



**Asian People's Disability Alliance**

# **Humare Avaaz**

## **(Our Voice)**

*'nobody had ever asked about their health or wider ... issues before'*

***Barriers to independent living  
faced by disabled Asian women***



**drill**  
Disability Research on  
Independent Living & Learning



**LOTTERY FUNDED**



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### EXECUTIVE SUMMARY

Funded by Disability Rights UK as part of its Lottery-funded 'Disability Research on Independent Living and Learning' project, the Asian People's Disability Alliance (APDA) conducted an 18-month community research programme into systemic, personal, familial, cultural and religious attitudinal barriers that impact on disabled Asian women's ability to live independently.

APDA is a Deaf & Disabled People's Organisation (DPPO) and in addition to direct delivery it has campaigned and advocated for the needs and rights of Asian disabled people in the UK for 30 years and has consultative status on Economic and Social Development with the United Nations.

The project's name – *Humare Avaaz*, meaning 'our voice' – is indicative of our intention to give a voice to the voiceless.

We used a social model definition of disability to include physical disability, learning disability, mental health or long-term health condition, or disability as a result of status or role as an informal ('hidden') carer. Our aim was to document personal experiences of disability or caring for a disabled person and to identify changes needed at a professional, policy or community level.

### EXISTING RESEARCH

Existing research shows that people from South Asian communities experience high levels of disability compared to the general population but that much of it is dated, albeit we accessed a growing body of up-to-date doctoral or clinical doctoral research. However, the focus has been on disability in children rather than adults, with a tendency to neglect social deprivation and exclusion and with insufficient emphasis on the interaction between identity, disability and gender.

We also noted a tendency to assume a homogeneity in the term 'Asian' that neglects the ethnic, cultural, religious and geographic differences within and between communities.

### RESEARCH METHODOLOGY

A qualitative approach was adopted using focus groups and interviews to encourage coproduction and the active involvement of disabled women from different Asian backgrounds.

#### Key research questions

- What are the systemic attitudinal barriers to independent living faced by disabled women in London's Asian communities?
- How have women overcome these barriers?
- What policies and what support are needed to enable more disabled Asian women to overcome these barriers?

#### Focus groups and interviews

Seven focus groups and 18 in-depth interviews were conducted.

### FINDINGS

Our findings largely mirror and update previous research, but add to the existing evidence base.

There were both commonalities and differences across ethnicities and disabling conditions. The women were delighted to participate in the research. Disability, health and independence were not usually talked about in their communities and they were glad of the opportunity to express their views. Nobody had ever asked them before.

#### Defining independence

Participants saw independence in terms of being able to undertake housework and care for family without help, rather than economic independence.

The findings suggest that low expectations of the potential of women with disabilities to lead an independent life, even with support, is a significant barrier for Asian women.

#### Beliefs, taboos and stigma

Participants talked about taboos surrounding disability, health and family but they described these taboos as being held by 'other people'. These views resulted from a lack of information and they explained disability affecting themselves in lay medical terms.

#### Encouragement and aspiration

Independent women studied believed their achievements were due to their own efforts with support from family, schools and, especially, third sector organisations. However, the invisibility of disabled Asian women results in few examples of what women can achieve.

Participants believed that disabled daughters would be treated no differently to disabled sons but cited low expectations at community level, especially among the older generation. However, defining independence in terms of homemaking ability, precluded disabled women deemed unable to fulfil that role.

#### Health service and professional barriers

Participants believed that Asian families/disabled people did not understand the health and social care system and that it was also difficult for them to access help and support. Those who had used health and social care services for years felt that systems were constantly changing and complained bitterly about the impact of cuts to services in recent years.

They said that many doctors and other professionals did not understand their culture and would not listen to them, often resulting in inappropriate support. Assumptions were made, e.g., blaming conditions on consanguinity and presuming they believed in curses or religious causes and or had low expectations of independence.

#### Social care and educational services

There was criticism of social care services, particularly where outsourced. Carers were unhappy about the quality and lack of continuity of support, e.g., not understanding disability or the demands of 24-hour care and frequently disbelieving, misjudging or making incorrect assumptions.



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Families are reluctant to complain for fear of being victimised. Those that had complained felt that nobody listened anyway. This neglect was not seen as racially motivated but participants were concerned that families with poor English, or those that did not understand the care system were particularly vulnerable.

### **The ethnic third sector – a lifeline**

A recurrent theme was the value of the third sector support. Without it participants would not have known about services or how to access them. Such organisations deliver support in ways that mainstream services are unable or unwilling to deliver.

### **Isolation from family and community**

The isolation of disabled people and their carers by family and/or community was evident. Participants were avoided, ignored or subject to negative comments. Some excluded themselves for protection against negative attitudes. Some even felt unwelcome in Asian places of worship. Most women were left to cope with little or no support.

### **Women and informal care**

Most informal care was undertaken by the women. Some disabled themselves were caring for spouses, ageing parents or parents-in-law, or children with physical and or learning disabilities, or autism or mental health problems.

An unexpected finding was the poor health of relatively young Bangladeshi participants. Most looked older than their years and some were disabled by various illnesses although none were apparently registered as such. A number spoke openly about depression and anxiety and suffered from physical aches and pains, possibly the somatic symptoms of stress. They rated their health as poor or very poor.

Some family carers were receiving no help from social services or any welfare benefits because husbands or other family members prevented them from applying from a desire not to rely on 'handouts' and the associated stigma.

### **Religious beliefs and practices**

Participants believed that older people and people from some faiths believed that disability was a punishment from God or a test to be endured for eternal reward but they generally felt that this was because of a lack of information about the problem. However, differing beliefs still caused tensions in the family adding to the stress of being disabled or caring. Mothers, especially daughters-in-law, tended to be blamed for a child's disability and were expected to do everything for the child rather than taking the tougher line of encouraging independence.

Although for most faith was a source of comfort and strength, participants of all faiths said they would not confide in a religious leader. They had major misgivings about their role and the advice they might give, their lack of understanding about disability in the UK context and, above all, the obligation, often ongoing, to pay for prayers or 'healing'.

### Mental illness and dementia

The stigma and taboos around mental illness were much worse than those around other disabilities. It affected the whole family and impacts on the marriage prospects of siblings.

Most participants talked openly about their own mental health once assured of anonymity. Several had been or were currently depressed. They suggested that while some people might believe in curses, spells or possession by jinns, they explained their own mental illness was due to bereavement, family or marital problems, or worry about children or other family members.

Some Bangladeshi women talked about children with autism and their struggle to cope with families and schools that blamed their child's behaviour on poor parenting, particularly mothering.

Most Bangladeshi women had never heard of dementia before it occurred within their family and there is no direct translation for the term in Bengali/Sylheti. They suggested the community did not want to talk about dementia but discussed it openly once assured of confidentiality.

### Planning for the future

A number of older women were caring for disabled adult children who were still dependent on them. Few had any strategic plans for the future when they would be unable to provide care. Some suggested a marriage might be arranged for a disabled daughter but some carers recognised that their daughters were too disabled to marry. They therefore hoped that siblings would continue to care.

The concept of a daughter living away from home in fully adapted supported housing was unacceptable. Families feared being judged by the community. However, participants understood that families were changing and siblings raised in the UK would not be so willing to undertake caring responsibilities and that it was unreasonable to expect them to do so.

## DISCUSSION OF FINDINGS

Although reluctant to be recorded, participants spoke openly. They described barriers similar to those experienced by other disabled women and although differences were evident, the cultural barriers they faced were common across the cultural and religious groups. It was evident that more recently arrived Bangladeshi disabled women and carers were still experiencing many of the problems the older Gujarati participants experienced decades ago.

Participants saw independence as being able to undertake housework and childcare; few saw independence in socio-economic terms. Such low expectations of a disabled Asian woman are rooted in overlapping cultural, professional and service related and structural causes.

Participants identified the social care system as a primary barrier to independence and repeatedly reported that family carers are at breaking point.

### Professionals and services

Relevant literature is still awash with the problems Asian people experience when trying to access

professional help or support services because of language, communication, stereotyping, expectations and assumptions about minority ethnic parents. Although there was some reluctance to access help, professional attitudes and service ethos rather than culture were responsible.

Language barriers preclude access to information as well as inability to communicate with professionals or understand the information provided. This is compounded by a lack of direct translation of medical or diagnostic terms. Professionals do not appear to appreciate this.

Although participants did not generally subscribe to the same beliefs as their elders, cultural beliefs may still impact on how they perceive disability and professionals must understand and respect this and work with them.

Families who had accessed educational support, homecare or learning disability or autism services had usually done so through ethnic third sector organisations, not health and social care professionals. Some younger, more recently arrived, Bangladeshi participants did not realise there was any alternative to the informal care they provided.

Housing professionals do not appear to understand the difficulties of caring for a disabled child, an elderly person or somebody with dementia and research data indicates that dementia does not appear to be grounds for securing more appropriate housing.

Participants reported professionals' assumptions of an extended family willing and able to contribute to informal care.

### Community barriers

The data demonstrated low expectations of what a disabled woman might achieve across all groups, reflecting a lack of knowledge about the cause and effects of an impairment. Lack of information was compounded by disability being hidden in the community.

Issues of family honour, confidentiality and fear of gossip were raised in all focus groups, suggesting that being open about disability or mental ill-health is still difficult for Asian women and their families.

Adherence to traditional, often supernatural, explanation of disability is waning but the influence of family attitudes often inhibited aspirations to be independent. Expectations of being homemakers still impacted on possible independence; living independently was unacceptable.

Whilst no participants would seek a faith leader's advice, the evidence contradicted earlier research that religious beliefs could be a barrier to seeking support. Most said that their personal faith gave them comfort.

The notion of the close-knit community was challenged. Participants and family carers felt cut off from the extended family and community. Despite the reality of an extended family and close knit community, women found themselves alone and isolated as carers.

Most participants would have welcomed external help but many were prevented from seeking it by husbands or other family members. An undercurrent of shame associated with 'handouts' was

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apparent. A small number of women believed that external help or money was not in keeping with being a 'good woman', reflecting research on the internalisation of cultural/religious views about women's roles.

Data confirmed taboos around mental health but participants spoke freely about their own mental ill-health and those of relatives but would not be recorded. They understood its causes and yet seemed trapped in a culture that blamed them for, particularly, their child's disability.

A recurrent theme was the positive role played by ethnic third sector organisations in providing support to the participants and the wider Asian community.

### Intersectionality

The research highlighted, but did not explore, the significance of structural barriers faced by disabled Asian women. Disabled people are poorer and have worse access to health and social care but being an Asian woman further compounds inequality.

Health, social care and education authorities are aware of the low or late uptake of services but appear content to presume that this is a choice made by ethnic minority communities. Most participants did not seem to understand the legal duty on public authorities to eliminate discrimination on grounds of race, gender, disability or other protected characteristics.

## LIMITATIONS OF THE STUDY

The limitations highlight areas for further investigation and exploration.

- It was only possible to recruit a small number of Pakistani women. This is not unique to our study and highlights the need for further research into Pakistani women with disabilities.
- The study's scope did not allow us to do justice to mental illness, especially among Bangladeshi women/their children; differences in generation, place of birth, education or level of acculturation; intersectionality and the impact of multiple social determinants.
- Although participants' experiences provide a broader understanding of the complexities of being a disabled Asian woman or caring for a disabled child or relative, the conclusions cannot be understood as generalisable to all disabled Asian women.

## RECOMMENDATIONS

### Health services and professionals

- Professionals must adopt ways of working that respect traditional beliefs but offer accessible and credible alternatives. They must recognise educational, generational or gender differences whilst not forgetting commonalities with the general population.
- There is a danger of ignoring structural, institutional and professional barriers and there is a lack of attention to the multiple disadvantages experienced by disabled Asian women and those caring for disabled relatives.



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- Given the ageing population and the increasing life-span of disabled people, the needs of people from diverse Asian communities must be planned for.
- The research suggests the need for further investigation into the Bangladeshi community, such as, an apparent high incidence of mental illness and autism disorders among young Bangladeshis and very poor health at younger ages.

### Social care and housing services

- Social services must not presume the willingness or ability of families to provide informal care.
- There is a considerable need for respite care. This is unlikely to be requested so should be offered
- Dementia is an increasing issue in Asian communities and services must be provided.
- There is a need for supported housing for disabled Asian people, particularly for women.
- Public health/health promotion bodies must target Asian communities and awareness campaigns should involve disabled people.
- JNSAs should include better data on Asian populations for health and employment planning.

### Asian community and faith leaders

- Beliefs and attitudes to disability within the Asian community need to change. There is an immediate need for information on the social model of disability.
- Asian media and businesses should do more to raise awareness of and 'normalise' disability.
- Faith leaders have a role to play in challenging discrimination and building a supportive network for people with disabilities and their carers. Places of worship must make the 'reasonable adjustment' required by law to become inclusive.
- Attitudinal change must come from within Asian communities.

### Third sector organisations

- Asian voluntary organisations, BAMER DDPOs in particular, can make a major contribution to helping Asian women overcome barriers to independence that they face.
- Carer support groups and peer support by disabled people should be encouraged.
- There are many Asian women in poor health who should be encouraged to register as disabled.
- There is particular urgency around planning for the future to prepare disabled adults to live as independently as possible. This will require a culture change where disabled women are supported to live from the family home with help to facilitate independence.



## **ABOUT THE ASIAN PEOPLE'S DISABILITY ALLIANCE (APDA)**

We are a user-led, non-political Deaf & Disabled People's Organisation (DDPO) and social enterprise managed by Asian people with personal experience of disability and caring.

Our mission is to provide support services appropriate to the needs of disabled Asian people and their carers and those who are elderly and lonely. We've been providing our culturally sensitive support to the local Asian communities from our centre in Harlesden in Brent for nearly 30 years.

We support those of all faiths and none and we are not part of any larger organisation.

We are unique in that we:

- Match services to the needs of Asian people with disabilities, their carers and families, a group that is disadvantaged not only in the wider community but also within its own.
- Provide support irrespective of age or situation.
- Provide services that consider Asian traditions, practices and family relationships as well as language, diet and religion.
- Engage with local authorities and housing, health and support agencies from a position of strength. We have a well-established and successful record of working in partnership.

### **OUR MAIN SERVICES**

Our main services are:

- Day-care, at our Alric Avenue centre.
- Home and respite care by trained staff that share a common language and cultural background with the client.
- Advocacy – we support our service users to make representations about their social care support, housing needs or medical care and manage their cases if asked to do so.
- Mental health – we support user-led groups for those with mental health issues.

### **OUR OTHER SERVICES**

- Befriending – a growing need as increasing numbers of elderly and disabled Asian people find themselves isolated within both their own and the wider community. Befriending enables them to retain their independence and identity.
- Information, advice and guidance – many of our service users and their families need help to access the support that is available. We provide a multi-lingual service.

Since its inception, APDA has also campaigned and advocated for the needs and rights of Asian Disabled People across the UK, it holds consultative status on Economic and Social Development with the United Nations.



### ABOUT OUR RESEARCH PROJECT

#### OUR FUNDING

Our research was funded by Disability Rights UK's 'Disability Research on Independent Living and Learning' (DRILL) project/Big Lottery.

The main aim of the study was to explore systemic, personal, familial, cultural and religious attitudinal barriers that impact on disabled Asian women's ability to live independently.

Disabled Asian women were involved at all stages of the project informing research objectives and facilitating access in order to reach voices not normally heard and helping those voices to describe the barriers they face from their own perspectives. The intention was to understand what policies and support are needed to remove obstacles to independent living.

*The main aim of the study was to explore systemic, personal, familial, cultural and religious attitudinal barriers that impact on disabled Asian women's ability to live independently.*

#### BACKGROUND AND INTRODUCTION

Under UK law, disability is defined as a physical or mental impairment that has a substantial and long-term effect on a person's ability to perform normal day-to-day tasks.

In the context of education for example, day-to-day tasks include studying. This means, for example, that someone with a diagnosis of dyslexia may qualify as disabled because of difficulties associated with reading and writing.

In general, long-term means a condition that has lasted, or will last, more than 12 months.

#### PROJECT OUTLINE

The project aimed to focus on Asian women whose disability fell into one or more broad categories:

- Physical disability
- Learning disability
- Mental health or long-term health condition, or
- Disability as a result of status or role as an informal ('hidden') carer.

The aim was to explore the impact of cultural and community attitudes to independent living for disabled women and how these differ among diverse Asian communities.

The intention was to document personal experiences of disability or caring for a disabled person and to identify what changes are needed at a professional, policy or community level. The project's name – *Humare Avaaz*, meaning 'our voice' – was indicative of our intention to give a



voice to the voiceless.

Our hope was that we would contribute to a better understanding of disability in Asian communities and among health and social care providers and professionals.

We aimed to provide case studies where disabled Asian women have overcome barriers and achieved an independent life and to showcase these examples to challenge negative perceptions of disability in Asian communities.

The research would also propose practical and cost-effective actions that could make a real difference to the lives of disabled Asian women.

*The project focused on Asian women with a:*

- *Physical disability*
- *Learning disability*
- *Mental health or long-term health condition*
- *Disability resulting from their status or role as an informal ('hidden') carer.*

### LITERATURE REVIEW

According to the 2011 Census (Office of National Statistics), approximately 8.8% of the English and Welsh population are South Asian: Indians, Pakistanis and Bangladeshis, and their British-born children make up the largest ethnic groups.

South Asian communities in the UK have different religious identities that are usually a reflection of their country of origin. For example, Indians tend to be Hindu, Sikh or Muslim and Pakistanis and Bangladeshis tend to be Muslim. South Asian communities also speak a variety of languages with some of the most frequently used being Hindi, Gujarati, Punjabi, Urdu and Mirpuri, Bengali and Sylheti.

There is widespread evidence that people from South Asian communities experience high levels of disability compared to the general population. The causes of disability vary but they impact disproportionately on these communities in all areas of their lives (Papworth Trust 2016).

*There is widespread evidence that people from South Asian communities experience high levels of disability compared to the general population.*

### EXISTING RESEARCH

The literature search identified a dated but expanding body of literature on disability in the Asian community in Britain. There is a growing body of doctoral or clinical doctoral research on disability, mental health, family care, gender issues that provides knowledge on under-researched issues and offers rigorous, evidence-based information on specific topics.

Searches suggest that more research has been undertaken in relation to intellectual disability or caring for a child with intellectual disabilities (Hatton *et al* 2003, Heer *et al* 2015, Malik 2011). Although a proportion of research referred to investigating the South Asian community, some studies focussed on particular groups such as Pakistanis (Malik 2011), Bangladeshi (Mahbub 2014, Barn *et al* (2002), Sikhs (Juttla 2014) or Muslims (Sabir-Syed 2004). Some comparison had been made between disabled people living in the UK and India (Heer *et al* 2012) or Pakistan (Sheridan and Scior 2013). There was a significant but dated body of work on young people with disabilities from BME communities including South Asian (Bignall and Butt 2000, Hussain *et al* 2002).

There is increasing interest in the impact of ageing on older people from Asian communities (Zubair and Morris 2015), as well as the growing evidence of dementia (Juttla 2014, APPG 2013). There is some limited research on sensory impairment, both related to age and genetic factors (Rauf *et al* 2013, Thomas Pocklington Trust 2005, NCDS 2014).

*There is increasing interest in the impact of ageing on older people from Asian, as well as the growing evidence of dementia.*

There is a sizeable body of research on mental illness in BME communities that includes (Fernando 1991, Bhui and Bhugra 2002, Memon *et al* 2016) or is specific to South Asian communities (Mooney *et al* 2016, Time to Change 2010). There is also a body of evidence specific to South Asian women (Anand and Cochrane 2005, Hussain and Cochrane 2004, and Husain *et al* 2006, Gilbert *et al* 2004). Several studies are pertinent to South Asian women (Mahbub 2014, Ray 2015) and particularly to their mental health (Thabusom 2005, Kapadia *et al* 2015, 2016) and disability (Hussain 2005).

Most research includes a discussion of cultural beliefs and values related to various disabilities (Heer 2012) but a number focus on beliefs and perceptions (Malik 2011, Sheridan and Scior 2013, Gilbert *et al* 2015, Dura-Vila *et al* 2010, Kaiser *et al* 2015). There is also a body of literature relating to stigma, mostly in relation to mental illness (Chaudry 2016, Gilbert *et al* 2004) but also with respect to having a disability or having a disabled person in the family (Singh and Orimalade 2009, O Hara 2003, Mir and Tovey 2003).

Uptake and use of services are addressed in most studies but there is a substantial body of research focussing on access to and experiences of services (Memon *et al* 2016) and the lack of or limitations of what is offered (Mir and Sheikh 2008, Barnardo's undated). There is also research on the expectations and demands of informal care (Byewaters 2003, Heer *et al* 2012, Heer *et al* 2015). Research invariably discusses the role of women as carers and the impact caring has on their physical and mental health.

*... there is a substantial body of research focussing on access to and experiences of services and the lack of or limitations of what is offered. There is also research on the expectations and demands of informal care [that] invariably discusses the role of women as carers and the impact caring has on their ... health.*

### LIMITATIONS OF SOUTH ASIAN CATEGORY

The term Asian covers a wide range of diversity that is not always recognised by researchers and policy makers who tend to assume a homogeneity that neglects the ethnic, cultural, religious and geographic differences within and between communities. In the UK, the widely used term South Asian refers to individuals of South Asian heritage, usually Indians, Pakistanis, Bangladeshis and to a lesser extent, Sri Lankans, Afghans, and Nepalese. It also includes people of Indian origin who lived in East Africa for substantial periods of time. The term excludes people of East Asian heritage, e.g. Chinese, Korean or Japanese, who tend to be defined by their country of origin in the UK census. Whilst not without its critics, the term Asian will be utilised as it broadly covers the largest and most common Asian communities in England.

### EXCESS INCIDENCE OF DISABILITY IN ASIAN GROUPS IN GREAT BRITAIN

The Papworth Trust (2016) shows there is evidence that Indian Asian people are significantly more likely to

experience higher rates of disability than Europeans (Williams *et al* 2012). Adults with an impairment from black or black British ethnic backgrounds report the highest number of life areas, e.g. education or leisure, in which participation is restricted compared to adults from white ethnic backgrounds (Papworth Trust 2016).

*Asian people are significantly more likely to experience higher rates of disability than Europeans.*

As the wider population ages, so do those who came to Britain in the post war period (Zubair and Morris 2015) and with age comes increasing disability. There is evidence of high rates of stroke-related disability especially in older people but also in younger South Asians (Bannerjee *et al* 2009). Williams *et al* (2012) noted a substantially elevated risk of disability among Indian Asian participants that is unexplained by known factors. It has been known for over two decades that the presence of learning disabilities among South Asians is significantly higher than in other communities (Azmi *et al* 1997, Mir *et al* 2001, Singh and Orimalade 2009).

*It has been known for over two decades that the presence of learning disabilities among South Asians is significantly higher than in other communities.*

## GAPS IN RESEARCH

There is evidence, however, that the existing literature shows a lack of attention to differences within groups (Hatton 2004) and, arguably, the similarity between BME groups and the majority population. Research has paid more attention to disability in children (Hatton 2002) than disability in adults. Some studies also focus on specific ethnic communities, diagnostic categories or access and service issues.

There is also a tendency to neglect the wider minority experience and the reality of social deprivation and exclusion (O Hara *et al* 2003). According to Hussain (2005), there is insufficient attention to disability and when identity, disability and gender are studied, they are dealt with separately rather than considering the interaction among them.

Age added to the high levels of diabetes and cardiovascular disease increases the risk of dementia (APPG 2013). Williams *et al* (2012) argue that a greater understanding of determinants of disability and normative functional beliefs of healthy ageing is required in this population to inform intervention efforts to prevent disability. Juttla (2014) argues for the need to understand the migratory identities and experiences of services in order to support families caring for older people with dementia.

The research on sensory impairment in South Asian communities highlights high levels of cataract and diabetic retinopathy (Rauf *et al* 2013, Thomas Pocklington Trust 2005). There is also some evidence of increased risk of Age-Related Macular Degeneration (Rauf *et al* 2013). There is a higher incidence of deafness in the Pakistani and Bangladeshi communities compared to the general population and this at least in part is due to intermarriage (NCDS 2015). There is a need

for further research on the experience and impact of sensory impairment given the evidence of visual problems and deafness within South Asian communities.

*Disability is experienced differently by people from minority groups than by the majority population. There is a tendency to neglect the wider minority experience and the reality of social deprivation and exclusion. [There is a need to] understand the migratory identities and experiences of services in order to support families caring for older people with dementia*

### RECURRENT THEMES IN EXISTING RESEARCH LITERATURE

#### 1 Lack of knowledge about disability and/or services available

In general, South Asian communities lack knowledge about disability (Heer 2012, Bignall and Butt 2000).

They are less likely to understand the health and social care system and may be unaware that there are services that may help them. Language is a major barrier to accessing information, as well as knowing about the services that exist. There is a particular lack of knowledge about specialist services and the roles of different professionals roles or responsibilities (Hatton *et al* 2003).

This leads to either limited uptake of services or later approach for help.

*There is a particular lack of knowledge about specialist services and the roles of different professionals roles or responsibilities.*

#### 2 Cultural/religious attitudes/conceptualisations of disability

Some studies have tended to neglect the differences within and between different cultural groups as mentioned in relation to the broad term South Asian. Cross-cultural research has indicated that geographical location and acculturation is likely to play an important a role in shaping the attitudes and beliefs of any community.

The South Asian community in Great Britain is diverse and although some studies have focussed on particular communities, they have not always recognised the difference generated by education, generation, migration experiences or acculturation.

*The South Asian community in Britain is diverse and ... some studies have ... not always recognised the difference generated by education, generation, migration experiences or acculturation.*

Syed-Sabir (2004) suggests that people from minority ethnic groups experience disability differently to the majority population. They experience many of the same barriers as anybody with a disability but are also influenced by and often juggle with beliefs and values within their families or communities (Heer *et al* 2015).

There is significant evidence that families have problems making sense of disability (Heer *et al*

2012, 2015, Malik 2011, Bignall and Butt 2000. According to Katbamna *et al* (2000) people from Hindu or Sikh background tend to see disability as a 'karmic' response to some sins of the past, settling bad debts from a previous life whereas Muslims saw it as destiny and from God and therefore to be tolerated.

*There is significant evidence that families have problems making sense of disability.*

Although the research is dated there is some suggestion that Asian families firmly believe that a learning disability is curable and that marriage of the person may help to alleviate it (Channabasavanna 1985, cited in O Hara *et al* (2003).

As families wait for an explanation of delays in their child's development, they often draw on a range of sources such as family, support groups and services (Heer 2012). Cultural models act as frameworks in the absence of other explanations. Parents rely on their own understandings of normative development until they can piece together different sources of information, cultural beliefs to help them understand (Kapadia *et al* 2015).

While cultural and religious beliefs and values are important, research suggests that people navigate between explanations (Heer *et al* 2012) but also that people rely on cultural/faith explanations when they receive insufficient explanation by professionals or do not understand what they are told (Byewaters 2003, Croot *et al* 2008).

*People rely on cultural/faith explanations when they receive insufficient explanation by professionals or do not understand what they are told [and they] tend to navigate between models of disability.*

Younger British-born South Asian parents are more likely to favour western medical explanations over traditional beliefs. Younger migrants also more likely to see the benefits of access to UK services but they also see the need to 'fit in' to support their children. This sometimes causes conflict with parents' traditional discourse (Heer 2012).

When making sense of disability, South Asian families have been shown to locate the cause of disability in traditional explanations, such as a belief in Karma (the notion of rebirth, whereby a person's actions in their previous lives determines the life they will lead once reborn), God's will, possession by spirits or consequences of an evil eye (Katbamna *et al* 2001). Such beliefs may account for a sense of resignation and reluctance to engage with educational or habilitative programmes (O Hara *et al* 2003).

South Asian communities may also focus on finding a cure through prayers or marriage (Katbamna *et al* 2000). When making sense of disability, families tend not to reject one model of disability in favour of the other, but instead tend to navigate between models of disability (Skinner and Weisner 2007, Byewaters *et al* (2003). It takes time to process a diagnosis of disability and parents go through various stages, among which might be adherence to religious alternative explanations.

Hatton *et al* (2004) highlights the parents' need of support at the time of diagnosis disclosure. If parents are not given appropriate advice and counselling, or do not have early intervention support, the welfare of their child will be at risk. Parents who had a shared understanding of their child's disability proved to be more able to mobilise informal networks through sharing their new 'medical' understandings with 'lay' understandings that could be held by family or friends.

The disclosure process impacts on how parents face the practical challenges with a disabled child and how they access benefits and formal services. There proved to be evidence that parental satisfaction with the information received during the disclosure process predicted receiving greater support from formal services. Such strong relationships between the disclosure process and practical gains for parents are not found in research with white families (Hatton 2002) who seem to cope even with a negative disclosure experience.

Maintaining a positive sense of identity is difficult for anybody with a disability in British society (Atkin *et al*, 2003). This struggle about identity is even more complex for young people who are deaf (Jones, Atkin, & Ahmad, 2001). Being deaf may be seen as a threat for the person to have full membership in family and society (Atkin *et al* 2002). Being deaf and belonging to an ethnic minority family may be experienced as even more of a threat. This is because of the need for communicating in sign language, a language that can be understood as a 'White' language. Thus, a Deaf identity may be experienced as a White identity. This may lead to ambivalence for the young person and the family. Identification as Deaf is therefore complicated for a young person from a minority ethnic background.

*Identification as Deaf is ... complicated for a young person from a minority ethnic background.*

Mental illness is a significant cause of disability for some South Asian people, and there are many similarities with physical or intellectual causes of disability. (Mental illness will be addressed as a separate theme.)

### 3 Stigma and exclusion

Stigma has been defined as 'a relationship of devaluation in which one individual is disqualified from full social acceptance' (Thara & Srinivasan 2000 cited in Chaudry 2016). The extent of stigma in relation to learning disability or physical disabilities and particularly with respect to mental illness among South Asian communities is well-documented.

Stigma targets multiple issues in society including physical diseases, homosexuality and especially mental illness, ranging from illnesses as severe as schizophrenia to more prevalent ones such as depression. It leads to people with certain conditions or characteristics being negatively labelled and as such excluded from wider society. It also means that people, self-exclude to avoid being labelled or avoid situations that might be embarrassing.

The concept of family shame figured large in lives of South Asian women (Gilbert *et al* 2004), more so than feeling personal shame about failing in their roles. Women were concerned to avoid



bringing dishonour on the family. Stigma is not confined to South Asian communities but is perpetuated by cultural expectations of public honour ('izzat') and the need to avoid labelling. Izzat is a complex set of rules that Asian people follow to maintain the honour and status of the family (Gilbert *et al* 2004). It is socialised within the family and while men appear to have the power to define, women are the guardians of family honour (Hussain 2005) and men can be shamed or lose honour by their failure to 'control' wives (Gilbert *et al* 2004).

Stigma is well-documented in relation to mental illness in South Asian communities (Chaudry 2016, Gilbert *et al* 2004). It is not just stigmatising for the person but impacts on the family who conceal it, isolating the person who is ill and also those who care for them (Chaudry 2016). Stigma, shame and izzat all impact on the willingness of disabled people to talk about their problem outside their closest family, often keeping a condition secret (Time to Change 2010).

*[Mental illness] is not just stigmatising for the person ... but impacts on the family who conceal it, isolating the person who is ill and also the one who cares for them.*

Although stigma about mental illness is widespread, collective cultures such as those from South Asia are more concerned about maintaining family honour and status (Gilbert *et al* 2004, Papadopoulos *et al* 2013). There is a fear of gossip in the (close knit) community. Time to Change (2010) argues that this is not necessarily a conscious decision, but almost a given that certain matters are not spoken about outside the family home. Scior (undated) demonstrates that stigma towards people with intellectual disabilities is increased in South Asian communities, although there are some differences when age is considered. They are less likely than other groups to have contact with anybody disabled, which may reflect the tendency of families to keep disability hidden. Croot *et al* (2008) highlight the impact of negative and stigmatising attitudes within the Pakistani community.

#### 4 Access to services – family and community barriers

Although it is easy to focus on cultural beliefs in failure or lateness in accessing services, there are more fundamental problems. There may be failure to recognise or accept problems (Memom *et al* 2016), especially not seeing some, such as mental illness, as amenable to medical treatment (Time to Change 2010). Parents may see disability in a child as genetic and have no knowledge that anything can be done to help a child. Some may be in denial that anything is wrong or believe that the condition is curable. Lack of experience of disability or experiences from the home society may suggest that nothing can be done. Language and literacy can mean a lack of accessible information about the condition or the help that is available.

At a cultural level, there may be pressure from the wider family not to seek help for fear of losing family honour and there may be tension with elders who encourage use of traditional healers, visits to holy shrines etc (Heer *et al* 2015). Family members may blame poor parenting, especially mothering and lack of effort by the disabled child, rather than an impairment that might be amenable to professional help.



Mental illness can be particularly difficult to articulate even if it is recognised by an individual or a family member. Apart from shame or stigma, cultural idioms of distress or the somatisation of symptoms make presentation to a health professional and subsequent diagnosis difficult. Although social networks can be a source of support for people and families, they can also discourage access to professional services (Memom 2016).

*Mental illness can be particularly difficult to articulate even if it is recognised by an individual or a family member.*

### 5 Access to services – structural barriers

The evidence demonstrates that BME parents of disabled children face the same barriers as the majority parents, but experience additional challenges related to language and communication, as well as stereotypes, expectations and assumptions (Heer 2012, Heer *et al* 2015).

*BME parents of disabled children ... experience additional challenges related to language and communication, as well as stereotypes, expectations and assumptions about minority ethnic parents.*

Language is an issue as is absence of or unwillingness to use interpreters (Heer *et al* 2012). Language is a barrier to information about disability or other disorders. It can preclude people from knowing about services to that the general population have access (Soderstrom 2013). It makes communication with health professionals difficult for those who speak little English (Singh and Orimalade 2009) and means that people do not understand the information they are given. Those who do not speak the majority language risk being devalued and losing their identity as independent and competent people (Soderstrom 2013).

While it is not surprising that people may misunderstand health information or advice, health professionals also overestimate the level of understanding when people speak some English. Even when interpreters are provided, some South Asian people (or health professionals) will not trust the confidentiality of the interpreter (Kapadia *et al* 2015). There are also issues about the use of jargon (Greenwood *et al* 2016) and the lack of direct translations for certain disorders in South Asian languages (Kaiser *et al* 2015).

*[H]ealth professionals also overestimate the level of understanding when people speak some English ... [and] ... some South Asian people (or health professionals) will not trust the confidentiality of the interpreter.*

Even when parents recognise a problem, there is often a delay in getting diagnosis. The system is unfamiliar and often confusing and opaque (Greenwood *et al* 2016). Health professionals do not understand cultural norms, such as those around family honour or experiences of discrimination (Gilbert *et al* 2004, Chaudry 2015), and people are talked down to and judged incorrectly. There is

also evidence that people may not be referred on for consultations (Bhui and Bhugra 2002). Families feel blamed for consanguinity, obesity or poor parenting. Professionals expect families to have religious explanations, feel shame, fail to seek help and have low expectations (Byewaters 2003 Poulson 2005).

Although some South Asian women prefer a practitioner from their own culture, there are concerns about confidentiality (Kapadia *et al* 2017). Asian people frequently report negative experiences of professionals from their own communities and many prefer white practitioners (Heer *et al* 2012).

While loving families might have low expectations of what their child /relative could achieve, professionals often expect Asian families to have low expectations (O Hara *et al* 2003).

*Asian people frequently report negative experiences of professionals from their own communities and many prefer white professionals.*

Professionals and providers recognise the low or late uptake of services but presume the issue relates to choices made by minority ethnic communities. Relying on family care is often a symptom as much as a cause of service under-use (ENC 2011). They rarely consider the barriers that people face in the system. Asian carers (and others) find the system confusing and opaque. Language, lack of information in community languages or media formats are major barriers to knowing what is available. Having to 'fight' for services adds to the burden of their caring role at a time when they are struggling to cope (Greenwood *et al* 2016). Insensitivity to cultural and religious mores mean that, on balance, carers decide that their energies are best focussed on caring, rather than wasting effort on services that are often unsatisfactory anyway.

*[Professionals and providers] ... rarely consider the barriers that people face in the system.*

## 6 Mental illness

Mental illness is a taboo subject in South Asian cultures (Time to Change 2010). It is not seen as a medical problem but one for the family to deal with. It is variously believed to be caused by black magic, spells or curses, the evil eye, punishment from God or it might be genetic. South Asians lack knowledge about how mental illness can be managed or that people can recover. In addition to the fear of loss of family status and honour, families can isolate the person with the illness and their carers by preventing them from talking about the condition and attending family or community events. This can be to protect the individual and carers from embarrassment or shame, but can also be about avoiding 'contamination' (Time to Change 2010).

*Mental illness is a taboo subject in South Asian cultures.*

### 7 Women and girls disproportionately disadvantaged

Hussain (2005) argues that there is a neglect of BME women in disability studies as well as ignoring the economic, cultural and discriminatory barriers faced by those who are disabled. Neither do they take account of hybrid identities as second and subsequent generations are schooled and socialised in English culture.

For disabled South Asian women their communities' views about disability add a further layer of complexity around izzat. Disabled children from all communities can be overprotected by families but Asian girls more than Asian boys (Atkin 2003). For South Asian women the body becomes the site where the power of others is realised. Izzat is one form of this, wider racism another and women can be additionally disabled by the attitudes and norms by which society defines them (Hussain 2005, Gilbert *et al* 2004).

*For South Asian women the body becomes the site where the power of others is realised. Izzat is one form of this, wider racism another and women can be additionally disabled by the attitudes and norms by which society defines them.*

Being married is the norm in South Asian communities but disability impacts on the ability to marry, more so for women than for men. Girls are seen as visitors in their parents' homes as they await transition to their husband's family, where the authority transfers from her father to her husband (Hussain 2005).

Girls or women with disabilities have poor marriage prospects as they are deemed unable to fulfil the traditional role of homemaker. Marriage in South Asian communities tends to be seen as a transfer of the caring role from parents to spouse, more as a carer than a loving partner or husband/wife. Parents are concerned that nobody will marry their disabled daughter and many resort to finding a husband from overseas. There is even evidence that people with intellectual disabilities are forced to marry (Clawson 2013) or that parents see marriage as a rite of passage even if the person is unable to consent.

*There is evidence that some parents see marriage as a rite of passage for people with intellectual disabilities even if the person is unable to consent.*

Despite high levels of mental health problems in South Asian communities, many go undetected (Gilbert *et al* 2004). High rates of suicide and attempted suicide among Asian women have been noted for around two decades (Bhui and Bhugra 2002).

There are various causes but domestic violence is high on the list, as is family conflict, unhappy (often arranged) marriages and adjustment to two cultures (Thabusom 2005, Gunasinghe 2015). In addition, Asian women become socially isolated by their lack of English, not being able to leave the home unaccompanied, expectations of their in-laws or their own families and internalised feelings of failure and shame (Gilbert *et al* 2004, Thabusom 2005). They are reluctant to seek help for fear

of bringing shame on the family, perceiving that white professionals will not understand them, or will require them to do things that might be contrary to their culture. At the same time, they do not trust professionals from their own communities to maintain confidentiality (Kapadia *et al* 2017).

Feeling trapped, not just within a physical environment but within a set of social values, is a major contributor to mental illness and suicide among South Asian women (Thabusom 2005, Gunasinghe 2015).

*Feeling trapped ... within a set of social values is a major contributor to mental illness and suicide among South Asian women.*

### 8 Gender and caring

The late or low levels of access to services by South Asians is well documented (Heer *et al* 2012). As in most communities, the responsibility for informal care rests with women and they invariably have problems accessing services. However, there are some additional differences that impact on Asian women and potentially add to their role as carers. Mothers, daughters or daughters-in-law do not necessarily see themselves as carers but as family members fulfilling their role as women (Parveen *et al* 2011). New arrivals from abroad in particular fall into this role and marriages may even be arranged to provide care for a person (usually a man) who is disabled.

*Mothers, daughters or daughters-in-law do not necessarily see themselves as carers but as family members fulfilling their role as women.*

Professionals may not offer services, expecting that women family members will care for the person concerned. Contrary to widespread assumptions, the large extended family is not necessarily a guarantee of support when caring for disabled children, frail parents or elders with dementia (Katbamna *et al* 2004, Bavishi 2013). Although children, especially daughters are required to help with housework and childcare, the main work of caring generally falls to the mother. Some men are helpful and supportive but not usually with the delivery of personal care (Katbamna 2004). Not all Asian families live in multiple generational housing, but those that do cannot necessarily rely on support from other family members (Bavishi 2103).

Existing research demonstrates that for Asian women, informal care is a duty undertaken out of a sense of obligation, whereas for White British families it is more likely to be part of a reciprocal emotional bond (Bavishi 2013, Parveen *et al* 2011). Informal care is stressful but there are cultural norms that add to the pressure for Asian women. Sons are not expected to care for elders so the care is undertaken by their wives.

There is often considerable strain within extended families, in particular between mothers-in-law and daughters-in-law. Daughters-in-law can feel that their efforts in caring for their husband's parents are not appreciated (Katbamna *et al* 2004). This is not unique to Asian women, but

because of differences in status within Asian families, it can be more stressful, especially if the carer does not feel in control or appreciated (Parveen *et al* 2011). Similar to other informal carers, Asian women experience considerable stress and depression that is not necessarily recognised by their families or other health professionals (Bunting and Jenkins 2016).

### 9 Looking to the future – marriage

Few studies have addressed this question directly, although research reports that in some South Asian communities, marriage confers ‘normalisation’ to a person with an intellectual disability (O Hara *et al* 2003). In the eyes of the community, marriage helps remove the ‘stigma’ of disability, reflecting a widespread folk belief that intellectual disability can be ‘cured’ or ‘improved’ through marriage, thus allowing a person with learning disability to lead a ‘normal’ life. In such cases, the parents might consider marriage of their children with intellectual disabilities part of their parental responsibility (O Hara and Martin 2003). This attitude is not related to the severity of disability or the socioeconomic status of the parents.

*... marriage is thought to help to remove the ‘stigma’ of disability, reflecting a widespread folk belief that intellectual disability can be ‘cured’ or ‘improved’ through marriage, thus allowing a person with learning disability to lead a ‘normal’ life.*

Parents often have low expectations about the marriageability of disabled daughters who they imagine will not be able to fulfil the role of homemaker. Marriage can be seen as the transfer of responsibility for care from the parents to the spouse (Hussain 2005). Parents and siblings see a marriage partner in the role of the carer, with sons marrying so that their wives could take over the role of the carer that they had been filling. However, this was different for the women, given the domestic expectations of married woman. Family members defined the disability as a burden and undesirable and unfair for a man. Being unmarried was therefore an accepted fact within the family.

Young disabled women tend to internalise the attitudes, values and forms of social behaviour as dictated by their ethnic, cultural and religious values (Hussain 2005). They express concerns about being able to cope with being a wife, homemaker, or bringing up a family. They believe it would be unfair to burden a partner with the responsibility for them (Hussain 2005). Those who did marry might feel they were accepting second best because of their disability.

### 10 Intersectionality

Hussain (2005) argues that debates about identity, disability, ethnicity and gender take place in isolation from each other, yet they need to be considered in relation to each other.

According to Anitha *et al* (2012) the emphasis on culture and identity has led to a corresponding neglect of structural inequalities, of lived everyday experience of discrimination. They outline that the low rate of economic activity among Pakistani and Bangladeshi women in the UK is explained by discrimination in accessing jobs in the UK labour market, lower levels of educational qualifications and fluency in English, and therefore different access to social capital.

*... the emphasis on culture and identity has led to a corresponding neglect of structural inequalities, of lived everyday experience of discrimination.*

Bhugra (2004) highlights that when socio-centric individuals from socio-centric cultures migrate to egocentric societies they may feel more alienated and more likely to stay with people who think and act like they do. Acceptance and welcome by the new nation will also be significant in the genesis of stress and how the individual deals with such stress. He argues that living in a new culture is stressful because of factors such as cultural identity, self-esteem and patterns of attachment and that prolonged periods of separation from one or both parents adds to stress. Persistent problems in cultural adaptation are associated with a higher risk for long-term mental health problems so it is the case that mental health can be improved by spending time with people who act like you (Bhugra 2004).

Bagguley and Hussain (2016) argue that there is a transformation of young Bangladeshi and Pakistani women's positioning not only in terms of their ethnicity but 'also in terms of gender relations and practices within their communities' that previous research had indicated. The findings showed that their Muslim religion encouraged education, and equality as well so it was inevitable for these young Muslim women that they would go to university. Finally, the paper showed that while the educational futures of British Bangladeshi and British Pakistani women is progressing, their attainment at university is not as high as other ethnicities; more research is needed to understand this.

### RESEARCH METHODOLOGY

The main aim of the study was to explore systemic, personal, cultural and religious attitudinal barriers impacting on diverse disabled Asian women's ability to live independently.

#### RESEARCH QUESTIONS

- What are the systemic attitudinal barriers to independent living faced by disabled women in London's Asian communities?
- What is the relative importance of each of these barriers from the perspectives of such women and their communities?
- How have women overcome these barriers?
- What policies and what support are needed to enable more disabled Asian women to overcome these barriers?
- How best might these barriers be removed over time?

#### RESEARCH APPROACH

Hearing the voices and listening to the experiences of disabled Asian women was best suited to a qualitative research approach and methods that lent themselves to coproduction with disabled community researchers from different Asian backgrounds. A qualitative research approach using interviews and focus groups allowed for rich descriptions and the flexibility to explore emergent themes that were not anticipated or that participants prioritised. A purposive sample was chosen of women with different disabilities or caring for somebody disabled and from different ethnic and/or religious backgrounds to take account of the diversity within Asian communities.

*A qualitative research approach using interviews and focus groups allowed for rich descriptions and the flexibility to explore emergent themes that were not anticipated or that participants prioritised.*

#### RECRUITMENT OF PARTICIPANTS

The research was discussed with Asian People's Disability Alliance (APDA) service users from the initial idea to apply for funding so APDA played a significant role in the recruitment of participants. Once funding was secured, information was disseminated at an AGM and service users, board members, relatives and volunteers brought into the project and helped inform wider members of the community. Women were canvassed about their willingness to be involved in designing the project, collecting and analysing data and producing the final report and there was much enthusiasm. Participant information sheets and consent forms were prepared as part of the ethical approval by Middlesex University. Partner organisations were identified and involved as part of the steering group.



Despite great enthusiasm to be involved, recruitment took a long time and also proved difficult in certain areas. The research team were conscious of the taboos around disability in Asian communities so took measures to approach individuals and organisations through trusted community/cultural organisations.

The APDA staff member allocated to the project was from a Bangladeshi Muslim background and gained the trust of women engaged in activities through FaithRegen at East London Mosque and later at APDA's 'Chat&Chai' sessions in Tower Hamlets. Arrangements were put in place to cater for language problems and funds were identified to reward interviewees and focus group participants for their time. Much of the information about the project was by word of mouth but posters and flyers were distributed through community organisations and places of worship. Interviews and focus groups were arranged to coincide with services or activities at APDA or partner organisations.

Convincing women to take part usually required a number of encounters, where they were told about the research and agreed in principle. There was usually little or no understanding of 'research' and the value of their lived experience and surprise that anyone would want to listen to them. In particular, Bangladeshi women were keen to participate but often went outside to make a phone call or went home and came back to ask further questions, usually about anonymity and confidentiality. Some agreed to take part providing the interview or focus group was not recorded. A couple of women returned to say they had been advised not to take part and a few did not return. As with most community research, interviews were postponed, women failed to turn up or arrived late often with a baby in a buggy or rushing to collect children from school.

*Convincing women to take part usually required a number of encounters ... [and t] here was usually little or no understanding of 'research' and surprise that anyone would want to listen to them.*

It proved virtually impossible to engage with the Pakistani community let alone recruit women of Pakistani origin. Despite emails, attempted phone-calls to local mosques, community centre managers and community leaders (with whom the research team had worked previously) we were only able to recruit five women of Pakistani origin. It was also especially difficult to find independent disabled women who might provide the positive case studies the project promised to deliver.

*It was also especially difficult to find independent disabled women who might provide the positive case studies the project promised to deliver.*



### PARTICIPANTS

#### Focus groups

Seven focus groups were undertaken

- FG 1 APDA – 11 disabled women, mostly of Gujarati origin, four Pakistani
- FG 2 Creative English class at the Maryam Centre – 13 Bangladeshi women carers
- FG 3 Monday Memory Sitting at East London Mosque – 10 Bangladeshi women, some disabled, mostly carers for family members with dementia
- FG 4 Navjiyot – 4 family carers, 2 Gujarati and 2 Bangladeshi
- FG 5 Minerva Centre – Chai&Chat – 12 Bangladeshi women, some disabled, mostly carers for children with learning disability or mental illness.
- FG 6 APDA – 11 disabled women, some also carers, mostly Gujarati
- FG 7 APDA – 9 women, (8 disabled and one carer) all Gujarati

#### Interviews

- Eighteen interviews were undertaken but one woman withdrew a week later. Nine women were caring for relatives with learning, mental health, physical or sensory disabilities.
- Eight were disabled women: four with learning disabilities, one with mental health problems, one visually impaired, two with physical disabilities.
- Seven were from Indian or East African Indian backgrounds, nine were from Bangladesh or British Bangladeshi backgrounds. One woman was a British Pakistani.

### COPRODUCTION AND CORESEARCH

The research team were keen that disabled women would be fully involved in coproducing the research and that they would gain skills and confidence through being co-researchers. We were particularly keen to hear the voices of the most excluded women. Our aspiration was that co-research would provide richer, more authoritative data that would value an undervalued group. We were conscious that many women had skills that could be captured for the project but that other women might be able to develop skills and confidence that would help them later. We were also anxious to make use of the different languages of Asian women and their understanding of cultural conventions that might allow for richer, illuminating and more relevant explanations.

Disabled women attending APDA were involved from the start in identifying issues that they felt needed to be investigated. These were very much in keeping with existing literature but as this was somewhat dated it was important to consider how relevant it still was and how different cultures or faiths might differ. These broad categories were therefore drafted into a series of semi-structured interview or focus group questions that researchers and co-researchers could use.

The women were all able to communicate, but none had any research experience. As such a programme of community research training was developed to prepare them to interview or

participate in focus groups with their peers and other disabled women.

However, despite all the enthusiasm, our attempts at helping women to undertake interviews or focus groups proved disappointing. The women were delighted that the project was happening and they had been involved in drafting the questions for the interview and focus group schedules but it became clear that despite our best efforts, they were unable to grasp the research process.

We believed that through our engagement in developing the research objectives they had the opportunity to talk about their own problems. However, it proved difficult to move beyond their own issues and all our attempts at training seemed like another opportunity for catharsis.

Although some disabled women agreed to interview each other, this did not materialise and at a later stage when we tried some gentle pressure, they opted out.

*[I]t proved difficult to move beyond their own issues and all our attempts at training seemed like another opportunity for catharsis.*

On reflection, our expectations of the very disabled women who had expressed an interest might have been too high and having agreed to the role they might have felt too embarrassed to say no. It may be that despite their concerns about other disabled women, they lacked confidence or might have been embarrassed about their own impairments and the benefits or help they were relying on. While disappointing, in retrospect, the strength of the research is the real involvement of some of the most excluded disabled Asian women.

Targeting disabled Asian women with higher levels of education as co-researchers would have been contrary to the spirit of the project – to give a voice to the voiceless – and probably difficult to achieve within the project's resources.

*[T]he strength of the research is the real involvement of some of the most excluded disabled Asian women.*

However, while we felt the women concerned were not willing or able to be co-researchers, they still had a role in coproduction. We used their skills to translate, clarify and challenge in the focus groups. We returned the findings to them to verify and confirm the credibility, highlight differences across cultures, faiths and generations. They also helped prioritise the major barriers and suggest how they might be overcome.

## DATA COLLECTION

Although it was anticipated that focus groups would be undertaken in community languages by co-researchers this was not possible. The groups had varying levels of English, but invariably wanted to practice their English. Therefore, focus groups were undertaken in English with translation or clarification of terminology by a staff member or a co-researcher. Focus groups at APDA and Navjiyot were translated as necessary into Gujarati whilst those at Minerva, East

London Mosque and Maryam Centre needed Bengali/Sylheti.

A semi-structured focus group outline was prepared but the agenda was mainly led by the participants, where they challenged each other, drew on their experiences laughing, joking and sharing often sensitive information. The use of a culturally adapted vignette in the later focus groups was successful in reaching views in an anonymous way, addressing issues that might not have been covered by the semi-structured interview schedule. The vignettes generated much discussion as participants empathised with and related to the story, challenged the attitudes towards disability and disabled women within Asian cultures in the UK.

*A semi-structured focus group outline was prepared but the agenda was mainly led by the participants, where they challenged each other, drew on their experiences ... sharing often sensitive information.*

Some interviews were conducted in English, some in Bengali or Sylheti and as with focus groups women were keen to practice their English but did not necessarily have the competence required. In these cases, the pragmatic approach used a combination of English and the relevant language.

*The use of a culturally adapted vignette in the later focus groups was successful in reaching views in an anonymous way, addressing issues that might not have been covered by the semi-structured interview schedule. The vignettes generated much discussion as participants empathised with and related to the story, challenged the attitudes towards disability and disabled women within Asian cultures in the UK.*

Where permitted, interviews and focus groups were recorded with the participant's permission. Field notes were also taken by the small number of co-researchers who were keen to play a part. Although many women did not agree to recording, all were happy for notes to be taken, providing their identity was not disclosed.

Where no recording was made, the researcher, co-researcher or project worker spent time at the end of the event reflecting on the findings and process. The recordings and/or shared notes were transcribed selectively as soon as feasible (usually within 24 hours).

Interviews followed a similar pattern, with notes or recordings written up as soon as possible after the event.

Data collection followed an iterative process, whereby unanticipated issues emerging were explored in subsequent focus groups or interviews.

## DATA ANALYSIS

Interviews and focus groups were analysed using thematic analysis. A number of themes emerged from the data and although some differences were noted across all participant groups, similar

issues were evident. The lead researcher was conscious of her own influence over the analysis and reporting as a white Irish academic researcher. Being able to check back with the project worker and co-researchers helped reduce the risk of ethnocentricity and bias.

The findings were fed back to two groups of women for clarification and verification. One was a group of mainly Gujarati disabled women and some carers and the second was a group of Bangladeshi women, who were mainly carers and some who were disabled. This was useful in comparing the different ethnicities and faiths, highlighting the similarities and the few differences that were evident.

The focus group and interview data were triangulated and later compared to existing research, particularly that from contemporary doctoral studies.

Reflexivity – the lead researcher was conscious of her potential for bias and repeatedly asked herself, the project worker and co-researchers to clarify her assumptions. The data is not generalisable because it relates to particular groups of women, mostly using the services of Asian community organisations at a particular time. However, existing research suggests it is broadly applicable to Asian communities in other cities in the UK.

*The focus group and interview data were triangulated and later compared to existing research, particularly that from contemporary doctoral studies.*

### FINDINGS

The interviews and focus groups produced a number of discreet but inter-related themes that highlight the barriers to independence faced by disabled Asian women from diverse cultural and religious background and disabilities.

There were many commonalities but also some differences across ethnicities and disabling conditions. Women from the different Asian communities, both disabled and non-disabled, were delighted to participate in the research even though they understood that it might not help them directly. They invariably said that matters like disability, health and independence were not usually talked about in Asian communities and they were glad of the opportunity to express their views and hear those of other women. Some of the focus groups included disabled women who coped with varying degrees of support and were happy to share their experiences. The Bangladeshi women in Focus groups 2, 3 and 5 and individual interviewees were particularly delighted because nobody had ever asked about their health or wider well-being and social issues before.

*The Bangladeshi women ... were particularly delighted because nobody had ever asked about their health or wider ... issues before.*

NB: Where possible we have given 'voice' to the women participants using direct quotes from interviews and focus group. The voice of a deaf woman unable to speak is presented as a paragraph. Their names have been changed to protect confidentiality.

### DEFINING INDEPENDENCE

The starting point was to establish how Asian women, defined independence and what level of independence they might aspire to.

What became evident was that women generally felt that being independent related to the ability to undertake housework and care for family without help from other family members.

**'Free ... not needing help from family ... able to do housework, maybe gardening' (FG 1)**

**'Able to look after your children' (FG 2)**

When we probed further and used the term '*azadi*' the Farsi/Urdu/Hindi word for independence, more women appeared to understand and added that it was also about being able to do things outside the house.

**'Going outside on your own ... taking a bus or a car on your own ... going to the market' (FG 1)**

One woman added that independence was:

**'Doing things alone, but if you have a wheelchair or a scooter, you don't need anyone to take you' (FG 1)**

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It was notable that only one woman mentioned working outside the home as a measure of independence and only one other said she was living alone. One very independent woman who was employed added that independence was:

**‘Doing what you choose, that you are not imposed by somebody else. People often say ‘let me do that for you’, but I can do it. I might just need slight support to be fully independent’ (Susma)**

The findings suggest that low expectations of the potential of women with disabilities to lead an independent life, even with support, is a significant barrier for Asian women. These low expectations are a product of many different factors within Asian communities, individual families and faiths and are compounded by professional attitudes.

*The findings suggest that low expectations of the potential of women with disabilities to lead an independent life, even with support is a significant barrier for Asian women.*

## BELIEFS, TABOOS AND STIGMA

Although all the participants were open and discussed disability, mental illness and other health and family problems freely, they invariably talked about taboos surrounding such matters in Asian communities. They suggested that Asian communities are embarrassed or ashamed to talk about a wide range of issues such as cancer, diabetes, or other illnesses and not just disability. Almost without exception, they described these taboos as being held by ‘other people’. They used terms such as ‘they’, ‘the community’, ‘the older generation’ or sometimes ‘people back home’, rather than views they held personally.

*Asian communities are embarrassed or ashamed to talk about a wide range of issues such as cancer, diabetes, or other illnesses and not just disability. Almost without exception, they described these taboos as being held by other people.*

When asked how the parents of a child born with a disability might explain the impairment, they suggested that they might believe that it was caused by curses, jinns, black magic, or the evil eye. But they then countered that by stating:

**‘We don’t think that, but our parents did’ (FG 6)**

The women understood these cultural beliefs but felt they were a product of lack of information about various disabilities.

**‘They understand this because they don’t know better’ (FG 6)**

**‘It’s because they don’t understand the illness or the injury’ (Rajini)**

Participants explained their own, child’s or spouse’s disability in lay medical terms such as infection, injury, birth trauma, stroke or medical neglect.

They identified that language, literacy and IT skills were a barrier to many Asian women accessing



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knowledge about disabling conditions. There said that they faced a lack of accessible information from health and other professionals.

*... they faced a lack of accessible information from health and other professionals.*

Participants described another reason why a family, particularly a mother, might not talk about or hide a child's disability and delay seeking help. Mothers, especially daughters-in-law tend to be blamed for the disabilities their children experience.

**'They might say it was caused by something the mother did wrong in her past life or it may be something in her family, genetic maybe' (FG 6)**

**'it's never their own child, never the son's child' (FG 1)**

Some might believe it was a failure of parenting, especially on the mother's part.

**'Why didn't the mother look after her from the first? Why didn't she take the child to the doctor? She waited too long' (FG 6)**

Again, the majority of women believed that attitudes within their communities were changing, even back in their home countries.

**'You can't stop them saying those things. When the old, old generation are gone it will be different' (FG 6)**

Although all the women in the study understood their own disability or that of the person they cared for, it was evident that such negative beliefs existed and might account for the reluctance to talk about disability and in some cases hide it for as long as possible.

*[T]he majority of women believed that attitudes within their communities were changing, even back in their home countries.*

## ENCOURAGEMENT AND ASPIRATION TO BE INDEPENDENT

Independent women in the study believed their achievements were due to their own efforts but with support from family, schools and, especially, third sector organisations.

**'It all depends on yourself. If you have your own willpower you can do it'. (Susma)**

They had been encouraged by their parents but mentioned their fathers in particular.

**'My father said 'never accept anything less'. My parents gave their whole life to support me. My parents, siblings and friends gave me the confidence to speak up' (Janki)**

However, despite these inspirational women, the relative invisibility of disabled Asian women who are hidden, self-exclude or generally do not work outside the home provide women with few examples of what can be achieved.



*[T]he relative invisibility of disabled Asian women who are hidden, self-exclude or generally do not work outside the home provide women with few examples of what can be achieved.*

Lack of contact with the wider disabled community could contribute to low expectations and lack of awareness of support available to maximise potential. The older generation and families recently arrived from abroad may have no concept of facilities to enhance access for disabled people.

Meena, a 42-year-old woman who is deaf, unable to speak or walk following meningitis at the age of two was watching TV one day. She saw how a disabled boy began to walk using his own willpower and she was determined to do the same. Her parents, doctors and family were shocked but encouraged and supported her to become as independent as possible, taking her on outings and participating in community events. Despite also having learning disabilities, she now walks, dances and does most things for herself independently.

Participants of all backgrounds believed that disabled daughters would be treated no differently to disabled sons, but at the same time cited low expectations at community level, especially among the older generation. Although the literature suggests that some families, especially Muslims, see illness or disability as God's will and as such to be accepted and suffered, this was not so among the participants. They recognised that this did happen but that they had a duty to help themselves.

**'Allah gives us the disease but he gives us the doctors and the pharmacy to deal with it' (FG 3)**

**'Even if you believe it's Gods will, you are expected to help yourself' (FG 7)**

*Although the literature suggests that some families, especially Muslims, see illness or disability as God's will and as such to be accepted and suffered, this was not so among the participants.*

Defining independence in terms of ability to be a homemaker, precludes disabled girls or women who are deemed unable to fulfil that role. They may be seen as unmarriageable, unlikely to leave the family home and therefore not encouraged to maximise their independence.

**'There was some tension with my sisters-in-law who thought I wasn't marriage material. They thought I couldn't do housework or look after children but we are good friends now' (Guljaan)**

The participants recounted cases where mothers are blamed for the disability of their child, they are expected to care for and do everything for them rather than letting them help themselves.

**'The elders would say it's the mother's duty' (FG 6)**

Although the Bangladeshi women believed that a disabled daughter should be encouraged to walk, learn to cook and look after herself, there could be pressure from the older generation. Parents and in-laws especially might say (almost punitively):

**'Don't expect her to cook or do things for herself. That's the daughter-in-law's responsibility.**



### **‘They wouldn’t say that if it was their daughter’s child’ (FG 5)**

All the participants felt that girls should continue schooling beyond the legal requirement but believed that some parents might say:

### **‘What’s the use? She is disabled, she won’t learn anything’ (FG 6)**

While the participants cited examples of reticence, self-exclusion and low expectations, they invariably felt that parents did this to protect the relative from distress and from the negative attitudes and insensitive treatment within the Asian community.

Meena is deaf and unable to speak and has learning disabilities but communicates using sign language. She is very outgoing and socialises well and people in the community who know her well treat her normally. However, in the wider Asian community, she can be stared at and does not feel accepted so her parents avoid certain community events. This means that her life and that of her parents is restricted.

Some of the lack of aspiration and encouragement relates to the relative invisibility of disabled women and especially lack of examples of independence in Asian communities. Although the women were adamant that attitudes were changing, they cited examples of the failure to talk about disability or ill-health within the family.

## **HEALTH SERVICE AND PROFESSIONAL BARRIERS**

The participants believed that Asian families or disabled people did not understand the health, social care or educational system and that it was also very difficult for them to access help and support.

Disabled women and family carers who had been using health and social care services for years felt that systems and responsibilities were constantly changing and they complained bitterly about the impact of cuts to services in recent years. It was hard to keep up with which body was responsible for which service, who managed it and how to access it.

*The participants believed that Asian families or disabled people did not understand the health, social care or educational system and that it was also very difficult for them to access help and support.*

Several women gave examples of supportive GPs and primary care professionals who had guided them in getting treatment or facilities for themselves or the person they cared for. Some individual hospital doctors, health visitors and social workers were proactive in providing support and information or referring the person for other types of support. Several women were happily registered with doctors from their own backgrounds and some practices employed interpreters with relevant language skills. With the exception of women’s health problems, participants were happy to see male doctors. Some chose to see Asian doctors but only did so because of language problems. Many participants preferred ‘English’ doctors believing them to be more professional, independent and, most importantly, they respected confidentiality.

### **'A small problem becomes a big thing in the Bengali community' (FG 2)**

However, many women found it difficult to get GP appointments and those who were older or had poor hearing or English found automated telephone systems difficult to negotiate. Unless there was an acute emergency, participants frequently had to wait weeks for an appointment even when whilst not an emergency their problem was urgent enough to benefit from a consultation within a few days. Since the majority of women and those they cared for had multiple morbidities, only being able to discuss a single problem was prohibitive but they were rarely able to book a double appointment. Participants acknowledged that this was not unique to the Asian community, although it could be worse for people with limited English.

There was also considerable dissatisfaction with the NHS, especially the long wait for referrals and consultations, notes being lost and limited communication between professionals. There is a lack of accessible information about systems and services; even when there is information, participants felt they had a fight to get it. They described being passed from one department to another when asking for help, but felt that this was an issue for everybody and not just Asian people.

### **'Not my department, sorry. Not about being Asian at all, it's about disability. All I needed was simple aids to bath the baby' (Guljaan)**

Participants felt that doctors and other professionals did not understand their culture and would not listen to them, often resulting in inappropriate help and support.

### **'I've had the odd experience of racism, but generally it's not that. It's about professional arrogance. They just make assumptions – because you are disabled you are stupid' (Guljaan)**

Doctors often used jargon and assumed that patients or families who spoke some English understood more than they did. Some women felt doctors and other health professionals treated them as if they were stupid, dismissing their concerns and talking down to them.

### **'I'm physically disabled, not mentally retarded. I get very angry when doctors patronise me' (Janki)**

*They just make assumptions – because you are disabled you are stupid. I'm physically disabled, not mentally retarded.*

Although the provision of interpreters has improved, interpreting takes time. The participants felt this meant that explanations about the disorder, what the person might achieve or how they could be helped was skimmed over. Some mistrusted interpreters from their own communities.

The participants felt that doctors made many assumptions about them, such as blaming their conditions on consanguinity and presuming they believed in curses or other religious causes. Professionals also assumed that the extended family was willing and able to support the person with a disability so help was rarely offered. One carer was told that no help was available.

### **'You have your family, they will be there to support you. There are other people worse off than you' (FG 7)**

*The participants felt that doctors made many assumptions about them, such as blaming their conditions on consanguinity ... Professionals also assumed that the extended family was willing and able to support the person with disability ...*

### SOCIAL CARE AND EDUCATIONAL SERVICES

Although the participants had both positive and negative experiences of the healthcare system, there was extensive criticism of social care services. Problems were exacerbated where outsourced agencies or facilities providers were involved. Carers were frequently unhappy about the quality of support and lack of continuity provided by homecare agencies. In some cases, this was because the care worker had not been allocated sufficient time to do all that was needed. According to one woman caring for her paraplegic husband, the social workers who assess the disabled person and carers needs do not understand disability or demands of 24-hour care and they frequently disbelieve, misjudge and make incorrect assumptions.

**‘they have never got somebody from bed to a chair, showered them, shaved them, dressed and fed them. If they did they would know it takes longer than an hour ... Because X is always smiling, they presume he is OK. He gets spasms and because he moved one hand they presumed he was making it (paralysis) up. She also judged that because his shoes were worn, that he was able to walk’ (Rajini)**

*[T]here was extensive criticism of social care services. Problems were exacerbated where outsourced agencies or facilities providers were involved.*

But mostly concerns were about workers arriving late, not turning up at all and requiring family carers to induct yet another new care worker. Although most participants had experienced some very conscientious and caring care workers, not all were sensitive or skilled.

**‘Lots of carers are rough and rude. One shouts at him and is very impatient. We have lost things from our home’ (Rajini)**

Participants also felt that at a practical level, care workers were restricted in what they were allowed to do. Their duties involved laborious care plans from which they would not deviate.

**‘If it’s not in the care plan, they won’t help you. They don’t seem to use their heads. It is usually something simple’ (FG 7)**

Carers also felt that care workers were unnecessarily bound by or choose to hide behind health and safety regulations. They understood the importance of safety but believed that care workers refused to do simple things they would do in their own homes such as taking something from a shelf just above their head.

**‘I’m not asking them to get on a chair or a ladder. Just to stretch up and get me a new packet of tea’ (FG 1)**

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**‘So much blooming red tape – they could see I was struggling [to hold the baby] but they couldn’t touch him unless he was falling on the floor’ (Guljaan)**

Most carers would have preferred an Asian care worker but understood that they were few and far between and the low wages they received was not conducive to recruitment. If family carers complained to an agency or the local authority, they were usually told that they could have direct payments and choose their own care workers. The majority of participants were reluctant to apply for direct payments. Apart from the paperwork and process of recruiting, women believed that the amount they could pay would not attract a skilled worker for a sustainable period.

Dealing with administration while being a full-time carer was an additional stress carers could not handle. Women or families with little English or older people would be particularly disadvantaged.

*The majority of participants were reluctant to apply for direct payments. Dealing with administration while being a full-time carer was an additional stress carers could not handle.*

Carers or disabled women themselves spent hours chasing up services, being kept on hold, passed from one department to another, leaving messages endlessly without being called back.

**‘The OT, says the problem is not hers, but with XXXXX (the firm contracted to renew the shower chair). The sales rep didn’t listen when I said that model wouldn’t work and now they are not responding to my calls. My social worker says it’s not her responsibility either. Four months without a shower chair (for disabled relative)’ (FG 7)**

Families are reluctant to complain for fear of being victimised but those who had complained felt that nobody listened anyway. Carers who are struggling with the physical and emotional demands of caring do not have the energy to carry on fighting.

**‘They [social services, agencies and councillors] know that if they ignore us long enough we will give up’ (FG 7)**

Participants did not see this neglect as racially motivated but were concerned that families who were not confident in English, or who did not understand the care system were particularly vulnerable.

## THE ETHNIC THIRD SECTOR – A LIFELINE

In contrast to the dissatisfaction and negative experience of health and social care services, a recurrent theme throughout the data is the value of the third sector in supporting, advocating and providing for disabled women and their families. Few participants believed they had been discriminated on grounds of race but without the ethnic third sector they would not have known about services or how to access them.

**‘I’ve had more help from the voluntary sector than all the public services. Bradnet, encouraged me from the start, helped me to get education and services, a car through mobility, things like childcare. They helped me and my social worker get me more accessible housing.’ (Guljaan)**



*[A] recurrent theme throughout the data is the value of the third sector in supporting, advocating and providing for disabled women and their families.*

Participants caring for now adult children with learning disabilities spoke about the importance of the Asian project run by Mencap in Barnet but now discontinued. The Asian project, Navjiyot and APDA (both of which are still struggling because of cutbacks), were instrumental in ensuring families were accessing special schooling, transport, benefits and entitlements. Individual staff and volunteers were named for going beyond the call of duty in supporting and providing services when the mainstream failed to provide.

**‘Thanks to APDA, they gave me my first job and the confidence to learn as I went along’ (Susma)**

Meena, a deaf woman, is unable to speak and has learning difficulties. She attends a voluntary sector activities centre five days a week. She has become much more independent, but not enough to live on her own yet. Her parents are doing all they can but have health problems and need more help than they currently get.

Roshni, who was troubled by depression, receives counselling from a third sector wellbeing centre. They helped her arrange work experience as part of her recovery and she is now working part time with another community organisation.

The memory café at the East London Mosque is an example of joint working between the Alzheimer’s Society, the London Muslim Centre and local Bangladeshi community. It is a social group for people with dementia, their families and carers who speak Bengali/Sylheti. It has been a lifeline for carers in particular.

**‘I would have been lost without the support this group gives’ (FG 3)**

**‘I get it all off my chest. We share our sorrows. We learn from each other’ (FG 3)**

Most ethnic voluntary organisations emerged to meet the needs of people from different cultures whose needs were not being met by statutory services, or whose experiences with mainstream services were unsatisfactory or in some cases discriminatory. Many of these organisations that still exist continue to pick up the fallout from spending cuts. They are sensitive to the needs of their communities, reach into the farthest corners of those communities and provide help and assistance in ways that the mainstream is unable or unwilling to deliver.

*They are sensitive to the needs of their communities, reach into the farthest corners of those communities and provide help and assistance in ways that the mainstream is unable or unwilling to deliver.*

## ISOLATION FROM FAMILY AND COMMUNITY

What was evident from the interviewees and focus groups was the isolation experienced by disabled people and the families that cared for them. In some extreme cases the mother and child

are disowned, as recounted by the mother of a daughter in her 30s born with Downs syndrome.

**‘When I needed support most, my husband left me. He was in complete denial and couldn’t accept the child’ (Hema)**

Generally, the disabled person and carers find their friends and sometimes even their family stop visiting.

**‘(Other) families believe they might catch it or be affected by it’ (FG 1)**

**‘There was no help from the community at all. It was a girl too and that made it worse’ (Hema)**

*It was a girl too and that made it worse.*

Some families excluded themselves to protect themselves and the disabled person from insensitive or negative attitudes of members of the community. The participants invariably spoke about being avoided, hearing negative comments within earshot and the person pushing the wheelchair being addressed rather than the disabled person.

**‘People make gestures that are really degrading – like you should be making repentance, blaming the parents’ (FG 1)**

Despite the myth of the extended family and close-knit community, families and particularly women felt alone in their role as carers. A small number of women felt they had the support of their spouses, siblings or wider family but the majority were left to cope with little support.

**‘When X was first ill, people came to visit but we became progressively isolated, especially when he didn’t get better. It was like they were afraid of being asked to help. They didn’t want to get involved’ (Rajini)**

Apart from the practical hassle and the cost of transport, disabled women or the persons they cared for did not always feel welcome at family gatherings or community events. Several mentioned not being made feel welcome in Asian places of worship. One woman, felt embarrassed when she was told she had to stay in a certain area of the temple so that her wheelchair would not damage the carpet.

**‘You feel segregated – like it’s them and us’ (FG 7)**

Although one family felt very supported by their faith community, the majority of participants found little help from their different religious groups.

**‘My neighbour is disabled and people from her church come and visit her every week and they come and take her to church on Sunday and to other things happening at church. That doesn’t happen with us Hindus’ (FG 7)**

**‘I haven’t found the temple or faith leaders helpful or supportive because they don’t understand disability’ (Hema)**

*[T]he majority of participants found little help from their different religious groups.*

### WOMEN AND INFORMAL (FAMILY) CARE

The majority of informal care was undertaken by the women across the different cultural groups. Women, sometimes disabled themselves, were caring for spouses, ageing parents or parents-in-law, children with physical and or learning disabilities, autism or mental health problems. Some women, were struggling under the demands of caring for disabled siblings having made ‘deathbed’ promises to their parents. Although a few carers felt supported by family members, others were coping alone under great pressure.

Many of the Bangladeshi women were in very poor health with a range of conditions such as diabetes, hypertension, high cholesterol; many suffered physical aches and pains and depression. They were generally younger than the Indian/Gujarati women and although the majority identified themselves near the upper end of a 0-10 dependent-independent disability scale, when we asked them to rate their health on the same scale, they were nearer 0, thus rating their health as poor or very poor.

*Many of the Bangladeshi women were in very poor health with a range of conditions such as diabetes, hypertension, high cholesterol; many suffered physical aches and pains and depression.*

Women were also caring in overcrowded or unsuitable accommodation and service cutbacks were having a negative impact. One woman caring for her 83-year-old mother lives in a one bedroom privately rented flat with a small inaccessible bathroom. She has been on her local authority housing list for 5 years and applied again recently. She was told because her mother had dementia and they were of the same sex, they did not qualify for a bigger property.

One woman, living in a multigenerational household found solace in the Monday Memory Sitting at London Muslim Centre.

**‘We have a bit of space here. I have nowhere to sit at home. I don’t want to go home’ (FG 3)**

Some family carers were receiving no help from social services or any of the welfare benefits to which they were entitled. This was because husbands, parents or other family members prevented them from applying, although a couple of women had gone against these wishes and were glad to have done so.

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The reluctance to seek help or benefits relates to a desire not to be relying on ‘handouts’. Some women felt that men might be embarrassed because they felt unable to support their families.



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They also talked about families who did accept social care or benefits but were so ashamed they kept it secret from outside the immediate family.

For a small number of Muslim women, however, not seeking external help was a way of proving they were 'good women'.

**'If you apply for allowances, you will get no (heavenly) rewards' (Shazia)**

Informal care was impacting on the mental health of the participants. A number of women experienced anxiety and several were being treated or felt they needed treatment for depression. Some women had nobody to turn to but others were able to talk to husbands, siblings or other family members although they did not necessarily understand the behaviour of an autistic child, an elder with dementia or especially the demands of the caring role.

**'My brother and sister are great and so is my husband, but he does not understand our son's condition (non-verbal autism)' (FG 2)**

However, some other women bottled up their problems and were unwilling to burden family members or friends.

**'They have their own worries' (Roshini)**

*Informal care was impacting on the mental health of the participants.*

## RELIGIOUS BELIEFS AND PRACTICES

Focus group participants believed that older people and people from some faiths held strong religious beliefs that disability was either a punishment from God or a test of strength to be endured for some eternal reward. However, they generally felt that this was because people did not have enough knowledge about the disabling condition and when people had better information they were less likely to believe in religious causation.

For the majority of participants, but particularly for the Bangladeshi (Muslim) women, their faith was very important. Faith and personal prayer gave them courage, peace and the strength to cope.

**'I was very spiritual as a child. We were brought up that way. Not rituals but real faith. I lost it a bit when X became ill but it gives me strength and courage now' (Rajini)**

One young woman, who rarely goes to the mosque except at Ramadan did not consider herself very religious but derived great peace from undertaking the Haj with her sick mother and extended family. When her grandmother died, she wore the hijab and niqab for several weeks.

**'When I was praying and into my religion I couldn't think about my problems or if I did I thought more positive' (Roshini)**

However, when asked whether they would confide in a religious leader about their own disability or that of a child or relative there was a resounding 'No' from women of all faiths.





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### **'It's not an imam issue' (FG 5)**

They agreed some families might visit a holy person or a sacred shrine either before or in addition to seeing a doctor, but they themselves would not. The group had major misgivings about the role of religious leaders, some of whom had advised people to stop medication and who told one paralysed man to stop being lazy.

*[W]hen asked whether they would confide in a religious leader about their own disability or that of a child or relative there was a resounding 'No' from women of all faiths.*

The participants also felt that old, male imams or priests did not understand disability, women or what being disabled in England was about.

**'There is not a lot of understanding of disability in the mosques. It's still a taboo. Also, if you can't get your point across they will walk all over you. The leaders told me I'm too outspoken but I still believe in Islam' (Guljaan)**

But their major objection to seeking help from religious leaders was because people were required to pay for prayers or 'healing'.

**'To them it's a business. They will keep making you come back to pay more and more' (FG 5)**

They understood that not all families were as sceptical as they were, but motivated by a need to find a cure.

**'People are so desperate to get better they will try anything, spend money they haven't got, taking out loans' (FG 6)**

It was clear that their respective personal faiths were important and gave courage and strength but there was a wariness about faith leaders, who could in the right circumstance play a significant role in supporting families and addressing stigma.

## MENTAL ILLNESS AND DEMENTIA

The participants identified that whilst Asian communities found it hard to talk about disability, the stigma and taboos around mental illness were much worse.

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They reported that mental illness does not just affect the person concerned but the whole family and in Asian communities impacts on marriage prospects for siblings.

Whilst most raised concerns about anonymity and confidentiality, women in some groups and in several interviews talked openly about their own mental health. Several women had been or were currently depressed. Although participants suggested that some people in their respective

communities might believe in curses, spells or possession by jinns, they believed their own mental illness was due to bereavement, family or marital problems, worry about children or other family members. One young woman was depressed because of a long-standing physical condition.

Several women were caring for children with mental health problems; some were in the care of community mental health systems but others had refused or had dropped out of services. A number of the Bangladeshi women talked about children with degrees of autism and struggles to cope with families and schools who saw the child's behaviour as the result of poor parenting, particularly mothering.

One young woman had been caring for her mother who had a severe and enduring mental health condition since her father left 20 years ago. She had struggled with depression at times during this period but after the birth of her daughter found the responsibility of caring for her mother, a new baby and running the home too much. She was able to talk to her husband and close friends but felt she needed professional help.

**'I felt I needed to sort myself out. I didn't want drugs; I saw what they did to my mother. I asked him (GP) to refer me for special help' (Roshini)**

Her GP referred her to a community wellbeing service that provided culturally sensitive therapy. She continues with this therapy and is now working in a third sector organisation. She is enjoying the job and planning to work towards a qualification in that field.

One focus group (FG 3) involved Bangladeshi women who were caring for older relatives with dementia. Most women had never heard of or never encountered dementia before it occurred within their family and there is no direct translation for the term in Bengali/Sylheti. Although they suggested the community did not want to talk about dementia, the women openly discussed this once they were assured of confidentiality.

*Most women had never heard of or encountered dementia before it occurred within their family and there is no direct translation for the term in Bengali/Sylheti.*

**'They (community) don't want to talk about it, but if they don't, how will they know? I knew nothing at first but coming to this group, I learned all about dementia. I would be lost without the support' (FG 3)**

The women understood that dementia was a disorder of the brain that was related to old age but they also rationalised that it was due to having a difficult early life and working too hard. A number of them used terms like 'overthinking' or 'too much thinking' to explain it.

They demonstrated a resigned acceptance that caring was their wifely or filial duty.

**'I raised my children and educated them and now it's time to care for my husband' (FG 3)**

Nonetheless, the women found caring for a parent with dementia challenging, especially not understanding why their loved one was behaving strangely.

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One woman living in a three-generational household spoke about her husband's dementia impacting on the whole family. Six people shared two bedrooms in a two-storey house largely unsuitable for two elders with limited mobility. She described not having any privacy and constant tension over noise, TV programmes and access to bathrooms especially in the morning. The family were told that dementia was not a housing priority for the LA.

**'We need a better house but it needs to be near the mosque so Dad can continue to go there and retain his independence' (FG 3)**

Several women felt their lives had contracted. They were constantly worrying about the person they were caring for but were also anxious to avoid upsetting their children or grandchildren. Many of the women had aches and pains that might well have been somatic symptoms of the distress they were experiencing.

## PLANNING FOR THE FUTURE

One of the most worrying findings was the number of older women caring for their adult children who were physically or intellectually disabled, or both, and who were still dependent on them. Invariably they were worried about what would happen when the mother or father were no longer able to care. However, it seemed that few had any strategic plans for the future.

*One of the most worrying findings was the number of older women caring for their adult children who were physically or intellectually disabled, or both, and who were still dependent on them.*

Participants argued that parents of disabled daughters would consider trying to arrange a marriage as a way of ensuring she was cared for by her husband when they were gone. However, some carers recognised that their daughters were too disabled to be able to marry. The general feeling was that British born or raised Asians would not marry a disabled person. Some carers wistfully hoped that they might find a nice boy from 'back home' who would marry their daughter. However, they believed it would be easier to find a girl from 'back home' to marry a disabled boy, than a husband for a disabled girl.

These views were more prominent in the Bangladeshi groups and several examples of marriages arranged overseas were discussed. There was a widespread anxiety, however, that young men from overseas might just marry to get a visa and once they were free to stay in Britain, they would leave the girl.

**'He will come here, get his papers and then be off' (FG 6)**

Participants recounted marriages from overseas that had worked, some that did not and many from the same countries that did not succeed. Although some of the participants were married to men from abroad, they felt the adjustment had not been easy for either party. Everybody acknowledged that marriage against the persons will, would be a forced marriage and illegal.

When asked if the girl wanted to marry a boy from another culture who was prepared to look after



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her, the participants thought some parents might be unhappy but on balance it might be preferable to arranging a marriage from abroad that might not work once the man got his right to remain.

**‘Some parents would be concerned that she might want to get married and they would lose a grip on their culture’ (FG 6)**

**‘If she is living independently and she meets a person who loves her and is willing to care for her, then that is OK’ (FG 6)**

The vignettes explored attitudes to allowing a disabled young woman to live away from the family in fully adapted supported housing to prepare her for an independent future. Participants from all backgrounds were clear that this would be highly unacceptable in Asian communities, although a few voices said

**‘She should go. Let her be happy and independent’ (FG 5)**

Families, especially fathers, would worry that the girl might not be able to cope alone and she might be exploited because of her vulnerability.

**‘They would worry that she is not safe on her own. It’s dangerous out there’ (FG 5)**

Families who allowed their daughter to live away from home would be concerned about being judged by the community.

**‘They will be afraid of what people might say, but families who make those decisions need to be supported’ (Susma)**

There were also practical reasons for parents wanting to keep their daughter in the family home as long as possible.

**‘Parents might rely on her benefits. They might be entitled to better housing or get help with rent’ (FG 5)**

In the absence of marriage and the inability of the individual or lack of preparation for independent living, the expectation was that when parents passed away brothers or sisters would take over. A small number of participants were caring for siblings having promised their late parents that they would protect them. Although many felt obliged to, the general view was that families are changing. Children raised in the UK would not be so willing to undertake these responsibilities and it was unreasonable to expect them to do so.

**‘People have their own lives to lead, their own children to look after, they are busy, women go out to work ... even if a brother or sister agreed, their husbands or wives might not and that would cause tension’ (FG 7)**

Many of the carers were growing old, some arguably before their time and were struggling with ill-health often the result of the strain of unsupported caring. Should a carer become suddenly ill, there were no plans in place to support the disabled relative.

Meena, a deaf, mute woman with learning disabilities is mostly independent in her day-to-

day activities but arguably not enough to live on her own away from the family. Her parents are making her as independent as possible but they have health problems and don't feel they get enough support from social services. They are somewhat over-protective and would not allow her to live on her own even if she were able to cope because of the stigma she would face in the Asian community. They are growing old and are hoping for a miracle so she can live independently with someone who can take care of her and protect her. In the worst-case scenario, they are thinking about a care home, which they would do with a very heavy heart, if they could find the right home.

*One family confided that they had considered voluntary euthanasia but although their religion forbade it, they had not ruled it out.*

A few parents and one spouse had reluctantly considered residential care but were not happy with what they found and a few had negative experiences of respite care. One family confided that they had considered voluntary euthanasia but although their religion forbade it, they had not ruled it out.

While it may be too late for some families, those with younger disabled children need support and encouragement to challenge some of the taboos within the community. They need help to ensure that legislation around education and employment are invoked to maximise the person's potential. They need to have courage to allow their daughters to live away from the family home, with whatever support is necessary.

Not everybody will be able to live independently but there is scope for a lot more to do so with the right kind of support.

**'They must start early, go to the council, talk to somebody who knows what to do because it won't happen overnight' (FG 7)**

*[T]hose with younger disabled children need support and encouragement to challenge some of the taboos within the community.*

## DISCUSSION OF FINDINGS

The data demonstrates that Indian women, Asian women from East Africa and Bangladesh and a small number of Pakistani women were delighted to be asked about disability. Although many were reluctant to have their voices recorded, they spoke openly in focus groups and interviews about disability, mental illness and other sensitive subjects. They described barriers similar to those experienced by other disabled women and although some differences were evident, the cultural barriers they faced were common across the cultural and religious groups. It was also evident that more recently arrived Bangladeshi disabled women and carers were still having many of the problems the older Gujaratis experienced decades ago.

*They described barriers similar to those experienced by other disabled women and the cultural barriers they faced were common across the cultural and religious groups.*

The research undertaken through the auspices of Asian Disabled People's Alliance (APDA) and partner organisations recruited women with a range of disabilities as well as women caring for adults or children with diverse disabilities. We encountered some disabled Asian women who were leading independent lives with support from family, external services, aids and technology. However, the overall impression from the interviews and focus groups was that women saw independence as being able to undertake housework and childcare with minimal, if any, support from others.

*However, the overall impression from the interviews and focus groups was that women saw independence as being able to undertake housework and childcare with minimal if any support from others. [F]ew women saw independence in relation to work outside the home or living away from the family.*

While not denying the value of this role and risking ethnocentricity, few women saw independence in relation to work outside the home or living away from the family. The low expectations of what a disabled girl or woman might achieve, or the support that could facilitate independence, is rooted in cultural, professional and service related and structural causes. These all overlap and interact to compound the problem.

*The low expectations of what a disabled girl or woman might achieve ... is rooted in cultural, professional and service related and structural causes. These all overlap and interact to compound the problem.*

When asked to prioritise the barriers to be overcome in ensuring independence for disabled Asian women, the participants were clear. They felt the social care system was a major stumbling block for disabled women or women caring for disabled family members. They reported repeatedly that

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family carers are at breaking point. Some of this relates to how health and social services have been eroded over recent decades. Although participants cited examples of health and occasional social care professionals who had informed, supported and guided them, there were more experiences of a fragmented, pressurised system that did not appear to care.

*They felt the social care system was a major stumbling block for disabled women or women caring for disabled family members.*

The literature, highlights the lateness to access or low uptake of health and social care services by South Asian families with disability or caring for children or others with disability (Hatton *et al* 2012, Parveen *et al* 2011). Language, literacy and lack of IT access or skill were major barriers in diverse Asian communities. Lack of accessible information about services and benefits are compounded by complex application processes and strict eligibility criteria. These problems affect all disabled people but are amplified for Asian families who, for various reasons, apply late and, do not understand the system, or lack the language to navigate it.

*Lack of accessible information about services and benefits are compounded by complex application processes and strict eligibility criteria. These problems ... are amplified for Asian families ...*

## PROFESSIONALS AND SERVICES

Studies since the late 1990s/early 2000s clearly demonstrate the difficulties experienced by disabled or mentally ill Asian people or the families of disabled Asian people accessing effective support (Azmi *et al* 1997, Bignall and Butt 2000, Jones *et al* 2001, Hatton 2002, Bhui and Bhugra 2002).

Around two decades later, the literature is still awash with the problems Asian people experience when trying to access professional help or support services because of language, communication, stereotypes, expectations and assumptions about minority ethnic parents (Heer 2012, Heer *et al* 2015). Although there was some reluctance to access medical help or seek services outside the family, the reasons given by the women in this research were less cultural and more to do with professional attitudes and service ethos.

*... the literature is still awash with the problems Asian people experience when trying to access professional help or support services ...*

Language barriers preclude access to information as well as clients not being able to communicate with professionals or understand the information they are given (Soderstrom 2013). As existing research shows (Kapadia *et al* 2017), participants had anxieties about interpreters maintaining confidentiality within their own communities. Although interpreting services had improved over decades, currently they are fewer and harder to arrange because of financial cutbacks.





*Although there was some reluctance to access medical help or seek services outside the family, the reasons given by the women ... were less cultural and more to do with professional attitudes and service ethos.*

The lack of direct translation of medical or diagnostic terms into various Asian languages (Kaiser *et al* 2015) was also cited by participants as a reason for delayed access to medical help. However, not being fluent in English was a real issue that doctors and other professionals did not appear to appreciate. While the women were embarrassed about their weak English, they nonetheless felt patronised, devalued and incompetent through their interactions with professionals.

*[N]ot being fluent in English was a real issue that doctors and other professionals did not appear to appreciate.*

Professional attitudes and experience of health and social care services were also barriers to independence. The literature suggests that professionals expect Asian parents to have low expectations of the potential of people with disabilities (Byewaters 2003, Poulson 2005). They also expect them to believe that disability is caused by curses, jinns or punishment for past misdemeanours while they, the professionals, focus on consanguinity (O Hara *et al* 2003). Conversely, participants variously described the underlying causes of their own or relative's disability in terms of injury, lack of antenatal care, birth trauma, medical neglect or communicable diseases.

*Professional attitudes and experience of health and social care services were also barriers to independence.*

Most participants knew the risks associated with consanguinity but felt blamed for cousin marriage because professionals were reluctant to consider wider factors such as medical neglect, lack of antenatal care or birth trauma. These feelings may well have impacted on their willingness to seek external help in a timely fashion. They were quite clear that couples who had more than one child with disabilities had been failed by health professionals who had not given enough information, or given it in a way that was not accessible or acceptable.

While the participants did not subscribe to the same beliefs as their elders or people from more traditional societies, cultural beliefs may still impact on how they perceive disability and professionals would be well-advised to understand, respect and work with them (Chaudry 2015).

*[C]ultural beliefs may still impact on how they perceive disability and professionals would be well-advised to understand, respect and work with them.*

Several participants talked about the struggle for information about children with mental health problems or autism spectrum disorder in the past and present time. Hatton *et al* (2003)



highlighted the importance of the disclosure process in helping parents to understand their child's condition and to share this 'medical' knowledge with family and friends. Parents felt they were given little explanation when a diagnosis was disclosed and they were rarely offered post diagnostic support. If as Hatton *et al* (2003) suggest, parents are given a diagnosis sensitively and honestly with as much information as possible about how to maximise independence, they might have been enabled to navigate the care system.

This could be cost-effective in ensuring the right treatment and support and reducing crises for the disabled person or their carers. They might also be able to help the whole family understand the biomedical reasons for a disability and support them in maximising the child's independence.

*Parents felt they were given little explanation when a diagnosis was disclosed and they were rarely offered post diagnostic support.*

Although several women lauded their own GPs, hospital doctors or health visitors, the data shows the difficulty of getting information, being referred for specialised help or receiving satisfactory care. Almost without exception the women understood primary care and felt that the population in general was dissatisfied with constraints and cutbacks. Although they were generally familiar with specialist services now, many were not aware originally about the specialist services that could help them. Families who managed to find educational support, homecare or learning disability or autism services had found them through the information, advice and advocacy of third sector BME organisations, not health and social care professionals.

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Family carers had mixed experiences of the health service, but most felt they had not been offered sufficient information about the social care services that could help maximise independence. Few were offered homecare to support them and did not ask because they felt they were doing their duty as wife, mother, daughter or other female relative (Parveen *et al* 2011). Some of the younger more recently arrived Bangladeshi participants looking after elders or disabled children did not realise there was any alternative.

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A few women carers were actually told they did not need external help because they had family to help them. There is a long history of presuming that BME families 'look after their own' but contrary to widespread assumptions, the extended family is not a guarantee of support when caring for disabled children, frail parents or elders with dementia (Katbamna *et al* 2004, Bavishi

2013). This resonates with the experience of the majority of participants, caring for elders, disabled children and in some cases both.

Although their children, especially daughters are required to help with housework and childcare, the main work of caring generally falls to the mother. Some men are helpful and supportive and often dealt with hospital or other professional appointments but not usually with the delivery of personal care (Katbamna *et al* 2004). Not all Asian carers live in multiple generational housing, but those who do cannot necessarily rely on support from other family members (Bavishi 2103). Again, while some women felt supported in large households, for the majority more tension was created.

However, there are other cultural norms that health and social care professionals need to note. Informal care is stressful but there are cultural norms that add to the pressure for Asian women. Sons are expected to care for parents, so personal care is mostly undertaken by their wives. Although participants did not express this personally, they gave examples of the considerable strain that often exists within extended families, in particular between mothers and their daughters-in-law (Bavishi 2013, Parveen *et al* 2011). Daughters-in-law can feel that their efforts in caring for their husband's parents are not appreciated (Katbamna *et al* 2004).

This is not unique to Asian women, but because of differences in status within Asian families, it can be more stressful, especially if the carer does not feel in control or appreciated (Parveen *et al* 2011). Similar to other informal carers, Asian women experience considerable stress and depression that is not necessarily recognised by their families or other health professionals until a crisis occurs (Bunting and Jenkins 2016).

The carer participants highlighted inappropriate assumptions made by social workers or outsourced agencies when assessing disabled people and their carers for homecare services and assistive equipment. Yet again, the women appreciated that this might not be unique to Asian families, but assumptions about extended family care might underestimate the need for services (Katbamna *et al* 2004).

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The eligibility criteria for homecare in particular had become much higher and families reliant on it were faced with a rapid turnover of staff, workers who were unqualified and tied to very short time slots in which to carry out several duties.

Although not everybody was comfortable with a careworker from their own community, the lack of Asian care workers or workers who understood and respected Asian cultures was a problem for many, particularly those who may have lost their ability to speak or understand English after a stroke or dementia.

Perhaps more distressing was that family members could not rely on care workers to arrive when

they were supposed to. Because they were rushing for the next appointment the care they gave was often rough and incomplete and distressing for the client.

The term 'fighting' was a recurrent theme across the participants' narratives. Carers for people with disabilities found themselves fighting for services in addition to the demands of caring. They were constantly on edge, spending hours on the phone or waiting for responses that never came. They were fearful of complaining in case services or benefits were withdrawn and felt they were constantly having to compromise and it was wearing them out.

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Housing professionals did not appear to understand the difficulties of caring for a disabled child, an elderly person or somebody with dementia (Hatton *et al* 2003). Living in a multigenerational household did not necessarily mean carers had additional support (Bavishi 2013). In fact, it was more often more stressful because of overcrowding, lack of space for a disabled child, or inadequate bathroom facilities for two or three families. Dementia did not appear to be grounds for better housing and because disabled mothers sharing with the daughters who cared for them were of the same sex, they did not meet eligibility criteria for an extra bedroom.

The experiences of social care services were unsatisfactory for the majority of participants. Although few felt their negative experiences were racially motivated, they agreed that their limited English and unfamiliarity with the health and social care system was a problem when trying to access services. This was compounded by professionals' assumptions of an extended family willing and able to contribute to informal care.

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## COMMUNITY BARRIERS

Although the participants prioritised the barriers related to health and social care systems, they also highlighted cultural beliefs and ideas that militate against disabled Asian women reaching maximum independence. These interacted with and were compounded by the limitations of health and social care services.

The data demonstrates a preponderance of low expectations of what a girl or woman with a disability might achieve across all groups. This generally reflected a lack of knowledge about the cause and effects of an impairment, especially when it first becomes apparent in a child or adult. Language, literacy and 'wait and see' all play a part in delaying seeking help. Lack of information is

compounded by the way disability is hidden and not talked about in Asian communities as well as the absence of accessible information from professionals and services.

Stigma, taboos and shame are recurrent themes in the literature on disability and mental illness in Asian communities and it impacts on the whole family and not just the person affected (Chaudry 2016, Gilbert *et al* 2004, Papadopoulos *et al* 2013).

Participants invariably said that attitudes to disability and mental illness were changing within Asian communities even within their home countries. Almost everybody spoke freely to researchers in interviews and in focus groups about their own disabilities, mental health or that of relatives they were caring for having clarified the anonymity and confidentiality of the research. Nonetheless they talked about stigma, taboos and traditional beliefs and an unwillingness to talk about disability or mental ill-health that persists among elders and some sections of all communities.

Concerns about family honour, confidentiality and fear of gossip mean that disability and mental health are not discussed outside the very immediate family (Time to Change 2010). This can mean that disabled people have no contact with others in a similar position, either in their own communities or the wider community (Scior undated). This deprives them of positive role models or the peer support that could reduce their isolation and signpost them to opportunities to maximise potential and enhance their independence.

These issues were raised by all groups, which suggests that they are still influential and the data suggests that to be fully open about disability or mental ill-health can still be difficult for Asian women or their families.

*These issues [such as stigma] were raised by all groups, which suggests that they are still influential and the data suggests that to be fully open about disability or mental ill-health can still be difficult for Asian women or their families.*

Existing research highlights how Asian communities understand disability and mental illness being caused by the wrath of God for some misdemeanour in the past, a test of spiritual strength, curses, black magic or other supernatural causes.

The participants confirmed this but believed that such beliefs were held by 'other' people, particularly the older generation or very religious people from traditional cultures. They described their own disability or that of the person they were caring for in lay medical terms such as injury, infection, genetics or medical neglect. In keeping with existing literature, beliefs about disability and mental illness were drawn from a combination of popular medical, religious and cultural systems (Heer *et al* 2012 and Weisner 2007). Participants argued that Asian people tended to adhere to religious and cultural explanations when they lacked other information. They themselves explored all possible explanations at some point and although they did not discard the traditional, once they understood biomedical reasons, gave those primacy.

*In keeping with existing literature, beliefs about disability and mental illness were drawn from a combination of popular medical, religious and cultural systems. Participants argued that Asian people tended to adhere to religious and cultural explanations when they lacked other information. [T]he influence of parental or wider family attitudes was often inhibiting.*

Although the study participants held a combination of beliefs about disability and the importance of maximising their own or their child's potential, the influence of parental or wider family attitudes was often inhibiting. Women described the tension that existed between the disabled woman or mother of a disabled child and parents, parents-in-law or wider family members. The data suggest generational differences whereby younger families tended towards western biomedical explanations whereas older or more traditional family members tended more towards traditional religious or cultural beliefs. As Heer *et al* (2012, 2015) found, this meant juggling with traditional beliefs in the family while trying to do what was best for the child or disabled person.

In communities where elders are respected and listened to, the struggle to encourage a child or disabled adult to be independent can be great when elders who may well live in the same household have lower expectations (Hussain *et al* 2002). The women in focus groups and interviews gave examples of how ignorance about what a disabled person could achieve was reflected in overprotection and a lack of encouragement for them to help themselves.

Participants reported a tendency among grandparents particularly to feel hopeless and sorry for the child and want to make life easy for them. There was often pressure from grandparents who felt it was the mother's duty to do everything for the child rather than encouraging them to do things for themselves.

The data repeatedly reports the cultural tendency to blame the mother for a child's disability as reported by Malik (2011) and Heer *et al* (2015). Beliefs varied, such as a past misdemeanour in the mother's life, a genetic trait in the maternal line, poor mothering or delay in accessing help.

The participants highlighted how daughters-in-law rather than daughters are more likely to be blamed, making it harder for a mother in such situations to go against the family. This could well be linked to the lack of encouragement for a child to help themselves and become independent (Hussain *et al* 2002). Apart from the potential to hurt a mother, the fear of being judged might well be a barrier to seeking help when the mother is struggling to understand and care for a child with a disability.

Participants acknowledged that boys were generally pushed more in life and this is probably bound up in the expectation that a disabled girl would never be marriageable. At a practical level, when there are other children to care for it may be quicker to do what is needed for the disabled child.

*Participants acknowledged that boys were generally pushed more in life and this is probably bound up in the expectation that a disabled girl would never be marriageable.*

The expectation of being homemakers clearly impacted on how independent girls and women were encouraged or aspired to be. The evidence resonated with existing research (Hussain 2005, Gilbert *et al* 2004) and was tied up with how ‘marriageable’ a girl was deemed to be and those thought to be incapable of housework were neither marriageable nor in need of education. For disabled Asian women, working outside the home, living away from the family and utilising various services and technologies to maximise independence can create tensions. Although participants did not necessarily subscribe to traditional beliefs about disability, they invariably felt that a girl living away from the family was unthinkable in Asian communities. Parents not surprisingly worried about a disabled girl being able to cope with living alone even in adapted accommodation.

*Although participants did not necessarily subscribe to traditional beliefs about disability, they invariably felt that a girl living away from the family was unthinkable in Asian communities. They recognised that supported accommodation might be empowering for a young disabled woman but except for a few participants it was almost a step too far.*

Although changing, participants talked about gossip in the community as a factor in not allowing disabled girls to live independently. Another reason is the desire to protect girls from being taken advantage of by men or becoming pregnant and being left to cope alone. They recognised that supported accommodation might be empowering for a young disabled woman but except for a few participants it was almost a step too far.

Although the literature suggests that religious beliefs can act as barriers to seeking help and treatment (Katbamna *et al* 2000), the data in this study does not bear this out. Participants talked about ‘other people’ or ‘the older generation’ who believed that disability was a punishment from God, or a test to be conquered, but argued that such beliefs reflected a lack of knowledge. However, the majority of participants of different belief systems found their personal faith helped them to cope and gave comfort. They invariably questioned their faith initially but later found it a support.

*Although the literature suggests that religious beliefs can act as barriers to seeking help and treatment, the data in this study does not bear this out. What was clear across all groups was that nobody would seek the advice of a faith leader and most would avoid it.*

What was clear across all groups was that nobody would seek the advice of a faith leader and most would avoid it. They were scathing of religious ‘men’ who did not understand but who saw it as a way of making money from vulnerable people. With a few exceptions, disabled participants and carers felt unwelcome in places of worship. They believed disability and mental illness were still taboo or at best misunderstood within faith communities and by religious leaders.

*With a few exceptions, disabled participants and carers felt unwelcome in places of worship.*



The notion of the close-knit community was generally challenged by the data and the isolation disabled people or those caring for a disabled child or adult experienced was repeatedly recounted. Contrary to expectations, disabled participants and family carers felt cut off from the extended family and community.

Some of this was self-exclusion that appeared more about protecting the person with disability or their carers from an ill-informed and often hostile community. In some cases, disabled people were not encouraged or not even invited to family gatherings or cultural events and some participants did not feel welcome at religious services or faith events. They described situations where their disabled relative was either avoided, not spoken to or treated in a patronising manner. What was clear was that carers of disabled adults and children self-excluded the family unit to protect their loved one's feelings and possibly their own and to avoid embarrassing situations.

It is important to note that this was not about shame, family honour or wanting to hide the disabled person mentioned in existing literature (Gilbert *et al* 2004, Papadopoulos *et al* 2013), rather than protecting them from an unwelcoming community who lacked knowledge and empathy.

*[C]arers of disabled adults and children self-excluded the family unit to protect their loved one's feelings and possibly their own and to avoid embarrassing situations. [T]his was not about shame, family honour or wanting to hide the disabled person ..., rather than protecting them from an unwelcoming community who lacked knowledge and empathy.*

The data demonstrate clearly that women, some of them with disabilities were caring for elders or children with learning disabilities, mental illness or dementia with limited or no help from family or social services. A small number of disabled women or family carers were supported by husbands, siblings, children or grandparents. While only a few women explicitly stated that their husbands were unsupportive, the data suggest that men neither expected nor were expected to help care for sick or disabled relatives except in emergency situation as shown by Hussain (2005).

*While only a few women explicitly stated that their husbands were unsupportive, the data suggest that men neither expected or were expected to help care for sick or disabled relatives.*

Most of the women would have welcomed external help with personal care for disabled relatives but were prevented by husbands, parents or wider family members from seeking external support. Some of this was related to lack of understanding about social care but there was also considerable suspicion about intrusion, mostly by husbands or wider family. However, what was apparent was an undercurrent of shame associated with contemporary discourse about 'handouts'. Participants who used social care generally did not talk about it outside the family and women described families who are so ashamed that they do not tell anybody they are receiving external help or welfare benefits.

For a small number of Bangladeshi women, reluctance to seek external help or welfare benefits was about the expectations of women, whose duty is seen as caring. A small number of women carers did not access social care or welfare benefits because they wanted to prove themselves to be a 'good woman', standing on their own two feet and coping alone. They believed that help or money from external sources was not in keeping with being a 'good woman'.

*[W]hat was apparent was an undercurrent of shame associated with contemporary discourse about 'handouts'. Participants who used social care, generally did not talk about it outside the family and women described families who are so ashamed that they do not tell anybody they are receiving external help or welfare benefits.*

This reflects internalisation of cultural or religious views about women's roles (Hussain 2005) that women, especially those from traditional societies or recently arrived from abroad, do not question. Additionally, if women feel blamed for their own or a child's disability they may accept this as part of their 'punishment'. For the majority however, feeling judged by the wider community, is a barrier that women can do without when trying to access the ever-reducing services to which they are entitled.

The research highlighted an issue the extent of which had not been anticipated. Although the Bangladeshi women were generally younger than the Indian or East African Asian participants, they had a very high level of poor health. Most looked older than their years and some were disabled by various illnesses although none to our knowledge were registered as such. Although the majority considered themselves independent, most identified their health as poor. Several women were having treatment for high blood pressure, diabetes, high cholesterol and some were being investigated for non-specific aches and pains. A number spoke openly about depression and anxiety.

*Although the Bangladeshi women were generally younger than the Indian or East African Asian participants, they had a very high level of poor health. Most looked older than their years and some were disabled by various illnesses although none to our knowledge were registered as such. A number of women, spoke openly about depression and anxiety.*

The findings show that contrary to beliefs and with the exception of women's' health problems, the participants were happy to consult male doctors. Although some women were happy with doctors from their own community, in keeping with Kapaida *et al* (2015) others preferred English doctors who listened to them and were unlikely to breach confidentiality as they believed Asian doctors might.

While the health of Bangladeshi women is a concern in itself, the impact of falling ill as a carer could have significant consequences. Carers were often struggling with limited support from family and because they appeared to be coping, little help was offered unless there was an emergency.



*While the health of Bangladeshi women is a concern in itself, the impact of falling ill as a carer could have significant consequences.*

The literature highlights the particular taboos around mental health (Gilbert *et al* 2004, Thabusom 2005) and this was confirmed to a substantial degree by the participant data. Although the majority of women refused to allow recording of interviews or focus groups, they spoke freely in individual interviews and focus groups. They talked openly about their own mental health and understood that the depression or the anxiety they were experiencing was due to the stress of caring, bereavement, an unhappy marriage or not being able to leave the home unaccompanied.

Several women were caring for children with mental health problems. Some were in the care of community mental health systems but others had either refused or had dropped out of services. A number of Bangladeshi women talked about children with degrees of autism and were struggling to cope with families and schools who saw the child's behaviour as poor parenting (particularly mothering). As Thabusom (2005) suggested, a few had internalised the stigma of mental illness, reluctant to seek help initially for fear of bringing shame on the family. However, many appeared trapped in a culture where they were likely to be blamed for their child's disability or behaviour or caring for an elderly in-law who did not appreciate them.

*[A] few had internalised the stigma of mental illness, reluctant to seek help initially for fear of bringing shame on the family. However, many appeared trapped in a culture where they were likely to be blamed for their child's disability or behaviour or caring for an elderly in-law who did not appreciate them.*

Women from all communities were clear that the physical and emotional demands of caring and either having to fight for services or not being allowed to apply for them was taking its toll on their mental health. Several women were having problems sleeping, feeling constantly anxious, on edge or unable to relax and a few were being treated by GPs for depression and anxiety. Despite extended families, women were caring alone with little support from other family members and few had anybody to confide in who understood the pressures they were under.

*Women from all communities were clear that the ... demands of caring and either having to fight for services or not being allowed to apply for them was taking its toll on their mental health.*

The data demonstrates that women with disabilities and those who were caring for somebody with a disability worried about what would happen to them or their loved one in the future. Ageing parents hoped that their sons would look after them reciprocally when they needed care but they could not be totally sure that children raised in the UK would be willing or able to do this. Perceptions of not being able to marry was a barrier to independence for disabled Asian girls/women. Some carers were clear that their daughters were probably too severely disabled to

marry because they would be unable to undertake housework or care for a husband and children. They admitted having pondered the possibility of finding a 'poor boy' from their home country who would marry and care for her when the parents were no longer able to do so. Although they believed it might be easier to find a poor girl to marry a disabled son, they would have been concerned about somebody who just wanted the right to stay in Britain and would not care for their daughter in the long term.

In the absence of being able to arrange a marriage for their daughter, there was an expectation that her siblings would care for their disabled sister. Some recognised the pressure that might mean for their children and the potential for conflict with their partners. Some women were already struggling under the demands of caring for disabled siblings having made 'deathbed' promises to their parents. However, others seemed to see this as the only way to go as residential care was not an acceptable option. Although several women were caring for disabled children who were now adults, it appeared that insufficient thought had been invested in planning for a time when they would no longer be able to care.

Clearly not everybody is capable of being independent but if families had been encouraged and supported in allowing their daughter to live away from home while learning to be independent, their anxieties might be reduced although not necessarily eliminated.

*[I]nsufficient thought had been invested in planning for a time when they would no longer be able to care.*

A recurrent theme throughout the data, is the role of the third sector, predominantly ethnic community organisations in having provided or continuing to provide advice, information, advocacy and support to the participants and the wider Asian community. Disabled women and parents of now adult children with disabilities highlighted the role of (mainly) Asian community organisations in helping them access mainstream health, education or employment services that enabled the disabled person to maximise potential.

These organisations now struggle in the face of increasing demand and reducing resources and many have closed or had funding reduced. They developed to meet an unmet need decades ago, working in partnership with mainstream charities and statutory bodies but are now struggling for survival in a competitive funding market.

These organisations are trusted by their respective communities, because they understand their constituents, speak their language literally and metaphorically. They provide information, advice and services that respect culture, faith and individual need and they deliver them in ways that work for the community, adopting approaches that the mainstream is either unable or unwilling to provide.

### INTERSECTIONALITY

Although beyond the scope of this research, the data highlights the significance of various structural barriers faced by disabled Asian women. Poverty, poor housing and low income are issues that impact on the ability to care for or empower disabled women. Disabled people are poorer, have worse access to health and social care services in UK society, but being an Asian woman and particularly Bangladeshi or Pakistani further compounds inequality.

*[T]he data highlights the significance of various structural barriers faced by disabled Asian women.*

South Asian women are confronted with multiple demands as carers but also live in a society surrounded by negative discourses of migration, terrorism and islamophobia. They may also be negotiating a new society with different beliefs and values and a new language while juggling with the responsibility of being a carer.

As the findings demonstrate, disability and informal care do not take place in a vacuum but against a backdrop of a society that is about austerity, negative associations with migrants, racism and Islamophobia and a (current) government determined to roll back the state.

Health, social care and education authorities are very aware of the low or late uptake of services but appear content to presume that this is a choice made by ethnic minority communities. They rarely question the barriers people face within public services. Language, lack of information in community languages or media formats are major barriers to knowing what is available. While there is much emphasis on learning to speak English, affordable classes that enable people to do this have been withdrawn.

The participants were very clear that there are many barriers within Asian communities and they understood that their health and social care experiences are not unique to Asian people. However, the majority did not appear to understand the legal duty on public authorities to eliminate discrimination on grounds of race, gender, disability or other protected characteristics.

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### LESSONS LEARNED

- Despite the taboos identified both in the literature and by the women in the study, their willingness to be open and frank once sure of their anonymity and confidentiality was encouraging.
- It is possible to reach and hear the voices of very marginalised disabled Asian women through voluntary sector organisations that are trusted and respected.
- Having researchers and co-researchers who spoke community languages made access easier but this still took several visits and much reassurance by the research team. The Bangladeshi participants were particularly suspicious and usually took advice from husbands or other family members before agreeing to participate.
- Being a non-Asian researcher was not a problem once introduced through a trusted Asian third sector organisation or the Asian project worker. Using conventional greetings or status titles was an added advantage.
- Women were generally unwilling to have their voices recorded but were content for researchers to take notes providing their identities were anonymised.
- It proved very difficult to access Pakistani communities, despite the lead researcher and project manager having good relationships with local mosques and community groups attached to them.
- Being able to reward participants for their contribution through gift vouchers was much appreciated, although it is doubtful it had any impact on recruiting participants.
- Conducting interviews and focus groups in a mix of English and Bengali/Sylheti or English and Gujarati with researchers/co-researchers from both languages took time but was practical and worked well. The women were keen to use English as much as possible and usually understood more than they were able to speak.
- It was advantageous to have two researchers for most of the data collection, one from the Asian community and the other a White Irish woman. Women from the different Asian groups felt able to share and were not necessarily concerned about presenting themselves in a positive light or giving answers they perceived either researcher might have expected.
- Culturally appropriate vignettes worked well in focus groups, giving women the opportunity to identify the views of community members rather than their own, although they interspersed discussions with personal perspectives and experiences.
- Vignettes were more tangible than open questions for participants and triggered examples of similar situations that occurred in their own family or community. They also generated dialogue among participants as they challenged each other and justified opinions or positions taken.
- Although we have heard the voices of some of the most marginalised disabled women, it is difficult to know how many disabled Asian women are not using community services.
- The scepticism towards faith leaders expressed by women of different faiths might account for

some of our problems accessing Pakistani women and may also suggest that attempting to recruit women participants via places of worship might be of little value.

- We overestimated the ability of most of the potential co-researchers to undertake research interviews or focus groups. Although there was no pressure, women may have felt some obligation to agree to collect data but later lacked the confidence to do so.
- There is a growing body of high quality doctoral or clinical doctorate research on various aspects of Asian health, including disability, learning disability, gender and mental health.

## LIMITATIONS OF THE STUDY

The findings of this study contribute to a broader understanding of the cultural, professional, service and structural barriers faced by disabled Asian women or Asian women carers. The data is broadly congruent with and develops existing research but the limitations highlight areas for further investigation and exploration.

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Despite attempts to capture the voices of disabled Pakistani women and carers, it was only possible to recruit a small number of women from this community. This is not unique to our study and highlights the need for further research about Pakistani women with disabilities. However, Guljaan, the British Pakistani woman's interview and case study are fine examples of the road to independence applicable to her own community and other Asian women.

The sample included women with a range of disabilities or caring responsibilities from across the age range in distinctly different parts of London. However, the scope of the study did not allow us to do adequate justice to mental illness, especially among Bangladeshi women or the children they were caring for. Nor were we able to explore differences in generation, place of birth, education or level of acculturation. The study could not afford adequate attention to intersectionality and the impact of multiple social determinants that exacerbate the experience of disability or informal care and contribute to mental and physical ill-health.

*[T]he scope of the study did not allow us to do adequate justice to mental illness especially among Bangladeshi women or the children they were caring for.*

Although rigorous and reflexive attention has been paid to ensure the opinions of all participants were considered equally, inevitably some women's voices were heard more than others. The quotes were chosen because they clearly facilitated understanding of a particular viewpoint or they illustrated a commonly held opinion.

Although the research has given voice to some of the most marginalised disabled Asian women in London, we do not claim that the experiences and understandings recounted in the data are generalisable to all disabled Asian women. However, the experiences and expressions of the participants provide a broader understanding of the complexities of being a disabled Asian woman or caring for a disabled child or relative.

The similarities of the themes emerging from interviews and focus groups of women of different cultures and faiths, with different disabilities, or caring for relatives with various disabilities in different parts of London, suggest the findings may be widely applicable. They provide a conceptual lens for health and social care professionals to work in culturally congruent ways with

disabled Asian women or carers and have the potential to inform proposals for further research on specific disabilities or particular cultural groups.

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### RECOMMENDATIONS

#### HEALTH SERVICES AND PROFESSIONALS

There is a danger of focussing on South Asian communities and ignoring the structural, institutional and professional barriers that disabled Asian women face. Despite race relations, gender, disability and equalities legislation in Britain for decades, there is a lack of attention to the multiple disadvantages experienced by disabled Asian women and Asian women caring for disabled relatives. With few exceptions, there have been limited efforts to understand the barriers they face, preferring instead to blame culture and presume that families adhere to traditional beliefs and choose not to access health or social care services.

*Despite ... equalities legislation ... , there is a lack of attention to the multiple disadvantages experienced by disabled Asian women and Asian women caring for disabled relatives.*

Breaking down some of the barriers faced by disabled Asian women relies on increasing expectations of what individual girls and women can achieve. There is a need for better and more accessible information about illness or impairments that are disabling. Sensitive and balanced disclosure is important in being realistic while giving hope to disabled people or families. Diagnosis is not a one-off event but a process and face-to-face consultations should be supplemented by information in languages and formats that take account of mother tongue, literacy and vision, hearing or other impairments.

*Breaking down some of the barriers faced by disabled Asian women relies on increasing expectations of what individual girls and women can achieve.*

Health professionals must be aware of cultural and religious beliefs but must not presume Asian people adhere to those exclusively. Rather the professionals must adopt ways of working with individuals or families that respect traditional beliefs but offer accessible and credible alternatives. Similarly, professionals must recognise educational, generational or gender differences within any community whilst not forgetting what a disabled person or family may have in common with the general population.

Consanguinity may be an issue for some genetic disorders and rather than avoid discussion for fear of offence, transmission must be explained in a non-judgemental way with accessible advice on the probability that other children might be affected.

*Health professionals must be aware of cultural and religious beliefs but must not presume Asian people adhere to those exclusively. Rather the professionals must adopt ways of working with individuals or families that respect traditional beliefs but offer accessible and credible alternatives.*



There is a need for better data on Black and Minority Ethnic groups and a more refined approach to the broad Asian category if differential inequalities within that category are to be addressed. Given the ageing population and the increasing life-span of disabled people, the needs of people from diverse Asian communities must be planned for.

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It is mistake to assume that there is an extended family able and willing to help care for a child or person with a disability. It is also incorrect to assume that external help will be rejected.

The research has demonstrated particular issues within the Bangladeshi community that merit further investigation. The evidence is not generalisable but the data shows what seems to be a high incidence of mental illness and autism spectrum disorders among Bangladeshi children and young adults.

The physical and mental health of the Bangladeshi women who participated in the research is worrying and suggests that culturally sensitive health interventions would be a sound investment. The high incidence of diabetes, hypertension and high cholesterol that the women reported might also account for increasing levels of dementia in the community.

*[T]he data shows ... a high incidence of mental illness and autism spectrum disorders among Bangladeshi children and young adults. The physical and mental health of the Bangladeshi women who participated is worrying and suggests that culturally sensitive health prevention would be a sound investment.*

## SOCIAL CARE AND HOUSING SERVICES

Many of the same issues apply to social care and housing professionals. In particular, it is important that social services do not make presumptions about the willingness or ability of families to provide informal care. Asian women like others are overburdened by informal care and this is impacting on their health. Relying on family is a symptom rather than the cause of low uptake and care that respects culture and faith will be valued. Asian families or carers will not necessarily ask for help to care for a disabled child or elder so it should be offered proactively.

*it is important that social services do not make presumptions about the willingness or ability of families to provide informal care ... care that respects culture and faith will be valued.*

It is a mistake to presume that a family carer will reject services, especially if they are culturally sensitive and, ideally, delivered by an appropriate Asian careworker. Continuity of care worker and where possible matching of culture and/or faith is more likely to be effective.

Many Asian women might well be able to handle the administration of direct payments but the effort involved is prohibitive when added to the physical and psychological demands of caring. Women with limited English or without access to internet would be particularly disadvantaged. Social care services outsourced to external agencies must be culturally sensitive and staff trained to respect and work with the client's culture.

There is a tremendous need for respite for family carers. It does not make sense to cut the provision of respite care when a carer falling ill leads to a crisis that requires hospital admission that is much more expensive and potentially dangerous for a vulnerable person.

*It does not make sense to cut the provision of respite care when a carer falling ill leads to a crisis that requires hospital admission that is much more expensive ...*

Although people from various Asian communities often live in multigenerational households, it does not follow that a three-bedroom house is suitable for three families, especially if there is one or more individual with a disability or dementia.

Dementia is an increasing issue in Asian communities and numbers will rise over the next decade. Although a person with dementia may not have mobility problems, privacy, protection from noise and unusual behaviour or sleeping patterns must be accommodated.

There is a need for supported housing for disabled Asian people, particularly for women. Although at present it might not be acceptable for Asian women to live away from the family home, older carers are now realising that it is a better option than residential care when they are no longer able to care for their daughters.

*Dementia is an increasing issue in Asian communities and numbers will rise over the next decade.*

The lack of English is a real barrier to Asian women's access to information and services and subsequently independence so provision for English classes should be re-established in collaboration with the voluntary sector or educational services.

*The lack of English is a real barrier to Asian women's access to information and services ...*

Public health or health promotion bodies in Local Authorities must target Asian communities on common disability issues relevant to specific communities. Cultural or religious events, such as Bangla Mela, Diwali and Eid celebrations provide considerable opportunities to raise awareness about disability in general or specific conditions, screening or prevention.

Events such as World Mental Health Day, Disability Awareness Day/Week, Stroke Week, Dementia Action Week, Autism Awareness Month, among others, should include local activities by Asian groups, to raise awareness within communities and make links with statutory and mainstream services.

## HUMARE AVAAZ

Such campaigns must involve disabled people and those who care for them to encourage dialogue at community level, breaking down taboos and challenging stigma. There is considerable scope for positive disabled role models from Asian communities, as well as inclusion of well-known disabled celebrities or spokespeople.

*Public health or health promotion bodies in Local Authorities must target Asian communities on common disability issues relevant to specific communities.*

Better data used wisely about the Asian population is essential if Joint Strategic Needs Assessments (JSNAs) are to have any meaning. Given the poor health in many Asian communities, there is considerable scope for prevention around heart disease, hypertension stroke and diabetes that will impact on health and healthy life years in the not too distant future. Culturally appropriate prevention might also ward off increases in the numbers of people with dementia that will otherwise rise more in BME groups than in the general population.

*Better data used wisely about the Asian population is essential if JSNAs are to have any meaning.*

## ASIAN COMMUNITY AND FAITH LEADERS

There is considerable scope to change beliefs and attitudes to disability within the Asian community. Although the research suggests that attitudes are changing, there is still a cultural lag that impacts on disabled people and those who care for them.

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To do this will require the influence and involvement of community and faith leaders as well as influencing younger generations. An immediate need is to provide information based on a social model of disability that focusses on barriers rather than the (bio-medical) impairment, looking at what can be achieved and how to go about this as a family.

*An immediate need is to provide information based on a social model of disability that focusses on barriers rather than the impairment ...*

Better information is needed about the causes and effects of different disabilities, shifting the blame from the mother or maternal line to genetic or medical explanations. Community events must proactively involve and include disabled people and carers and encourage interaction between disabled and non-disabled people.

Asian media and businesses could do more to raise awareness of and 'normalise' disability, showcasing disabled people or family carers and telling their stories. Mental illness must be talked



## HUMARE AVAAZ

about and not hidden within the family and people with mental illness or caring for somebody must be encouraged and supported to tell their stories.

Faith leaders and places of worship afford an ideal opportunity to begin dialogue about sensitive issues such as disability or mental illness. This could simply be places to meet and interact with other people in a similar position. Faith leaders or scholars would be best placed to highlight the importance of caring for others from holy books such as the Quran, Bhagavatam Gita, Guru Grant Sahib or Bible.

Faith leaders have a particular role to play in challenging discrimination and building a supportive network for people with disabilities and their carers.

*Faith leaders and places of worship afford an ideal opportunity to begin dialogue about sensitive issues such as disability or mental illness.*

Places of worship have a legal duty to make reasonable adjustments to make their premises and services inclusive for disabled people. They must not hide behind Health and Safety regulations prohibiting or limiting people in wheelchairs or requiring other forms of support but take reasonable and timely action to ensure that the physical and social environment is inclusive.

*Places of worship have a legal duty to make reasonable adjustments to make their premises and services inclusive for disabled people.*

The women believe that much more must be done to open up dialogue about disability and mental illness. Community organisations and faith groups as well as professionals from Asian backgrounds should be taking the lead in this. Ethnic media needs to do more, providing information through public service broadcasting but also through documentaries, soap operas and social media. While mainstream services and society have major roles to play, attitudinal change must come from within Asian communities, if it is to be credible and meaningful.

## THIRD SECTOR ORGANISATIONS

The third sector has already made a tremendous contribution to advising, advocating and providing services for Asian people who are disabled or caring for disabled relatives. They are credible, trusted and both accessible and acceptable to Asian people. They need funding to continue to meet the needs of the increasing numbers of people who rely on them. If funded adequately, they can make a major contribution to helping Asian women overcome many of the barriers to independence that they now face.

*If funded adequately, [Asian voluntary sector organisations] can make a major contribution to helping Asian women overcome many of the barriers to independence that they now face.*



Asian community organisations are ideally placed to initiate campaigns raising awareness and challenging cultural attitudes to disability and mental illness. Community events, national or local awareness days, cultural festivals and specific campaigns can be used to highlight issues to the various Asian communities. With the right kind of funding they might develop or expand existing services to encourage disabled people and families to meet socially and develop support networks. Carer support groups and peer support by disabled people for other disabled people should be considered.

There is also an urgent need to address wider health issues in the communities since the health of so many is already poor. There is a sizeable number of Asian people in poor health who should be encouraged to register as disabled and gain the benefits that registration can offer.

*There is a sizeable number of Asian people in poor health who should be encouraged to register as disabled and gain the benefits that registration can offer.*

There is a particular urgency around planning for the future in a timely fashion to prepare disabled adults to live as independently as possible with support in place as needed. This will require a culture change where girls and women are concerned, where living away from the family home is preparation for and a normal part of independent living. Families must be encouraged to think about this much earlier and while they may need help to access accommodation and supportive equipment and technology, support to challenge conventional community norms will also be necessary. When a disabled person is unlikely to achieve independence, families may need help to make a will, take out power of attorney and plan for emergencies.

*There is a particular urgency around planning for the future in a timely fashion to prepare disabled adults to live as independently as possible with support in place as needed.*

Voluntary organisations providing advice and information about benefits and supportive services can help change the negativity that surrounds welfare entitlements and social care. They may be able to provide culturally and linguistically appropriate homecare services and may wish to broker direct payments for families who choose to purchase their own care. However, these activities are reliant on sustainable funding, and a level playing field for small organisations who are focussed on delivery and may not have the capacity, skills or time to compete with major charities or statutory providers.

## DISABLED ASIAN WOMEN LIVING INDEPENDENTLY

### SUSMA

Susma manages the homecare service of a busy third sector organisation in north London. She was born in Kenya of Indian origin but her family went back to live in India when she was small. Susma has severe sight problems due to retinitis pigmentosa, a hereditary condition. She describes herself as totally independent with the support she receives from technology, a support worker and her family.

Susma was one of four daughters whose father firmly believed in educating girls so she attended a convent school in India. She did well at school, learned English and became a Montessori teacher.

She had problems with her sight when her children were small but did not notice her inability to see at night because she rarely went out in the evening. At first, she thought her glasses were not right and the diagnosis came as a shock. However, she could manage with bright lights at home.

Susma married in 1980 and went to live in Tanzania, where she worked as an educational supporter when her children were small. Susma's husband would have preferred her to stay at home but he did not stop her doing anything she wanted to do. She was encouraged by women from western embassies in the area in which she lived to use her education and abilities rather than being solely a housewife. However, she fulfilled the role of mother and housewife after work, not leaving her household responsibilities to anybody else.

Susma had a British passport and came with her family to London in 1997. She was told by some members of the Asian community that she was very unlikely to get a job as a blind woman at the age of 40. However, although her sight had deteriorated, she did not listen and, with encouragement from other people around her, she explored rehabilitation jobs and was offered her first job at APDA.

She was assisted by the Access to Work scheme that funded travel and hours of support to enable her to work. As her sight deteriorated the hours of support were increased and Susma was provided with computer software to help her read. In recent times she has been using a smart phone with voice technology.

Susma's consultant at Moorfields Eye Hospital has been excellent in keeping her up-to-date about new technologies and she has had to continuously learn and adapt as software became more elaborate. Susma is also part of a research project that she recognises may not help her but will help somebody else later.

Susma believes her independence is in large part because she never gives up on things. She has experienced negativity when people ignored her, assumed or actually told her she could not do things or felt that her blindness reduced her ability to do what other people did. She has not been pressurised by her husband, her family or her in-laws, which she feels inhibits some disabled Asian women from maximising their independence. Although sometimes painful, Susma largely chose to

ignore any negativity, low expectations or pressure from within the community. She believes that if you have skills and abilities you should use them and that there is no shame in asking for help. She did not see her role as purely one of looking after the house and caring for children, although she never shirked those responsibilities.

Susma also felt that being financially independent made a difference to her being able to be herself.

Susma believes that disabled Asian women should not be discouraged by those around them. It is difficult to rely on others but if you are motivated you will generally find there is help and support. If women with disabilities do not talk to an employer or prospective employer, they will not know what reasonable adjustments can be made to enable them to undertake what the job requires.

If Susma had listened to what she was told when she first came to London, she would not be the active, independent woman she is today.



### ROSHINI

Roshini is a 24-year-old married mother of a two-year old child. She was born in Britain of Bangladeshi parents and works part-time in a voluntary organisation. She has suffered from depression for some years and is now coping well following culturally sensitive therapy through a voluntary wellbeing service.

For many years Roshini has cared for her mother who has enduring mental illness. Her mother was born in Bangladesh and became mentally ill while studying in England, before Roshini was born. She was cared for initially by Roshini's grandparents and uncles but when her grandmother died in 2009 Roshini became her mother's primary carer. Responsibility for bathing, cooking, cleaning and household finance falls on Roshini. Her brother who also lives at home helps with shopping.

Unlike other Bangladeshi couples Roshini and her husband live with her mother and care for her. Her husband also cares for their little daughter when she is at work. Roshini's depression became worse after her daughter was born. In addition to caring for her mother, she now had a new baby, plus all the other responsibilities.

Although she describes her husband as very 'hands on', she found she was always anxious, missing her friends and her social life. She does not think she had postnatal depression but was anxious, in low mood and unhappy all the time. Her mother was deteriorating and her uncles who are very close did not realise that things were getting on top of Roshini. She was able to talk to her husband and close friends but felt she needed professional help. She went to her GP but did not want medication having seen the impact it had on her mother. She felt the need to focus on herself so the GP referred her to a local wellbeing service.

Roshini's therapist is Bangladeshi so understands the cultural factors without the need for lengthy explanation. She has provided the opportunity for Roshini to get things off her chest, having bottled everything up for ages. She has taught Roshini a variety of techniques to express her feelings and handle her stress that Roshini found helpful. She also referred her to another voluntary sector facility where she could meet, chat and engage with other women. This resulted in the part-time job she now has. Roshini enjoys her new job and it has given her great confidence. She is using her skills and learning new ones and hopes to find a similar job in the future.

Roshini is a positive example to other Asian women. She has overcome many barriers in relation to her own mental health and caring for a mother with mental health problems. She does not broadcast her mental health problems but is not embarrassed to talk about them either. She has sought and found support to help her cope in ways that are suitable for her culture. Being able to rely on her husband to care for her child and her mother and her uncles' support has made a difference.

She is also another example of the significance of the voluntary sector in enabling Asian women to challenge gender expectations and become more independent.



### GULJAAN

Guljaan is a 46-year-old married woman with three children. She was born in Bradford of Pakistani parents. Guljaan is paralysed down the right side of her body as a result of a fall aged eight months that caused a bleed on the left side of her brain resulting in right hemiplegia. She describes herself as totally independent with the help of her family, loads of gadgets and online shopping!

Guljaan describes being treated 'like a princess, like a lady of leisure' by her family as a child. She feels they believed that she would always need care, and would never be able to do much to help herself. Her grandmother also spoiled her as she looked very much like a daughter who had died in childhood. She admits taking advantage of her parents and grandmother, doing very little for herself as a child. She believes her family were doing what they thought was best but now feels it was the worst thing that could have happened to her.

Guljaan went to a primary school for disabled children before going on to state secondary school. Unfortunately, she could not attend secondary school regularly as she was in and out of hospital for two or three years for investigation of severe headaches. When she was sixteen, her mother was suddenly admitted to hospital with a suspected heart attack. When Guljaan came back from the hospital her brothers were waiting for her to cook breakfast but she did not have a clue what to do. She vowed never to be in that position ever again. With the help of a voluntary organisation in Bradford she was encouraged to go to college and complete her education. She joined self-help groups, learned to cook, sew and do housework. She also learned to drive and got a car through the mobility scheme at the time. This gave her confidence and independence and she began to take responsibility within the family.

Guljaan's parents initially felt she would never be able to marry but as she became more independent they began to think about finding a husband for her, a decision she resisted until she was about 27. Back in Pakistan a number of family friends were asking to marry her but she was concerned that they were only interested in getting a British Visa. She admits some concerns about being able to cope with being married, 'the bees and the birds bit', but more about her ability to settle having been so independent. She eventually chose a man from a selection of family friends arranged by her family and married at 28.

Guljaan has had problems with various services over the years. Although she has experienced some racism most of the problems were to do with professional arrogance. This was largely because professionals did not understand the needs of a disabled mother and did not ask her what she needed to be independent. She has frequently done her own research and has been helped greatly by a voluntary sector organisation that supported her to obtain accessible housing with a downstairs shower, more bedrooms and various adaptations and pieces of equipment to help her.

Guljaan freely acknowledges the encouragement, help and support she has had from her GP and from the voluntary sector. They have in different ways given her the confidence to be herself, to speak out and be assertive about what she needs.

She describes herself as ‘telling it as it is’ but knows many women from her own community who are disempowered by their families. Her brothers have always been supportive and encouraged her and she describes herself as being ‘the Mum in the wider family’.

Guljaan’s husband copes well with her disability and helps her although her independence can be a source of tension at times. She is raising her children, boys and girls to cope if she is unwell, such as making tea, or cooking a simple meal, rather than relying on her to do everything.

Guljaan volunteers in a Bradford charity several times a week and is very keen to help other disabled people, especially women to reach their potential and overcome cultural barriers to independence.

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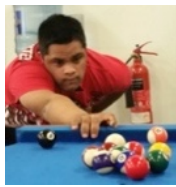
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