



**Meeting the needs of black and
minority ethnic young carers:**

**A literature review and research
study for the Willow Young Carers
Service.**

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September 2003**

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EXECUTIVE SUMMARY

The findings of this report are based on research conducted with a group of Black and minority ethnic (BME) young carers and their families contacted through the Willow Young Carers Service. The main aim of the study was to explore the current situation for BME young carers and suggest possible ways for the Willow to best support BME young carers. The research was carried out by means of:

- A focus group with BME young carers.
- Interviews with current BME service users and their families.
- Interviews with BME young people who were referred, but did not take up the service offered by the Willow.
- Referral agencies questionnaire.

In total 11 young people and 8 parents were interviewed, and 10 professionals took part in the research.

Findings

Perception of caring

- There was not a strong identification amongst respondents with the idea of being a young carer.
- The young person's responsibilities were more likely to be recognised by their parents than by the young person.
- Schools were usually aware of the young person's caring role, but were not seen as particularly supportive by the families.
- Beyond this, it was unlikely the young person's caring was widely known about outside the family.

Support needs of BME young carers

- There were 5 common support needs amongst the young people:

i. Emotional support

- The young people provided a great deal of emotional support to the care recipient.
- The young people were not comfortable talking about caring and consequently many parents were concerned about their children's emotional wellbeing.
- Parents recognised the difference the Willow had made to their child's self-esteem by encouraging them to be more open about their caring.

ii. Isolation

- Young carers appeared to have fewer leisure opportunities than others and therefore were potentially more isolated.
- Contrary to the common assumptions about BME families, part of the reason for this isolation was because many families did not have strong support networks or did not receive help from their extended families.
- The opportunity to try out new things and go to different places was considered the most helpful aspect of the service offered by the Willow.

iii. Information

- The young people wanted to gain information about the care recipient's illness, particularly in the case of mental health problems.
- Many parents believed their children may have built up false perceptions about their illness which were having a negative impact on the young person's ability to cope.

iv. Bullying

- There were incidents of racial bullying in schools/ local neighbourhoods for the majority of the young carers interviewed.
- Increasing self-esteem was found to be an effective method of combating this situation by the Willow service users.

v. Basic needs

- Many families had a high level of need, and required support to access services in relation to housing, financial benefits, holidays and transport.
- This was particularly the case when English was not the parent's first language.
- The level of assistance from the Willow, although appreciated was insufficient for some families.
- Some families did not feel informed by the Willow about what was happening with their support claims.

Are these support needs any different from white young carers?

- There was no suggestion the needs of BME young carers are necessarily any different to white young carers. However, bullying, social isolation and a need for advocacy may be an increased risk for BME young people compared to white young carers.
- Those families for whom English was not their first language were in need of the most support and assistance.

Appropriateness of current service

- No family had any concerns about the cultural appropriateness of the current service provided by the Willow.
- The young people often had concerns about group work at the Willow with other young people.
- There was broad agreement about the Willow's service gaps. These are – the regularity of service, the length of time spent with the young people, and contact with families.

Culturally appropriate provision

- There was no agreement on what developments might be culturally appropriate to the service. Some respondents felt increasing the ethnic diversity of the workforce would be beneficial; others were not supportive of this.
- Ethnicity was not considered an issue in relation to respondent's involvement with the Willow by either parents or young people.

- The idea of having a group for BME young carers was not seen as important or relevant to most young people and their parents. With the exception of one respondent, this was seen as restrictive.

Recognition by professionals

- There was a low response rate by professionals to the questionnaire.
- Professionals had experienced some reluctance from BME families to 'outside' help and considered BME young people may be more likely to have a high level of responsibility because of their cultural obligations to their family.

SECTION 1: INTRODUCTION

The Willow Young Carers Service is a partnership between Barnardo's and Leeds Social Service Department and was set up in February 1994. It aims to support young people aged 5-17 years old who are close to someone with a mental health problem, serious illness or disability.

The Willow has recently increased its efforts to meet the needs of young carers from Black and minority ethnic families, including appointing 2 new workers to increase the involvement of minority ethnic communities with the service. This is due in part to an awareness that Black and minority ethnic young carers appear to be less likely to successfully engage with the Willow than other service users. The service therefore wished to evaluate the extent to which it meets the needs of young carers from black and ethnic minority communities, and to gain a greater understanding of how caring is perceived in different cultural contexts.

Service aims and objectives

The purpose of the service is to provide support to young carers and improve their quality of life. It offers young people:

- Support in getting practical help
- Opportunities for going out and having fun
- Group work activities to meet with other young people in similar situations.
- Befriending support
- Support to help better understand what is happening to the person cared for.

Purpose and outline of research

This research was conducted by Helen Mills of Barnardo's Policy, Research and Influencing Unit between February and August 2003. The aim of the research was to assess how caring is understood by black and minority ethnic (BME) groups and how the Willow can be appropriate to their needs. The following research questions formed the focus of the evaluation:

- How is the nature of caring perceived by different ethnic groups and what impact does this have on young carers?
- To what extent is the role of young carers from BME families recognised by professionals working with their families?
- What are the support needs of BME young carers?
- Are these support needs necessarily different from white young carers?
- To what extent is the current service provided by the Willow appropriate to BME families' needs?
- What developments might it be appropriate for the Willow to consider to more effectively meet the needs of BME young carers? In particular, would it be appropriate to have a separate group for BME young carers?

Explanation of terms used

The term **BME** has been used throughout this report. The Willow's definition of BME with is anyone of non- White British origin. This is not to suggest that all BME young carers and their families are a homogenous group or that the same considerations are applicable to all BME service users. Furthermore, this definition is not necessarily the young person's own, the ethnicity of the young carer is as defined by the service.

The term **young carer** has also been used to describe the young people consulted as part of this research. Again, this is the definition recognised by the service and is not necessarily the young person's own definition. The definition the Willow works with is; "a young carer is someone who is affected by, or helps support, a member of the family who is physically ill, physically disabled or who has a mental health problem."

Methodology

Literature review

- The main focus of the literature review was to investigate the current experience of BME families in which there is a care recipient and to gather evidence of good practice with BME young carers.
- As very few studies were found that specifically focused on BME young carers, a range of literature was also reviewed on BME service users, and BME carers.

Consultation with young people

- In April 2003 a focus group with BME young carers was carried out at a residential organised by the Willow.
- All current and past BME Willow service users and their families were invited to be interviewed.
- BME young people and their families who had been referred to the Willow but had not engaged with the service were also contacted to take part.
- Subsequently 8 families were involved with the research and 11 young people were interviewed.
- The interviews took place in the young people's homes, usually with a parent present.¹

Consultation with parents

- Parents were contacted at the same time as the young people.
- In total eight parents were interviewed.

Consultation with professionals

- A short questionnaire was sent to 47 statutory and voluntary organisations in Leeds who were known to the Willow, including health, education and social services.
- In total 10 questionnaires were returned, providing a response rate of 21%.

¹ See appendix 1 for interview schedule.

SECTION 2: LITERATURE REVIEW

Ethnicity and caring

Ethnicity

Key Issue: There is a lack of research about BME families generally. The differences between BME young carers and white young carers should not be taken for granted or simply assumed as they may not always exist. Other factors may impact more on the young person's caring role, particularly the amount of support available to the young person. However, BME young carers are more likely to be socially excluded than white young carers.

There is very little 'hard' information about BME groups. This is partly because of a lack of research in this area. No relevant research was found on family relationships and obligations for BME communities, including those where caring was taking place.² However, it was also recognised across the literature that definitive statements about BME families and their needs are impossible to make. Rather, it is considered that the needs of BME young people must always be carefully assessed on an individual basis.ⁱ

Following this, ethnicity may not always be the 'key' to understanding BME young carer's experiences. The literature shows:

- No evidence that a caring role a BME young person undertakes is necessarily different from that of a white young carer. Indeed some research suggests there may be more differences between the views of BME young carers and their parents, than between BME and white young carers.ⁱⁱ
- Other factors may impact more on the caring role undertaken. Ethnicity may not always be the central way to make sense of the young carer's experience.ⁱⁱⁱ

While factors such as ethnicity, gender or family structure influence the young carer's role, particularly in terms of moral identities and obligations, this was not considered to be the most important consideration:

"It is the ability or lack of external support services, coupled with the adequacy or otherwise of a families financial resources, that are the most important determinants of whether or not a child will become a carer and what tasks they will have to do."^{iv}

However, while not underestimating the common problems that all young carer's may face^v, it is well documented that BME young carers are generally found to be in greater need than their white equivalents.^{vi vii}

The key issues are:

- Discrimination
"The experience of Black young carers needs to be understood within the wider context of discrimination for BME families in general."^{viii}

² There is a forthcoming Barnardo's publication which may address some of the issues around cultural understandings of caring. 'Inter-generational Obligations in Pakistani Families.' Due to be published June 2004.

- Lack of resources

This includes an increased likelihood of social isolation, emotional anxiety, and difficulties at school, putting them at an exacerbated risk of ‘multiple adversity.’^{xix}

- Lack of external support services

BME young carers are less likely to be successfully engaged with relevant services than white young carers. ^x

Caring identity

Most young carers do not identify with the term ‘young carer’. This is likely to be even more the case for BME young people, particularly for males.

The term ‘young carer’ is perceived negatively by young people generally and therefore tended to be disassociated from. ^{xi} One study suggests that it was understood by the young people as making them different from others their age, and a ‘do gooder’ or ‘martyr’. They also saw their role within the family as more positive than the term ‘carer’ would suggest. ^{xii} For many young carers their responsibilities were seen as inseparable from feeling part of a loving and caring family. ^{xiii} As well as making them feel different, young people also felt the term carer did not affect the services they received. ^{xiv} The stigma attached to caring was found to be particularly prevalent amongst BME young people, and even more problematic for boys. ^{xv} This was identified as a difficulty in the research carried out by Hammersmith and Fulham Borough Council, as no males completed the questionnaire sent to them. ^{xvi} It was concluded this was because a caring role is still stigmatised as a female one, hence they did not identify with it.

Engagement with services

BME families’ hardships are believed to be under recorded. There is likely to be a considerable deficit between the level of need and the take up of services for BME young carers. This is believed to be because of service barriers to BME families involvement, e.g. mainstream services not having links with local BME organisations, and the reluctance of BME families to access services.

Service barriers

The main service barriers to BME families’ involvement are considered to be:

- Agencies not providing service information in appropriate languages.
- Individual and institutional racism (both overt and covert)
- Language barriers between service users and providers.
- Geographical isolation of the service from BME community. ^{xvii}
- Services failing to build links with BME communities and local organisations. ^{xviii}

The literature identified a lack of general awareness amongst some professionals about both caring and ethnicity. A number of cultural myths about BME families were

recognised as impacting on professionals' interaction with such families.^{xix} The most common assumption was that BME families were always able/ want to 'look after their own'. Similarly, the availability of extended family and community support was also found to be frequently over emphasised by support agencies, often without any real evidence.^{xx}

The literature questions the validity of this approach, with evidence it both acts to rationalise what was often inadequate provision, as well as making BME young carers feel guilty if they felt uncomfortable/unhappy in their caring role.^{xxi} Such cultural stereotypes were found to be particularly prevalent when professionals were dealing with South East Asian families:

“young carers in South Asian communities are all too frequently trapped in isolation, ...left to fend for themselves and the person they are caring for in the name of cultural sensitivity.”^{xxii}

Although the family and the local community are sometimes a preferred means of support for some BME young carers and their families, this is not always practical. The literature suggests that it is not correct to assume that a large family means sufficient support is available.^{xxiii} Atkins and Rollings in their research with Asian and Afro-Caribbean families found the main responsibility for caring usually fell on one member of the immediate family.^{xxiv} Qureshi, Berridge and Wenwan similarly found the extended family may not live close to the young person and therefore they may not be able to provide substantial support.^{xxv} In addition, stigma was still attached to certain health problems in some communities, resulting in families receiving little support from their relatives, particularly in the case of mental health problems.^{xxvi}

Consequently, many BME young people interviewed in Atkins' and Rollings research felt they were stereotyped by services and assumptions made as to what their role as a carer should be according to their ethnicity.^{xxvii} The young carers interviewed felt services assumed they were willing and happy to care for a member of their family as part of their “family responsibility”.^{xxviii} Across the literature it was recognised that BME families were more likely to be perceived as ‘coping’ by agencies, resulting in the caring responsibilities of BME young people being “largely made invisible to agencies, but essential to maintaining family life.”^{xxix}

BME families' perception of services

The identification of BME young carers is not just impeded by professionals believing that their caring role is in keeping with their cultural practices. BME young carers are typically a harder to reach group than their white counterparts. Again some generic issues were identified as influencing BME families' decision not to engage with a service:

- They are more likely to lack knowledge about the services available.^{xxx}
- They may have less faith in an organisation's ability to deliver a culturally appropriate service, including respecting their religious beliefs.^{xxxi}

A number of issues were also found to be particularly prevalent barriers to BME families accessing a young carer's service:

- Parental fears of being judged ‘a bad parent’ by service. ^{xxxii}
- Young person’s fear of being taken away from their family. ^{xxxiii}
- Parents not recognising the caring responsibilities children may have, rather consider them part of ‘normal’ family role. ^{xxxiv}
- Families not wanting to have ‘outsider’ involvement. ^{xxxv}

Jones found that Black young people were more likely to be involved in inadequately supported caring arrangements than other young carers due to an increased value placed on family obligation:

“Black people are custom-bound to act as carers in the family and find it difficult to ask for help. They feel it’s their problem and they should tackle it alone.” ^{xxxvi}

Some BME families’ attitude to services and caring are recognised as ‘hiding’ BME young peoples caring responsibilities. ^{xxxvii} BME parents did not want their children to be seen as ‘in need’ as this made the assumption their parenting was inadequate. ^{xxxviii} Families also worried projects would encourage the young person to do less caring and so disengage from the family unit. ^{xxxix} It is suggested this tension is particularly prevalent amongst immigrant families, as there may be an increased pressure to maintain the stability and the values of their own community.^{xl} Similarly Ellahi and Hatfield’s research with Asian families found they would be reluctant to access a service if they did not know of any other Asian families using it as they would feel like ‘outsiders’. ^{xli}

Overcoming barriers

The literature suggests the key to successful engagement of BME families is allaying fears that the service will have a negative impact on the family. One way this can potentially be done is through improving links with the local BME community. For example, Barnardo’s ‘Care Free’ Young Carer service in Leicester encountered problems identifying young Asian carers. This was rectified by the service joining forces with a local Asian voluntary organisation, which was the main source of support for Asian families in the area. ^{xlii} Similarly, the referral rate of black young carers in Southwark increased when training was given to local black voluntary organisations. Other suggestions for appropriate links to BME families include community shops, mosques, temples, churches, community centres, libraries and GP surgeries. This was seen important because it gave confidence to those families using the service that their culture would be understood and valued. ^{xliii}

Appropriate support and services to BME families

There is a gap in current provision for BME young carers. Providing a culturally appropriate service varies greatly between different BME groups, but support is considered most appropriate when it is focus on the individual and is non-stigmatising. Specific issues which may be more likely to arise for BME young carers are linked to financial hardship and having a wider range of caring responsibilities than white young carers.

As well as barriers to accessing services there is a recognised gap in current service provision specifically for BME young carers.^{xliv} There is also a lack of research about services which support BME young people and their families. This dearth may have resulted in an over-reliance by service providers on unfounded assumptions about BME families' lives^{xlv}

A key issue was that mainstream services do not take adequate note of racial identity.^{xlvi} The National Black Care Workers Network have produced a good practice guide for providing culturally appropriate services.^{xlvii} They believe that support should always be focused to an individual's needs and lifestyle, rather than on cultural assumptions. It recommends projects should:

- Train workers to respond to the cultural diversity of Black service users
- Collect accurate information regarding the people that access the service, including religion, spirituality, gender and disability.
- Respect specific spiritual and cultural requirements.
- Allow users flexibility and choice of engagement.
- Record carers' needs and desired action outcomes.
- Educate the BME community about caring.
- Listen to the views of BME carers and incorporate them.

Hatton found that the following developments to services were rated as the most important by the South Asian carers he interviewed:

- Receiving information about services in appropriate languages and formats. (80%)
- Increasing the number of South Asian staff throughout services. (65%)
- Improving the cultural appropriateness of services, such as recognising appropriate diet, activities and same-sex workers for women. (48%)
- Establishing a specific support network for South Asian carers. (24%)^{xlviii}

Having a diverse ethnic workforce was a common suggestion across the literature to encourage BME groups to access services.^{xlix} However, Qureshi, Berridge and Wenwan found the idea of 'ethnic matching' users and providers more complicated than it first appears. In their research many South Asian families expressed a preference for white, male social workers.ⁱ

The provision of a culturally sensitive service may relate to the provision of appropriate food but must also include organisational changes if this is not just to be tokenism.ⁱⁱ Vernon's research of community care for Asian disabled people emphasises the need for services to be flexible, equal and have transparent, non-discriminatory decision making. The most important way for a service to be appropriate to all users was therefore through consultation.ⁱⁱⁱ

Issues for BME young carers

The literature suggests that the lack of appropriate services for BME carers can lead to feelings of isolation, forced dependency on family members, frustration, anxiety and distress.^{liii} Silence about caring can have an extremely detrimental effect on the young carer. For example, young black males with caring responsibilities are at a high risk of school exclusion, with schools often being unaware of their caring role.^{liv}

BME families are also more likely than white families to be in financial hardship, often due to a lack of awareness about their rights to benefits and how to access them. As a result possible developments suggested by the Good Practice Guide for working with Black Carers are:

- To have a checklist to ensure the family is receiving advice and is maximising their potential income.
- Be proactive in engaging with other agencies, such as voluntary sector, housing, education and local authority leisure department.
- Be proactive in identifying unmet/inappropriately met need and take responsibly to ensure this is fed into appropriate services
- Engage with available advocacy services.^{lv}

Other specific issues to be aware of are the increased responsibilities some BME young carers may have, such as interpreting for other members of their family. This may be an issue of concern when personal matters are being negotiated by health care professionals.^{lvi}

The idea of balancing the needs (and rights) of young carers, their parents, and their families is acknowledged as a particularly difficult problem in the case of BME young carers.^{lvii} There may be cultural barriers to the young people using the service. For example, Asian young women may be unable to participate in a mixed sex youth group setting.^{lviii} There was also a recognised tendency for some families to only see a young person's caring role in positive terms, and not to recognise any negative impact it may be having on them.^{lix} The literature recommends services find out about the lives of families and their approach to parenting.^{lx}

Example of a Black Young Carer service: The Bibini Centre in Manchester.

The Bibini centre was established specifically for Black young carers. The following practices were seen as helpful by service users:

- It was a safe space where young people were not subjected to racism
- It took into account the diverse communities and lifestyles encompassed in the broad category 'black'.
- Workers and peers had insight into young people's experiences and didn't judge them.
- There were opportunities for young people to develop their own sense of cultural identity and have their cultural identity affirmed.
- It provided diverse and flexible services around each family's particular circumstances and in the young person's own context.

- Family members were supported to understand pressures on young people and the whole family.
- Inclusive definitions enabled children with diverse care responsibilities and ages to access services
- Services were provided to strengthen and celebrate relationships between parents and the young people, not undermine them. ^{lxi}

*For a list of the literature consulted, please see bibliography page 40 - 41.
The endnotes are listed on pages 42-43*

SECTION 3: RESEARCH FINDINGS
Profile of Interviewees

Sex (F/M)	Age (years)	Ethnicity	Engagement With Willow	Family Circumstances SFH =Single female household TPH = Two Parent House	Siblings	Care Recipient and Nature of Health Problem.
F	11	British, Jamaican Parents.	Yes, since Nov 2002	SFH Mother Interviewed	0	Mother Thyroid problem and depression
F	17	British, Jamaican Parents.	No involvement	SFH	1	Elder sister Schizophrenia
F	12	British, Black Parents.	Yes, for about a year	SFH Mother Interviewed	0	Mother Depression
F	14	Dual Heritage British. (Asian/ White British)	Yes, since Oct 2002	TPH Both parents interviewed	1	Mother Schizophrenia
F	15	Asian	Yes, for three months	TPH Mother Interviewed	4*	Mother Depression
M	10	Asian	Yes, since Oct 2002	SFH Mother Interviewed	0	Mother Asthma and panic attacks
F	10	Dual heritage. British, (Black/White British)	Yes, for about two years	SFH Mother interviewed	0	Mother Arthritis

* The 4 female siblings were also interviewed (aged 8- 14 years old)

- Religion was not specifically asked about during the interview, although two families were of Muslim faith.
- All the young people interviewed spoke English, although in two families Urdu was the parent's first language
- In addition just the mother was interviewed in one family. Her daughter was dual heritage (Chinese/ English) and she suffered from depression.

Research Limitations

It is only possible to draw tentative conclusions from such a small sample of families. The issues identified by the respondents are not suggested to be unique to BME young carers nor necessarily due to ethnicity or indeed to caring.

It is appropriate at this stage to draw attention to the nature of research group and the possible reasons which can be suggested for this.

- Only one male was interviewed.

This could be linked to the suggestion in the literature that 'caring' is still seen as a female activity; hence the caring role of male young people may be hidden. In one family interviewed both the son and daughter had been referred to the Willow. However, only the daughter had engaged with the service long-term and wished to be involved with the research.

- The high proportion of mental health related problems.

In all but one of the families interviewed, the care recipient suffered from mental health problems. It could be argued this is a strongest common link between the families interviewed rather than their more diverse BME backgrounds. This has clearly affected the needs and issues identified by these young carers and their families.

- The majority of families were British

With the exception of two young people, all of those interviewed were British. Most did not consider themselves as belonging to a minority and did not have a strongly developed BME identity. This may suggest there is significant group of BME young people who are not British that are failing to engage with the Willow.

- Only one of the interviewees had not engaged with the Willow.

Consequently the extent to which the findings can be applied to BME young people who are not in contact with service is not known.

SECTION 4: THE VIEWS OF RESPONDENTS

Perceptions of caring responsibilities

Young people's view of caring

The young people interviewed generally did not have a strong identification with the idea of being a young carer. Before engaging with the Willow the young people tended to have very little understanding about caring, beyond having heard of the term:

“Not really. I just thought I’ve just got to do this, it’s just a job.” (Young Person)

“I was never a carer cos it didn’t really change the things I did; I just had a few problems to deal with.” (Young Person, never engaged with the Willow.)

Amongst the young people spoken to the idea of being a young carer was a relatively new concept and therefore was not the principle way most young people would choose to describe their role or responsibilities. The young people considered their responsibilities as unique and normal to their experience:

Interviewer – “And did you think of yourself as a carer before you heard of the willow?”

Young Person – “No, I don’t even think of myself as that now.”

Interviewer – “How do you see yourself?”

Young Person – “Just normal (laughs.)”

Only one young person considered herself as a young carer and was able to explain why they thought this. The majority of young people were either unable to recognise the caring responsibilities they had without the assistance of their parents, or did not have the language to explain the things they did. Instead, the young people’s description of their responsibilities tended to be focused on small scale, routine tasks:

“Cleaning, helped me mum out of the bath... Oh yeah cooking sometimes... Oh yeah coffee, tea (sighs)...” (Young Person)

While the majority of young people spoke of finding their caring responsibilities sometimes tiring, they were not necessarily seen negatively:

“...it’s alright that she’s ill cos then I’ve learnt how to cope with it. And then when I’m older I’ll be able to support people and stuff and it’s helped me change my mind about my career and stuff like that.” (Young Person)

Parents View of Young Person Caring

The Parents were more likely to recognise the wide range of tasks that the young people did and to consider them as caring responsibilities, as the following exchange between a young person and their parent shows:

Father - "She says she's not but she is a carer, she doesn't do shopping or housework and things like that... but what she is very aware of is whether her mum has taken her medication. And if, like yesterday I was having a rough day and she followed me round and asked me if I'd like to listen to some music. Now that's caring. So she's aware of people's moods and she is a carer."

Young Person - "I think I've always done that."

Father - "Yeah you probably have, it still makes you a carer even though you don't think of yourself as one. I never think of myself as a carer I think of myself as a husband and a father, but that doesn't mean that you're not a carer. But it's something you don't see yourself as, you see yourself as something else."

The parents did not take these responsibilities for granted and spoke very proudly about what their children were able to do:

"So she can use the microwave to make the tea or whatever. She nearly does it all." (Parent)

How others view caring

The young people did not seem to speak directly about their caring role to many people. Whilst there was no indication that the young people were trying to hide their caring role, it did not seem something they were comfortable talking about openly. There was no evidence of how widely the young person's caring was really known about beyond their school:

"If I want them to know I'll just tell them if it's something important or whatever but I don't think so no." (Young Person)

"I don't know...A few people, but I'm not sure." (Young Person)

The young people did not raise any specific concerns about professionals knowing about their caring responsibilities. They did not however seem comfortable for other young people to know about their caring responsibilities. The young people did not see why this would be helpful and it was felt other young people would not understand:

"Adults alright, but kids no." (Young Person)

Relationship with school

For all but one of the young people spoken to, school had some knowledge about their caring role. However, this knowledge tended to be limited and many young people did not see their school as being able to influence or help with their caring:

Interviewer – "Do you think the school knows?"

Young Person – “Maybe not completely... I’m not really bothered if they know. I don’t really care. Well I do care. But I think they take the information and they’re happy with it and that’s it.”

Parent – “I don’t think so no. I’m not sure what effect telling one of the teachers has had.”

Young Person - “I don’t think it’s changed that much. Maybe she might be able to do a tiny bit more, but I don’t want to be singled out of anything like that. At least they know about it I think.”

“Not that many people in school know, like my teachers or anything like that, only my tutor knows... Yeah. It’s hard at home, and then school works hard, and then... My coursework things hard so I suppose (help with that would be good.)” (Young Person)

The school’s recognition of the responsibilities the young carer’s had and their knowledge of the action it is appropriate for them to take also seemed quite limited. While no young person had problems having time off when required, none of the young people spoke of any day-to-day allowances or support at school available for them. The extent of the caring role some for these young people took therefore does not seem to be fully understood by the school:

“Sometimes when I’ve got homework and my mum’s poorly. And then sometimes if I don’t do it, if it’s something about school then I have to do it at playtime... if I don’t go in then my mum writes a letter on the second day but I don’t think they really understand.” (Young Person)

“They could be a little bit more, information, about what they have to do... But I think they could do with someone to tell them a bit more about the carers, because I should imagine some kids find it harder than her.” (Parent)

In the one case where the school was not believed by the parent to be aware of the young person caring the reason given was of the stigma attached to having mental health problems:

“I don’t know, I don’t think I really want them to know about my self-harming.” (Parent)

Caring support needs

Emotional impact of caring

A number of comments from the young people and their parents suggest the emotional impact that living with a family member with an illness has had on the young people:

“I just go completed balmy... Sometimes I do get a bit oh, it’s the end of the world but that’s it really.” (Young Person)

“I wanted someone to come in and see the children because of my illness sometimes I can just shout at the children for no real reason ‘you go upstairs I don’t want to see you.’ I know they get upset but they can’t tell anybody.” (Parent)

Young people also clearly provided a great deal of emotional support to the care recipient:

“When I cry in pain, she cry also... but what I do know now, other people have said to me, is she don’t like to talk about me and when she do she break down and cry... But she’s getting a bit better and better each time.” (Parent)

However the young people spoken to were less likely to recognise this aspect of their caring or be able to express it than their parents were. The young people found it hard to talk about how they felt about the illness their family member had and may not have the space or language to talk about their emotions:

“He gets problems sometimes but he don’t talk about it. He worries but don’t like to talk about it, he getting annoyed and angry.” (Parent)

There was a suggestion that this aspect of caring had made some of the young people introverted and lacking self-confidence:

“I find it hard to say it... is it all right if I don’t say anything? I try and talk to my mum but sometimes I just like to keep it all in... (The Willow’s) a place for young carers to go to when their mum’s ill and that and it really helps you to be stronger... not to be sad that your mum’s ill.” (Young Person)

Some situations the young people had experienced were clearly quite frightening to them, and worried them a great deal:

“I ended up on a life support machine. Well that frightened x to death. So all year now when I go for check-ups, as soon as x knows I’m going to hospital it’s like panic stations you know... she couldn’t cope with that at all.” (Parent)

Many parents felt the Willow had been able to help their child to open up and talk about caring and their parent’s illness:

“I’ve noticed she’d got more open, she’ll talk about her problems, her worries, where as before she was quite withdrawn. She’d sit and talk to you if you asked a question, but she were right shy. But now she’s different again, which is nice to see. She’s got the confidence to talk for herself, which they have pumped into her you know, whatever’s the problem, don’t be afraid to talk to us about it, and she does and she stands up for herself which I’m right happy about. That brought her out definitely.” (Parent)

Parents perceived that being able to talk had increased their child’s self-esteem and confidence. They believed that the Willow had helped young people emotionally and aided their personal development:

“She has changed; she was just a child I couldn’t reach. The way I would put it then, I didn’t know about it, she don’t want to know that I am ill. She wish I was better. She don’t want to talk about it, it hurts her very much... she is a much stronger person. (Parent)

“(Bullying issue was resolved because of) her being more assertive and I put a lot of that down to the effect the Willows have had. Because I couldn’t raise her self esteem... one of the reasons you’ve probably got more friends is because you’re more confident in yourself and I think the willows helped.” (Parent)

Isolation

One of the strongest themes arising in the interviews was being isolated from social activity:

“Sometimes when we want to go out on a weekend we can’t go out places because of the way I’m feeling so we are stuck in here.” (Parent)

A major concern to the parents interviewed was the limited opportunities their children had in general, but particularly in terms of not having many leisure prospects or breaks. A number of reasons for this were raised amongst the families. The most common reason was of parents being restricted due to their illness in terms of the recreational opportunities they could provide. In some cases parents had periods where they were house bound:

“But as far as I go is in the garden...Without Willows there’s nothing for her.” (Parent)

“But when I get like this... I know I get angry with her but I know it must be hard for her as well because I can’t do ‘owt... you know just little things. So it’s good if she goes somewhere like that because, ... I can’t drive or anything.” (Parent)

This restriction was compounded by the often limited networks of support the families had available to them, reducing the young people’s opportunity for breaks from caring:

“Because we used to be in a hostel and I’ve got no family, so he wants to go out more. Cos he don’t got any friends or anything, you know, once he comes home from school. He wants to join boxing or I don’t got a car and because of my financial problems we couldn’t get a taxi everywhere because it’s so expensive. He always says ‘I wanna do this but I can’t afford it and with my health... At least if they, like when the holidays start, they could take him somewhere. He doesn’t have a social life. If I knew he had a social life then I’d be happy.” (Parent)

Support from an extended family either was not available or, in the one case where it was, the relationship was problematic and not considered an option by the mother. She found her local community oppressive:

“I don’t get on with my husband’s family, that’s one of the reasons I’m trying to move out of this area...they don’t understand my illness.” (Parent)

A further issue which influenced the isolation of the majority of the families interviewed was the limited financial resources available to them which reduced the opportunities available to the young people:

“You have to learn to play out, which I find really difficult because if it were a house she would play out more innit?.. she just don’t have the same freedom other children have” (Parent) *The family live in a high rise block of flats*

Even small trips out could be difficult and expensive for some families, as many did not have access to a car and thus were reliant on taxis if there was no public transport available.

The extent of this isolation was acutely felt by one parent who had serious anxieties about what would happen to her son if her health deteriorated. This anxiety was impacting on her wellbeing and increasing her problems with panic attacks:

“I always have in my mind that something serious could happen to me and I don’t have anyone you know. There’s nothing for him. God knows but if something happened to me I don’t know where he’d go so I’m really worried. You never know what’s going to happen. I don’t know who’s going to look after him.” (Parent)

In response to these problems, the young people emphasised the importance of the recreation and leisure aspect of the service:

“I just like going out and doing something different, rather than just being sat in the house... I think the going out part is the best. Not just like –um, I’m going out but it kind of gets me out and not watching TV.” (Young Person)

“I like getting to do new things... I would recommend it to other people that have problems of their own and they just want a break away to relax and clear their mind...Cos it’s helped me with my mum’s illness. Helped me to get away from my mum and have time away.” (Young Person)

Focus Group: What makes a good young carers project?

1. More excitement
2. Play station 2/ X box etc
3. Good information on illnesses
4. People who understand people’s feelings
5. Friendly workers
6. Supportive Workers
7. Less talking, more fun

- | |
|--|
| <ol style="list-style-type: none">8. Group Work9. Hard Work |
|--|

The young people found the opportunity provided by the Willow to try out new things and go to different places the most helpful aspect of the service. The focus group was also asked what a good young carers service should have and, as a group, to rate these in order of preference. The two factors considered the most important by the young people related to recreational facilities and the opportunity for the young people to have a break. The young people also valued the opportunity to meet others in a similar situation and establish their own networks of peer support. Being part of a group appeared to help to reduce the young people's potential feelings of isolation:

“I think it is really good, that you get people out of the house and you give them someone to talk to.” (Young Person)

Similarly parents appreciated the chance the Willow gave for a break which they felt the young people may not be able to have otherwise:

“It used to get me right upset cos she were doing nothing. And erm then like Willow, I saw a big difference in her when she started to go, she were getting out and about and they used to go and do some pottery. She used to love making stuff. And I saw a big difference in her. I mean she were happy but you could see that difference, just that something to look forward to.” (Parent)

Information

There was a recognised need amongst the young people and their parents for more information about the health problems their family member had. The amount of information the young people had about the actual health problem was often poor. In some cases professionals involved with the family had not explained directly to the young person what the problems were:

“I didn't really have much to do with the doctors or other workers. I remember them all coming round and talking about my sister in a room but I wasn't invited in and no one really told me what was going on.” (Young Person)

Many parents were concerned that their child was worried about their condition or had concerns that they were keeping to themselves. Parents feared this was effecting their child's wellbeing, and in one case damaging their relationship with them:

“It would be nice for someone to talk to x about sort of, problems we're having, me self-harming and that. It would be nice to have someone to help her understand it and try and tell her it's not her fault, she's not why I do it. Cos that's what she thinks, I think... And someone to talk to her and question her about the problems she's having at school. Why she's so angry and frustrated and that, cos there's a reason why and I want someone to get to the bottom of it.” (Parent)

In contrast to other services, parents viewed the information provided by the Willow for young people as accessible and useful. This was particularly felt in the case of mental health, as young people may not feel comfortable asking their parent(s) or may be unsure of what to ask:

“They decided (professionals at a care plan meeting) she ought to know the full extent of her mother’s illness and Willows were very helpful... it gives you someone else you can ask questions to, cos some of the questions she felt she wanted to ask us she probably felt she couldn’t cos it’s not the sort of thing you say, ‘oh mum you’ve got schizophrenia, tell me all about it?’ it doesn’t quite work like that.” (Parent)

Bullying

It was clear from the interviews that a key issue for the young people was bullying. The majority of bullying incidents took place in school, with one situation relating to problems in the neighbourhood:

“It’s like I need to move from here because they kicked him two or three times, it’s really bad, the other children are really bad, so racist.” (Parent)

Bullying is a problem for many young people. However for the young people interviewed it was often linked to ethnicity. Another issue raised was of low self-confidence amongst the young people:

“It wasn’t so much she was a carer it was more to do with finding some strategies for her to cope as she has had some bullying and racial comments...I’ve been trying to raise her self-esteem so she wouldn’t react and those strategies haven’t worked. And (name of CPN) said willows because they might have other strategies and it may be someone else telling her the same things you’re telling her but it may help coming from someone else.” (Parent)

It was felt the Willow had positively impacted on this situation by increasing the young person’s self-esteem and in another case it was clear the young person had benefited from another source of outside intervention:

“Cos at one time we were having problems with bullying at school. There was a white lad... The times I’d phoned schools and sent notes into school. And one of the girls got this Indian girl to come out. And she were all for this racist thing and bullying and stuff like that... See they could come into willow with problems like that, and there’s nobody there for her for that is there?” (Parent)

Basic Needs

A number of families required help with fulfilling basic needs or obtaining services. The main problem in the majority of cases was financial hardship. Families had specific difficulties gaining support with:

- Having holidays
- Acquiring appropriate accommodation
- Obtaining appliances and furniture
- Getting transport to school/ place of worship
- Dealing with household bills

For some of the families spoken to, the level of needs appeared to be high. In two cases this was exacerbated by the fact that English was not the first language of the parent(s) and as a result these families were unfamiliar with what services were available to them. This was clearly causing great distress to those concerned and impacting on the parent's ability to cope, as the following extended quotes show:

“It's like I need to move from here ... so at least he can start at the Mosque. So (Willow worker) is helping with the housing, filling the forms and I have problems with washing machine. So I don't know if (Willow worker) is getting me or not. But (Willow worker) is trying to help me out...I need to arrange a transport so he can go to Mosque everyday. If they could arrange the transport it would be really good you know. He's getting older now, and I want him to learn about religion. So if we can move then there's no need for transport, at least he can go on his own... the social worker, she said they can't afford to give me two transports to mosque, (she) says its been a long time now for transport to school so maybe we stop the transport now cos there is other people. So I'm really worried if they stop the transport from school so I don't know what's going to happen. Because I can't walk` ... I can't afford to get a taxi, so I don't know if it's going to stop after the holidays. That's the thing I'm not sure what's going to happen.” (Parent)

“The holidays, the computer, all these things they ask me and I just can't you know. So any service, anybody who can help cos I feel like a bad mother sometimes because I can't...Housing needs, nobody can help me with that. I cannot afford to pay bills. I was sent a gas bill for around £50. I couldn't pay and didn't know what to do so I just left it and then I got a bill for over £300. I don't know what to do. I've tried ringing them up. We don't use the gas anyway. I never know what to do when we get a bill in. I just read them, put them to one side and then keep going back to them and reading them again... panicking.” (Parent)

A number of parents were not receiving any assistance and were clearly not aware of the help the Willow could provide. One family had benefited a great deal from the assistance the Willow had given to them; however they had only become aware of this aspect of the service by chance:

“I know Willow have helped us out with a holiday, two holidays, which you know I couldn't afford cos I'm on income support and everything. They've also helped us with furniture and that. I were worried you know. And it were just a matter of chance, I just mentioned it, and they said 'oh yeah, we can help with that.' Which I didn't know of course.” (Parent)

In some instances with the families who were receiving help from the Willow, the level of support they were being given was not meeting their needs. However parents acknowledged the efforts made by individual workers:

“She works so hard for us so I sometimes think maybe something’s not on her hands. Because sometimes she can’t do anything. Like she doesn’t have a bed frame just a mattress and she wait for weeks and she tried to get her a furniture grant. She got something but it was very old and smelly. These things sometimes are just making you feel worse... I see she is trying all the time, like she said about the holiday, She’ll try hopefully to get something for the children. And she is helping you know sometimes these things bother you more. When I go upstairs and see where she sleeps I just I feel like a bad mother. This has been going on for maybe 6 months now. I can’t...” (Parent)

“(Willow worker’s name) said she was going to support us with holidays, because we haven’t been on holiday for over six years now, so she said that she were going to give us some funds, but she hasn’t done and most of the holidays are going to have gone by the time..... She hasn’t really explained.” (Young Person)

Appropriateness of current service

Referral process

Referred by	Number of families interviewed referred
Hostel Worker	1
Mental Health Services	3
Social Worker/ family Service Unit	3
Not known	1

From the small number of families interviewed, the majority of referrals came from two sources, through the mental health service the parent was engaged with, or through social services.

Urdu was the first language in two households. Whilst this did not represent any problems for the young people, neither received any information from the Willow in their first language. One parent explained they had been able to understand most of what the Willow was offering, but they were not as confident that they would be able to understand spoken English in a face-to-face visit by the worker.

First impressions and hopes about the Willow

Most of the young people had quite ambivalent first impressions of the Willow. They were prepared to try it, but many were unsure what they expected it to be like:

“I thought oh.. yeah right ok... I wasn't actually that bothered about it I just thought I'd give it a go.” (Young person)

The major barrier described by the young people to wanting to engage with the service was not linked to any specific cultural considerations. Their main concern was of not knowing the other young people there and worries about how they would get on with them:

“I thought it would be alright, check it out and stuff and I found it good... (I was worried) people, who would be there, other children, wouldn't like me.” (Young Person)

“She break down crying. Sometimes I've had to really push her, but in the end I don't need to push her.” (Parent)

The young person interviewed who chose not to engage with the Willow did so because they believed the service was not relevant to them:

“I didn't really give it much thought. I did plan to go but then I forgot about it.” (Young Person)

Although this young person's sibling's mental health problems began when they were 8 years old, they were not referred to the Willow until their late teens. While no conclusions can be drawn from an isolated case, it may suggest that the need for support for young people whose siblings have health problems may not be as recognised by professions compared with a parent.

While unsure about specifically what they wanted, for the majority of young people the Willow was seen as exciting; providing a break or something different for them to do which they could look forward to. Similarly parents often did not know what to expect from a young carers service nor did they consider caring necessarily the central problem in need of support:

“We wasn't sure first what this is about. She told us she was going to come every fortnight to take him out for an hour.” (Parent)

“It's just a support, I mean originally when we got involved the first time it wasn't that we thought they actually needed anything in particular we just weren't sure if we were giving them everything that they needed...It wasn't so much x was a carer.” (Parent)

Views of service

Once involved with the Willow, all of the young people and parents valued the service provided:

Young Person – “I think it's ...wonderful... the best... Because I get a break from my mum and they take me out but they also help me to understand what my mum's illness is. Learn more and understand more about it.”

Interviewer - "So what would you say to someone who said that they were shy and they didn't want to go along (to the Willow)?"

Young Person – "I would try and encourage them and tell them how I feel about going and what you do there and hopefully that might bring up their hopes a little bit more."

Most parents were very happy with the Willow's involvement with their family. They viewed the service as supportive and of benefit to their families:

"It seems alright if its somewhere where x can go and have some time out, and when she can't talk to me." (Parent)

The experiences the young people had not liked all related to group work. The problems raised here suggest the importance of:

- The appropriateness of the group.
- The young people being taken seriously and the workers responding appropriately to conflict within groups.

"The first group that I went to, which I don't go to now. Err, they were always talking about committing suicide and stuff like that, and they had cuts and stuff like that, so I stopped going to that group. And when I spoke to (Willow worker) the next week, she said we got another group starting next week, do you want to go to that? So I said I'll come and if I don't like it I'll leave. I went but it's alright though." (Young Person)

"Um. Someone hit me and I told them and they never said ought." (Young Person)

Exploring ideas for culturally appropriate provision

Young people's interpretation of ethnic identity

The concept of ethnicity was not clear cut for the young people spoken to. The idea of being BME was not something the young people could relate to, it was either something that they had not considered or something they perceived negatively as being seen to be different:

"I've never really thought about it." (Young Person)

"I can tell you now... she didn't want people to know he was Chinese (X's father). She's ashamed of it. She doesn't even like her surname; she changes it to my old name... She's classed as white to her." (Parent)

The young people interviewed often related to a number of different ethnic backgrounds:

"I am mixed. My Great granddad was white." (Young Person)

The majority of young people did not recognise any aspect of their experience as culturally defined and did not consider their experience and needs in anyway different because of their ethnicity. However, some respondents recognised this could be an issue for others:

“I’ve not thought about it... but this girl, this Asian girl, at the Willow, she were there for a few times, but no one really played with her, so she didn’t go any more.” (Young Person)

Cultural appropriateness of current service

None of the parents spoken to had concerns about the cultural appropriateness of the Willow to their families. All the families seemed happy with the level of knowledge and understanding the Willow currently have about cultural issues which may affect their families:

Parent – “They’re more aware of it now, food, hair, stuff.

Interviewer – “You’ve never found it a problem for you?”

Parent – “With the willow? No.”

“No, they have... (Willows worker) knows it all already, she’s part of the group that I go to and she always does things there.” (Young Person)

While at first ethnicity was not an issue for the young people, on further exploration some suggested the Willow would benefit from a more ethnically diverse team of staff. It was felt that some people may be more comfortable working with someone from a similar background to themselves, as they would understand and have empathy with the issues which may arise for them:

“I wouldn’t have minded working with a black or white workers... but I know some people who would be... a bit funny, you know about who they went to, like some people would only want someone the same as them.” (Young Person)

“Maybe have a worker there who’s maybe mixed race or black and for a black child or you know the white workers and say ‘I want to have a talk about this’. And if they think it’s something to do with a black person’s problem, maybe or whatever, then there is always a black person there they can talk to. I don’t know.. er I think if there’s a person there that understands.” (Parent)

However, in one case the parent specifically did not want service providers to come from the same ethnic background as her. This was based on previous negative experiences when personal information was spread quickly throughout the tight knit Asian community in her area, resulting in her not trusting Asian workers to maintain confidentiality. She also refuses to work with male Asian workers as she feels the judgements they have made about her have affected the service she has received in the past. This highlights the importance of not stereotyping or making assumptions on the basis of culture and trying to meet needs on an individual basis.

Views of having a separate BME group at the Willow

The idea of having a group for BME young carers was not something the young people interviewed felt strongly about. None of the young people recognised their ethnicity as an issue nor was ethnicity seen as a priority for group work:

“It wouldn’t bother me no... No cos my groups mixed race anyway.”
(Young Person)

“Not bothered... Well I’d like more people that are my colour to come, and more people that are white to come.” (Young Person)

The young people interviewed were uncomfortable with a division being made between BME and white individuals:

“No I think everyone’s just the same, no one should be racist or anything... We are not aliens, you know, one’s aliens and one’s human... I don’t think it affects me at all (race) I don’t mind working with black people or white people or whatever colour they are, if they are purple, green or that colour (points to something)... I like hanging out with them (White friends).”
(Young Person)

In general, the young people saw singling out ethnicity as negative and discriminating in itself. It was seen as stigmatising and there was concern amongst some BME young people that this would be defining them as ‘different’ from white young carers. No young person suggested they would feel more comfortable in a group of young people just from their own background. On this basis young people did not want a group exclusively for BME young people. It was seen as restrictive and that it removed their freedom to choose which group they wanted to be part of:

“I don’t think it should be like that... Everyone should be able to do what they want... I’m not bothered what race would be there.” (Young Person)

Similarly to the young people, the majority of parents believed the creation of a specific BME group to be unnecessary:

“Well I don’t think they should. I think it would be far better for a child, no matter what colour to mix... Cos if it’s separated into black groups and white groups and what have you, you know people do that in the world, they think black is... they keep away. It’s hard really... When I’ve gone there’s been quite a few black children and mixed race, and they’ve all got on... And I think if it’s made into one black group and one white group it will spoil it.”
(Parent)

One Asian parent did favour her son attending a group for young people from the same ethnic background. She felt her son would be more comfortable with those from a similar background and the workers would understand her son more and be better aware of his needs.

Views of Professionals

Response

Despite efforts being made to contact professionals, there was a very low response rate to the questionnaire. This has impacted on the ability to draw findings from professionals in this piece of work.

- Only ten replies were received from professionals known to the Willow.
- Four respondents had each referred one BME family to the Willow.
- Only two respondents had referred two or more young people to the service.
- No professionals that worked specifically with BME young people responded to the questionnaire.

Whilst the majority of respondents believed there was likely to be specific considerations for BME families and a young carer's service, only two respondents felt they had significant experience to be able to comment on this matter. Again this may suggest there is a significant lack of awareness and gap in knowledge amongst professional as to:

- The identification of young carers generally.
- Cultural awareness in working with BME families and the issue of caring.
- The service offered by the Willow and when referrals may be appropriate.

The following issues are based on the comments of two professionals.

Reluctance

Both professionals had experienced reluctance from the BME families to take up available services. Cultural considerations were judged as playing some part in this, it was felt the families were reluctant to seek help from 'outsiders' and accepting support from such sources may not be a cultural norm for some. Two other factors were also considered key in understanding families' reluctance to involvement:

1. The nature of their parent's condition (particularly of wanting to keep mental health problems 'under wraps'.)
2. The young person's perception of themselves as normal and so not in need of help.

Greater responsibilities

From their experience with black families, one practitioner felt that the eldest daughter in black families may be expected to take on a lot more responsibility than that typical of other young people their age. Another practitioner acknowledged the often false assumption made by some professionals that Black and Asian families want or are able to do everything themselves, and that this could result in these families often receiving inadequate support.

SECTION 5: CONCLUSIONS

Nothing that has arisen in the course of this research suggests BME young carer's needs are necessarily different from white young carer's. The core services recognised by this group are largely the same as the ethos and support currently available at the Willow. It would be misguided to suggest specific changes to the service the Willow provides to make it culturally appropriate to all. However, some possible considerations for working with BME young carer's are that they may be:

- More likely to be socially isolated (particularly if English is not the family's first language.)
- In situations of a high level of need.
- More susceptible to bullying.
- Less likely to have their caring responsibilities readily identified by agencies.

The need for the Willow not to over assume the importance of ethnicity to all BME young carers was also raised in this research. To develop specific services for BME young carer's was certainly not relevant to the Willow's current service users we spoke to. However, based on this research it is likely there is an unmet need for support amongst the hardest to reach BME young carers. The following groups were identified as likely to be under referred to the Willow:

- Male BME young people
- Those for whom English is not a first language
- Those who have been caring for a long time.
- Those who care for siblings
- Those from South-Asian backgrounds

SECTION 6: RECOMMENDATIONS

The Willow is clearly providing a valuable support service to some BME young carers. What follows are recommendations for service development in this area. This includes recommendations from young people and their families, professionals, and those that have been drawn from this research.

1. To increase the accessibility and take up of the service by BME families the Willow could:

➔ Hold an information sharing day/ workshop for professionals to increase knowledge about BME young people's caring responsibilities and challenge possible cultural assumptions about BME families.

➔ Attend events such as Carnival and the Mela as well as visiting centres such as the Bangladeshi, Shantana, and Vietnamese community services to increase awareness amongst the local BME community about young carers.

➔ Build specific links with education staff which was found to be an area particularly in need of address.

➔ Develop service information in appropriate languages for those for whom English is not the first language, such as in Urdu.

➔ Produce a 'jargon busting' leaflet for those referred to the service with the input of current service users to explain their involvement with the Willow.

➔ Emphasize the opportunity for breaks to the families referred, this was the most recognised need amongst BME families.

2. Developments to the service

It is clear the BME families currently engaging with the Willow are benefiting from the support it provides. In particular the Willow should continue:

➔ To offer a space where the young people feel confident in talking and exploring their emotions and home lives.

➔ To provide an opportunity for the young people to have access to leisure facilities which they otherwise may not have. These activities should be as varied and extensive as possible.

➔ To provide information about care recipient's illness, particularly as there may be some myths about condition which may cause young people distress

Where service capacity and resources are willing, the existing service could be developed by considering the following suggestions made by the young people and their families:

➔ Offer more practical support to enable the young person to best cope with caring:

“Right if they could help with like people who like you don't want to let know about your mum, helping to let them know about your mum and how you feel about it.” (Young Person)

➔ Provide support and information in schools:

“I've been thinking of the Willow maybe getting more involved with schools.” (Young Person)

➔ Have more facilities at the centre:

“You know that place we go to? That would be bigger and better (Young Person)

➔ Extend the service at the times when young people may be most isolated, such as the summer holidays and at weekends:

“But I think if Willow’s did something maybe through the school holidays it would be good. Once it week it would be nice. They would have a lot more to look forward to. Even if it’s a run around in the park, you don’t have to spend money really.” (Parent)

➔ Provide resources for the young people to follow their specific hobbies. This may involve researching local facilities, organising transport and accompanying the young person:

“If somebody arrange the transport and take him on a regular basis, a few hours for boxing, karate or sometimes swimming...” (Parent)

➔ In addition to the newsletter currently produced for young people, a newsletter and diary of the forthcoming season’s events/activities could be produced for parents to ensure they are aware of what they can expect from the service:

“Give more details about trips you know things that are going on, outings and that... To keep more in touch... (Willow worker) hasn’t been in touch or left a message. So it’s like, I don’t know what to do cos I’m stuck... I don’t know why. Maybe because she turned it down.” (Parent)

“She told us she was going to come every fortnight to take him out for an hour. Take him out and bring him back. But I think in the middle it just stopped for three or four months... and no one contact us.” (Parent)

The following developments could also be beneficial to meeting the needs of BME carers:

➔ Build on the current group work activities on bullying and consider some strategies for the young people to manage bullying situations.

➔ Ensure there is appropriate signposting and links to advocacy organisations to support families to meet their basic needs and obtaining services, particularly:

- Be proactive in making sure parents are aware of the help which could be provided to them.
- Provide practical assistance to put families in contact with organisations who can provide help.
- Make families aware of the help they can expect to receive
- Offer guidance to families on how to access services and having confidence in asking for assistance.

3. Considerations for a culturally appropriate service

It appears that, for the current users of the Willow, having a separate BME work group would not be appropriate. However possible suggestions made were:

- ➔ To have more BME female workers who speak community languages
- ➔ To have support workers from a variety of cultural backgrounds

→ To develop monitoring tools that record not just ethnicity but also religion, spirituality, and cultural requirements. This way the Willow can be responsive to individual requirements.

Appendix 1

Young People's Interview Schedule

Individual overview

Establish – name, age, gender, ethnicity, who caring for and how long.

Identification

How did you first hear about the Willow?

Prompt – mum/dad GP, social services, school, friends, community group?

What did you first think about getting involved with the Willow?

What did you want to get out of it?

Did you think of yourself as a carer?

Do you think of yourself as a carer now?

Who do you think knows you help your (.....)?

Is there anyone you wouldn't want to know?

Views of Willow

Do you feel listened to and that your views were taken into account at the start?

What do you think of the Willow?

What do you like about it?

Prompt – leisure activities, having someone to talk to, information, time with friends, group activities, practical support

What sort of things have been helpful to you?

Is there anything you would change?

What sort of things would you have liked to have been available but which have not been?

Do the people at the Willow take note of any important matters relating to your race/ culture or religion you might have had?

Attitude/ Relationship to Other Services

Apart from Willow, do you know of any other services (official people) you or your (mum/dad/carer/sibling) uses?

Prompt – social services (any knowledge of having an assessment done), doctor, Home care assistants?

How helpful have you/ your family found them?

Prompt – provided services, visits, help.

Has anything ever stopped you from wanting to get involved with a service?

Prompt – language (if appropriate), not knowing anyone else, being worried, feeling nervous, don't think its necessary?

Is there anything you haven't liked?

Is there something which you think could be improved?

Needs

What kind of things do you do around the house?

How are the things you do different from the things you would do in the family if your (...) wasn't (.....)?

Do you enjoying doing (.....)?

What do you do when you have a problem, or you're finding things difficult?

Do you find it hard to fit everything in?

Who do you ask for help when you need it?

Prompt – family, friends, social services, school, doctors

Is there anyone you wouldn't feel comfortable asking?

Do you talk to your friends much about caring?

Who do you find helps you the most?

How do you think that caring for (.....) affects you?

Prompt – school, friendships, feelings, hobbies, thoughts about future, time to yourself, relationship with (....)

What kind of things would help you right now?

What kind of help would you like?

Prompt – practical, advocacy, emotional, information

Do you feel you and your family have enough support?

How much do you feel your race affects you – generally?

- In regards to the service?

Appendix 2

Parent's Interview Schedule

Identification

How did you first hear about the Willow?
What did you first think?
Prompt – did you think it was relevant to you?
Did you have any concerns/ reluctance?
Did you consider (.....) to be a carer?

Feelings about Willow

What do you think of the service?
Do you think (...) has benefited from getting involved with the Willow?
What aspect of the service do you feel your family has benefited from?
Prompt – Young person having fun and meeting people, practical help, advice
If there was funding available, are there any services or developments at the Willow you would like to see?
Do you think the Willow adequately caters for your families needs?
Is there anything the Willow could do to improve this?
Would you prefer a specialist service/ group for young people from non- white backgrounds who go to the Willow?

Relationship to Other Services

What other agencies are you involved with?
Prompt – social services, Home help, doctors?
How useful have you found these services?
Are there any services you haven't found helpful?
What kinds of support have you been offered by services?
Is there anything that hasn't been offered you feel you would like?
Do you feel services are provided in an appropriate way for your needs?
Is the school aware of (.....) caring role? Are they helpful?
Did they recognise the role of (...) in caring?

Needs

How does (.....) role differ (if at all) from the responsibilities and jobs you would expect them to do in the house if they weren't a carer?
What kind of support would you like your family to have?
Is there anything which concerns you about your child caring for?

Appendix 3. Questionnaire sent to Professionals

Willow Questionnaire
1. How many people have you referred in total to the Willow?
2. How many of these have been from Black or minority ethnic (BME) backgrounds?
3. In your experience, have you noticed any reluctance from BME families generally to take up the Willow or similar services when offered? (compared with white families)
4. How would you explain this difference? (If any?)
5. In your experience, have you recognised any difference between BME young carers' responsibilities and the issues which face them, and white young carers?
6. From your experience, what (if anything) do you think the Willow can introduce to make its service more appropriate to BME young people?
7. Name Organisation Contact Details All responses will be anonymous.

Bibliography

- Arthur, V and Wiffin, J. A Plea to Practitioners. Community Care. 1995
- Atkin, K and Rollings, J. Informal care In Asian and Afro- Caribbean Communities. 1992
- Barnardo's and University of Leeds. A Health Needs Assessment of Black and Minority Ethnic Children's Needs. June 2002
- Black Carers' Manifesto 2000. Available at www.carers.gov.uk/bcm.htm
- Butt, J and Mirza, K. Social Care and Black Communities. 1996. Race Equality Unit
- Craig, G. Must Do Better. Community Care. July 6 2001
- Dearden and Becker, S. Young Carers in the UK. London. Carers National Association. 1998
- Ellahi, R and Hatfield, C. Research into the Needs of Asian Families Caring for Someone with a Mental Handicap. 1992
- Frank, J. Veil of Secrecy. Community Care. June 12, 2000.
- Fulgini, A and Pedersen, S, Family Obligation and the Transition to Young Adulthood. Developmental Psychology vol38, pp856 – 868 2002
- Hatton, C. Informal Carers of Adolescents and Adults with Learning Difficulties from South Asian Communities: Family Circumstances, Service Support and Carer Stress. British Journal of Social Work 28. pp821-837 1998.
- Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families in Which Young People have Caring Responsibilities.
- Katbamna, S. et al. The Needs of Asian Carers: A Selective Literature Review. University of Leicester. 1997
- Mapp, S. No Stigma in Caring. Community Care. 31st May 2000
- Newman, T. Culture, Ethnicity and Care Giving. The Situation of Black and Asian Young Carers. Sachdev, D and van Meeuwen, A. Are We Listening Yet? Working With Minority Ethnic Communities. Barnardo's, pp27- 43. 2002.
- Newman, T. 2003. Children of Disabled Parents. Russell House Publishing
- Reeve, C. Unknown Quantity. Community care. 10 May 2000.
- Qureshii, T, Berridge, D and Wenwan, H. Family Support For South Asian Communities: A Case Study. JRF

Shah, R and Hatton, C. *Caring Alone, Young Carers in South Asian Communities* Barnardo's. 1999

Shah, S and Priestley, M. *Better Services, Better Health. The Healthcare Experiences of Black and Minority Ethnic Disabled People.* Leeds Involvement Project. 2001

Teen Team Solutions. *Care and Health.* July 2nd, 2003. Issue 39

Vernon, A, *User's Views of Community Care for Asian Disabled People,* JRF

Valios, N. *Young, Alone and Marginalised.* Community Care. 8 May 2000

We Care Too! Good Practice Guide for Working with Black Carers. Published January 2002. Available at www.afiya-trust.org.

Useful Sources of Information

The Bubbly Crew

Young Carers Project Website maintained by young carers. Available at www.bubblycrew.org.uk

The Afiya Trust

Supports projects that involve carers, and provides multi-lingual information for families living with cancer, or mental health problems.

Publications include:

Caring for someone with cancer.

-A language tape available for carers of people with cancer from Asian and Chinese communities.

Breaking the Circles of Fear.

-A review of the relationship between mental health services and African and Caribbean communities.

Available at <http://www.afiya-trust.org/>

Medway Young Carers project

Young Carers Project Website. Available at

www.medwaycarerscentre.org.uk/youngcarersinformatin.htm

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- ⁱ Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities.
- ⁱⁱ Newman, T. 2003. Children of Disabled Parents. Russell House Publishing
- ⁱⁱⁱ Barnardo's and University of Leeds. A Health needs Assessment of Black and Minority Ethnic Children's Needs. June 2002
- ^{iv} Reeve, C. Unknown Quantity. Community care. 10 May 2000.
- ^v Newman, T, Culture – Ethnicity and Care Giving- The Situation of Black and Asian Young Carers, pp27- 43 in Are We Listening Yet? Working With Minority Ethnic Communities. Sachdev, D and van Meeuwen, A. Barnardo's, 2002.
- ^{vi} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities
- ^{vii} Newman, T. Are We Listening Yet? Working With Minority Ethnic Communities. In Sachdev, D and van Meeuwen, A. Culture, Ethnicity and Care Giving, 2002
- ^{viii} Jones, A, Jeyasingham, D and Rajasooriya, S. Invisible Families. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities
- ^{ix} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities.
- ^x Butt, J and Mirza, K. Social Care and Black Communities. 1996. Race equality Unit
- ^{xi} Newman, T, Culture – Ethnicity and Care Giving- The Situation of Black and Asian Young Carers, pp27- 43 in Are We Listening Yet? Working With Minority Ethnic Communities. Sachdev, D and van Meeuwen, A. Barnardo's, 2002.
- ^{xii} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities.
- ^{xiii} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities.
- ^{xiv} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities.
- ^{xv} Mapp, S. No Stigma in caring. Community Care. 31st May 2000
- ^{xvi} Frank, J. Veil of Secrecy. Community Care. June 12, 2000.
- ^{xvii} Shah, R and Hatton, C. Caring Alone, Young Carers in South Asian Communities Barnardo's. 1999
- ^{xviii} Shah, S and Priestley, M. Better Services, Better Health. The Healthcare Experiences of Black and Minority Ethnic Disabled People. Leeds Involvement Project. 2001
- ^{xix} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities
- ^{xx} For example, Shah, R and Hatton, C. Caring Alone, Young Carers in South Asian Communities Barnardo's. 1999
- ^{xxi} Atkin, K and Rollings, J. Informal care In Asian and Afro- Caribbean Communities, 1992
- ^{xxii} Shah, R and Hatton, C. Caring Alone, Young Carers in South Asian Communities Barnardo's. 1999
- ^{xxiii} Butt, J and Mirza, K. Carers. In Social Care and Black Communities. 1996. Race Equality Unit
- ^{xxiv} Atkin, K and Rollings, J. Informal care In Asian and Afro- Caribbean Communities, 1992
- ^{xxv} Qureshii, T, Berridge, D and Wenwan, h. Family Support Fro South Asian Communities: A Case Study. JRF
- ^{xxvi} Shah, S and Priestley, M. Better Services, Better Health. The Healthcare Experiences of Black and Minority Ethnic Disabled People. Leeds Involvement Project. 2001
- ^{xxvii} Atkin, K and Rollings, J. Informal care In Asian and Afro- Caribbean Communities, 1992
- ^{xxviii} Atkin, K and Rollings, J. Informal care In Asian and Afro- Caribbean Communities, 1992
- ^{xxix} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People Have Caring Responsibilities.
- ^{xxx} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities
- ^{xxxi} Vernon, A, User's Views of Community Care For Asian Disabled People, JRF
- ^{xxxii} Frank, J. Veil of Secrecy. Community Care. June 12, 2000.
- ^{xxxiii} Frank, J. Veil of Secrecy. Community Care. June 12, 2000.
- ^{xxxiv} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities
- ^{xxxv} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities

-
- ^{xxxvi} Veronica Ikzue, co-ordinator of a care support agency. In Mapp, S. No Stigma in caring. 31st May 2000
- ^{xxxvii} Frank, J. Veil of Secrecy. Community Care. June 12, 2000.
- ^{xxxviii} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities.
- ^{xxxix} Butt, J and Mirza, K. Carers. In Social Care and Black Communities. 1996. Race Equality Unit
- ^{xl} Qureshii, T, Berridge, D and Wenwan, H. Family Support For South Asian Communities: A Case Study. JRF
- ^{xli} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities.
- ^{xlii} Valios, N. Young, Alone and Marginalised. In Community Care. 8 May 2000
- ^{xliiii} Ellahi, R and Hatfield, C. Research into the needs of Asian Families Caring For someone With A Mental Handicap, 1992
- ^{xliiv} Dearden and Becker, 1998 Young Carers in the UK. London. Carers National Association
- ^{xlv} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities.
- ^{xlvi} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities.
- ^{xlvii} Black carers' manifesto 2000. Available at www.carers.gov.uk/bcm.htm
- ^{xlviii} Hatton, C. Informal Carers of Adolescents and Adults with Learning Difficulties from South Asian Communities: Family Circumstances, Service Support and Carer Stress. British Journal of Social Work 28. 1998. Pp821-837
- ^{xlix} For example in Barnardo's and University of Leeds. A Health needs Assessment of Black and Minority Ethnic Children's Needs. June 2002
- ^l Qureshii, T, Berridge, D and Wenwan, H. Family Support For South Asian Communities: A Case Study. JRF
- ^{li} Shah, S and Priestley, M. Better Services, Better Health. The Healthcare Experiences of Black and Minority Ethnic Disabled People. Leeds Involvement Project. 2001
- ^{lii} Vernon, A, User's Views of Community Care For Asian Disabled People, JRF
- ^{liiii} Vernon, A, User's Views of Community Care For Asian Disabled People, JRF
- ^{liiv} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities.
- ^{liv} 'We Care Too' Good Practice Guide for Working With Black Carer. Published January 2002. Available at www.afiya-trust.org.
- ^{lvi} Craig, G. Must Do Better. Community Care. July 6 2001
- ^{lvii} A Plea To Practitioners. Community Care. 26 November 1995.
- ^{lviii} Barnardo's and University of Leeds. A Health needs Assessment of Black and Minority Ethnic Children's Needs. June 2002
- ^{lix} Frank, J. Veil of Secrecy. Community Care. June 12, 2000.
- ^{lx} Arthur, V. Wiffin, J. A Plea To Practitioners, Community Care, 1995
- ^{lxi} Jones, A, Jeyasingham, D and Rajasooriya, S. The Strengths and Needs of Black Families In Which Young People have Caring Responsibilities