980s. Safa's mum Shila says she feels 'blessed' to have been educated in England. Encouraged by her parents, she qualified and worked as a teacher and now cares for her children full time. She is a driving force for the family but says she could not cope without the help of Safa and the continued support of their Barnardo's worker. Shila said:

"When my eldest son was diagnosed with autism there was denial from all my family members. No one wanted to accept he had a disability. I learnt very early on that I needed to embrace it and learn as much as I could about autism to make his life better.

"At first, I was scared to get in touch with social services. It's the connotations you grow up with and that are often reinforced by the media – if social services get to know you, it will lead to trouble for your family. But I eventually came round to thinking that I had to do this for my children. So I self-referred and was later referred to the Barnardo's young carers' service too."

"Today I like to educate people about autism. I unpick my kids' behaviours and translate for my family. It can be hard as most of my family want to understand the reason why my

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[19] For example, at the one of the London teaching Hospitals where there is a large Bangladeshi community there is reception with just Bengalis reception staff – male and female – who can also help with interpretation.

kids are who they are. There are lots of misconceptions in my community about disability. There's one school of thought that autism is like a possession which comes from a place of fear, seeing children have fits or tantrums. Another common thread in my community is that you must have done something bad in life, that's why your children are disabled."

"I know of women in my community with children with disabilities won't talk about or acknowledge it because it would mean asking for help. They're frightened of authority and if they do get help, are scared to raise questions. Most of the time they don't understand and are reluctant to accept that their family is different because they are ashamed. If we don't talk about what we're experiencing, how can we understand and get the best for our children? I think it's important that we break down cultural barriers to ensure that the children get the support and understanding they need. The Islamic view point is that you cherish and nourish the child that you have been given and that a girl is a blessing.

"I do think things are gradually improving and changing. I'm second generation so things are progressing, and our children will have different ideas too.

"In our house we accept autism as being the norm. With Safa's help, I'm juggling the needs of three kids with autism who are all so different. We have become a strong family unit, dedicated to all our children."

"Safa is a very special little girl and I am so lucky to have her. She is patient, kind, attentive and bright. I couldn't do it without her. I do know that if it wasn't for Safa, things would be so much harder for us."

Safa said:

"I like being a young carer and helping my family. It can be difficult sometimes because I get a lot of homework on top of caring for my sister and brothers. I don't do play dates after school but my cousins come round and I get to play with them. My mum says I'm a little star but I just help out around the house and make sure my brothers and sister and ok. When I grow up I'd like to be an artist, a scientist, author or a YouTuber."

Recommendation 5 –NHS England and community outreach groups need do more within BAME communities to reduce the stigma of mental illness, special needs and disability in order to ensure that families access support that is available.

3. Understanding belief systems and experiences

The concept of being a young carer is alien to many communities and families particularly minority communities. Some of our practitioners felt that BAME young carers were less likely to access support because of a lack of understanding of what help is out there and also an acceptance that caring for older relatives or siblings is a child's role within a family.

The Government's 2008 report 'Carers in the 21st Century' states that although reports vary on numbers of BAME carers (young and adult), they are certain that a lot of them do not self-identify as carers due to cultural expectations.[20]

The Children's Society report includes a few messages from BAME parents which focus specifically on the cultural responsibility for BAME carers to perform acts of care as part of their culture, likewise problems with social services normalising caring duties of BAME carers as it is 'in their blood.'[21]

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[20] Carers at the heart of 21st century families and communities, HM Government, 2008

[21] https://www.childrenssociety.org.uk/sites/default/files/young-carers-of-bame-families.pdf

Practitioners working with BAME families with young carers directly need more awareness and understanding of the issues that impact on these communities. Issues, of course, vary from community to community and family to family. Expectations are often different within certain BAME communities and trusting people outside of their communities is often difficult. Barnardo's young carers practitioners cited the impact of the amount of time a family had been living in the UK and their immigration status as a key determinant of a family's willingness to seek support. With even the Windrush communities affected by immigration injustice, distrust and fear on immigration does affect a wide number of people's access to government services. Two respondents to our survey made reference to cultural differences/expectations with one pointing out that 'within Asian families it seems that a far greater caring role is expected of females than of males. This is difficult to challenge due to cultural differences'.

Having services and outreach workers who understand the cultural differences and the language is vital to gain trust from families and children in the community. This needs to happen across all of social care to ensure that these families are accessing support and engaging with services as early as possible. Information and guidance needs to be available in more languages and they need to be more targeted at these specific communities. Working with cultural and religious leaders is vital and Black, Asian and Minority Ethnic media can help to spread these positive messages within communities.

One young carer practitioner wrote that families from BAME communities often *'Feel unsupported'.* They also said that *'there are a lack of resources and appropriate support in place and a lack of awareness of cultural, religious, heritage, background, needs, translators. Links to communities may also not be in place and this needs addressing to ensure raised awareness of services available. Information/leaflets/posters are only in English and there is little understanding & knowledge of BAME issues within agencies.'*

Recommendation 6 – Local authorities, NHS England and young carer services need to work to better engage BAME communities through targeted promotional work and should look to employ specific BAME outreach workers who understand the community they are working within.

4. Additional vulnerabilities

Poverty and housing issues are often a huge feature within BAME families. Twenty per cent of people living in Asian and Black households lived in persistent low income[22], the highest percentages out of all ethnic groups.[23] Our practitioners report that the impact of austerity on these families has been profound, the changes with Universal Credit and the changes from disability living allowance (DLA) change to personal independence payments and rising thresholds have made a real difference to the amount of support that families can access. In our young carers report from 2017 'Still Hidden, Still Ignored' practitioners told us that the squeezing of adult social care had led to children picking up the pieces. This is just as stark in BAME families.

Our young carer practitioners also say that domestic abuse continues to be notable within BAME young carer families. Despite being just as likely to experience abuse as any other ethnic group, research shows that the level of disclosure for BAME victims of domestic abuse is far lower than that of the general population.[24] From the charity Safe Lives own national dataset of 42,000 cases, we know that victims from BAME communities typically suffer abuse for 1.5

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[22] Persistent low income is defined as earning less than 60% of the UK median income before housing costs in at least 3 out of 4 years

[23] https://www.ethnicity-facts-figures.service.gov.uk/work-pay-and-benefits/pay-and-income/low-income/latest

[24] Walby & Allen, 2004

times longer before getting help than those who identify as White, British or Irish[25].

One of our domestic abuse services in Wales told us *"We have very few referrals from black and minority ethnic families. When we have received referrals it has been a challenge to encourage male perpetrators to engage with support. There has generally been reluctance about how the community will react and expressing cultural difference as a reason not to engage".*

This can mean that BAME children are in abusive households far longer than they should be. Our Rotherham young carers service reported that they had six families with 7 young carers who were referred to them within the last 18 months where children were caring for mothers with mental health issues stemming from domestic abuse. This combined social isolation can have a devastating impact on young carers if they are not identified early and supported effectively.

Recommendation 7 – Services working with BAME families impacted by domestic abuse and other vulnerabilities need to be more joined up and work more closely together to ensure that young carers within these families are identified and referred for support.

The way forward

Children and young people continue to lose their childhoods and jeopardise their futures to care for relatives. Parents are having to rely on the very youngest members of the household to care for them. Although we welcome the recent action from the government to improve the support and identification of young carers, what Barnardo's wants is the Government to make more of a concerted effort to reduce the burden of care from these young shoulders. This cannot be done without specific action for the most marginalised young carers from Black, Asian and Ethnic Minority families.

It is clear that Black, Asian and Minority Ethnic young carers and their families have unique vulnerabilities which many agencies struggle to understand and to mitigate their impact. When young carers are 1.5 times more likely to be from these communities and twice as likely to not have English as their first language, it is clear that more work needs to be done in order to break down barriers and reduce the stigma they feel in asking for help and the imbedded fear of agency involvement within these communities. This stigma is dual though as they are also battling stigma within their own communities over mental health issues, domestic abuse and disability. Services need to be accessible and visible and work to overcome any language and cultural barriers that may lead to BAME families not seeking support.

The NHS must seize the opportunity to focus its 10 year plan on the most vulnerable communities and examine the impact the changes they have pledged to make will have on them and the children and young people in these communities who selflessly act as carers for their families.

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[25] Safe Lives – (2014), Marac national dataset 2014. Bristol: SafeLives

For more information about the
work of Barnardo's please contact:

Emma James,
Senior Research and Policy Officer
T: 020 8498 7827
E: emma.james2@barnardos.org.uk

www.barnardos.org.uk

Barnardo House, Tanners Lane, Barkingside IG6 1QG | 020 8550 8822
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