



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:
Executive summary***



drill
Disability Research on
Independent Living & Learning



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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 away from the family home with help to facilitate independence.





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