

The impact of having a disabled child on Pakistani parents' employment opportunities

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- Impact of caring responsibilities in the UK
- Challenges for the Pakistani community in the UK
- Participant families in this study
- Accessing adequate support from services
- Fathers juggling work and home responsibilities
 - Case study
- Mothers' need for work outside the home
 - Case study

There are **6.5 million carers**
in the UK today. That's **1 in 8 adults**.



This **unpaid** care saves the state £119 billion a year.

45% of us have **given up work to care**

Many more are **stretched to breaking point** trying to juggle work and family life...



61% of us have **faced depression because of our caring role**

Many are on duty around the clock, **unable to maintain a life of our own.**

49% of us are **struggling financially because of our caring role**

Many of us live with **constant worries about money**, as well as the person we're looking after.



Informal care in the UK

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- Informal carers - close relatives, friends, neighbours - make an enormous contribution to care
- Financial and practical support from the government is not sufficient
- Financial impact on families with disabled children:
 - 3 ½ times as expensive to raise a disabled child compared to a non-disabled child. Even if maximum government benefits are received this does not cover this difference (EDCM campaign, 2007).
 - Childcare costs are so high that there is usually no financial benefit to mothers returning to work.

Childhood disability and poverty

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“There is a two-way relationship between disability and poverty in childhood. Disabled children are among the most likely to experience poverty and poor children are more likely to become disabled than those who are better off.”

Institute for Public Policy Research (2007)

The Pakistani community in the UK

- Higher levels of poverty (3x)
- Higher levels of unemployment (2x for men, 3x for women)
- Poorer housing
- Higher incidence of self-reported ill-health (2x) and disability (1.5x) across the lifespan
- Limited English proficiency depending on age, generation, length of settlement and 'residential density effect'
- Prejudice based on both racism and Islamophobia
- A lack of faith and culture appropriate provision of social and leisure activities.

(The Poverty Site, current; Nandi and Platt, 2010; Khan, 2006, Modood, 1997)

Pakistani families with disabled children

A higher prevalence of childhood disability in the Pakistani community

High cost of raising one or more disabled children

Less likely to receive benefits at appropriate rates

More difficulty in accessing health and social care

Specific issues in the Pakistani community:

- > blaming the mother for the child's disability
- > a belief in disability as God's punishment
- > this leads to lower levels of support received in the extended family and the community
- > therefore high levels of distress to disabled children and their primary carers (mostly mothers)

(Beresford, 1995; Bywaters et al, 2003; Chamba, 1999; Fazil et al, 2002; Hatton et al, 2004)



Participant families

Six Pakistani Muslim families with disabled children were facilitated through Participatory Action Research, to explore their support needs within the family, in the community and through services,.

Quite diverse:

- One disabled child in each family
 - Intellectual impairment, autism, physical impairment
- Most parents born in Pakistan (one in the UK)
- Level of education of parents varied from primary school to PhD student
- Level of income varied from minimum wage to owning own business
- Some Shia and some Sunni Muslim
- Proficiency in English varied from fluent to very limited
- Mostly 2-parent families, one 1-parent family (divorced)
- Mostly nuclear families, one had grandmother living with them

Sample

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Inclusion criteria meant that only complete households (all people living on the same address as the disabled child) could participate.

6 out of 18 families contacted met this criteria

Of the remaining 12 most declined to participate because the father was not willing to participate (other reasons were age of the disabled child or nature of diagnosis, i.e. resolved, or the child not wishing to be described as 'disabled').

The above means that this sample was possibly relatively 'positive'.

Nevertheless many challenges were identified, including:

combining work and family life

Barriers to working (general)

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In most families only the father worked

General barriers:

- Poor English proficiency
- Pakistani qualifications not recognised (e.g. teacher)
- Visa restrictions
- Adequate, affordable child care is not available

A key barrier: lack of support

- **Community attitudes:**
 - the myth that Asian families have plenty of **informal** support through extended families is untrue
 - Hatton et al (2004) found that they had LESS of this support than the average family with a disabled child in the UK.
- Also that **getting information** about **formal** support can be difficult:
 - Language: availability of written information in minority languages; difficulty filling in forms for benefits
 - Understanding the 'system' and their entitlement to benefits and services
 - Social / healthcare workers do not check whether families receive what they are entitled to
- **Respite care:**
 - Poor availability
 - Parents worry about:
 - The child not being happy there – letting go!
 - Muslim faith related: wish to have same gender carers (includes worries about abuse) and need for food laws to be followed (Halal)

Challenges faced by fathers

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- All provided some level of emotional and/or practical support to their wives for the care of their disabled child
- They acknowledged that their wives did most of the caring work
- Fathers said it was difficult to do extra hours / overtime
 - need to spend time with the family and the disabled child
 - practical caring support
 - taking child to medical and other appointments
- This limited them in two ways:
 - lower income
 - lower chances to get promotion, which is also keeping the income low in the long term
- Fathers did not talk about their need for leisure activities much – too busy!
- The worksheet on the next page was used to help the men reflect on their roles and responsibilities

HEAD:
thinking skills: what are you good at?

EARS:
who or what do you listen to?

SHOULDERS:
what responsibilities weigh heavily?

TRUNK:
how do you maintain balance in your life?:
home / work / relaxation / leisure

HANDS:
in what ways do you help family members?

BAG:
what things / resources do you have
or can you use?

FEET:
what is your foundation?:
e.g. values, worldview, etc.



what '**HATS**' do you wear? (roles)

EYES:
what is your vision?

MOUTH:
language and communication skills

HEART:
social skills and network /
who is important to you?

HANDS:
what practical skills are you good at?

LEGS:
what steps could you undertake
to change life for the better?

Case study Mahboob

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Mahboob's son Imran had severe learning difficulties and autism, with challenging behaviour – a tall and heavy teenager.

His wife had diabetes and had difficulty doing personal care tasks for Imran and became very stressed when his behaviour was difficult.

They lived in a small flat on the 8th floor of an apartment block, with a tiny balcony.

Imran needed a parent to sleep in his bed to be able to sleep, but he still got up in the night, banging the windows and disturbing the neighbours

Mahboob had finished primary school in Pakistan, his English was poor and he worked in a food-packing factory.

Mahboob worked early shifts only, so that he could be at home when the children came home and take care of Imran

He was grateful for this adjustment by his employer, but the inability to work longer hours limited his income and chance for promotion

He did not get time for leisure / free time and regretted that he had not been able to attend Friday Prayers at the Mosque in many years.

Mahboob was highly committed to the wellbeing of all family members.

As part of the project evaluation he drew a picture of what he dreamed of (next slide).



Challenges faced by mothers

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- The mothers expressed their wish/need to work or study frequently, because:
 - It would provide contact with the outside world – reducing isolation
 - It would allow her to focus on something other than childcare and family – providing me-time
 - Studying would improve opportunities for future – better family income
- Barriers to working:
 - Practical care needs of the child and family
 - Cultural expectations for mothers to “sacrifice all” for their child and family
 - Husbands did acknowledge that their wives did most of the work.
 - One quoted the Quran as stating that the wife’s only duty is to “guard her husband’s honour” and NOT to do any work – if she does it is a favour to her family; she is entitled to ask for servants to do the work

Case study: Tahira

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Four sons, one of whom – Tariq – had learning disabilities and challenging behaviour.

Husband worked a lot – employed by a company, plus owned his own clothes' shop.

Relationship between Tahira and her husband had been difficult for a long time.

Poor support, especially emotional support from husband, but felt supported by her oldest two sons.

Stated that Pakistani wives/mothers were expected to 'sacrifice all' for their families and that their own needs and interests were not deemed important

Described how her difficult circumstances led to her praying more and her faith becoming stronger, providing her significant support

Tariq's behavioural difficulties prevented her from attending community events, e.g. weddings, and he was told not to come to the Quran classes at the Mosque.

Tahira worked for 1 ½ hours per day as a dinner lady at a nursery, which she highly valued, but she wanted to do more

Being, Doing, Becoming, Belonging

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To help the women reflect on the occupational (im)balance in their lives, I used Wilcock's concept of occupation as doing, being, becoming and belonging (2006).

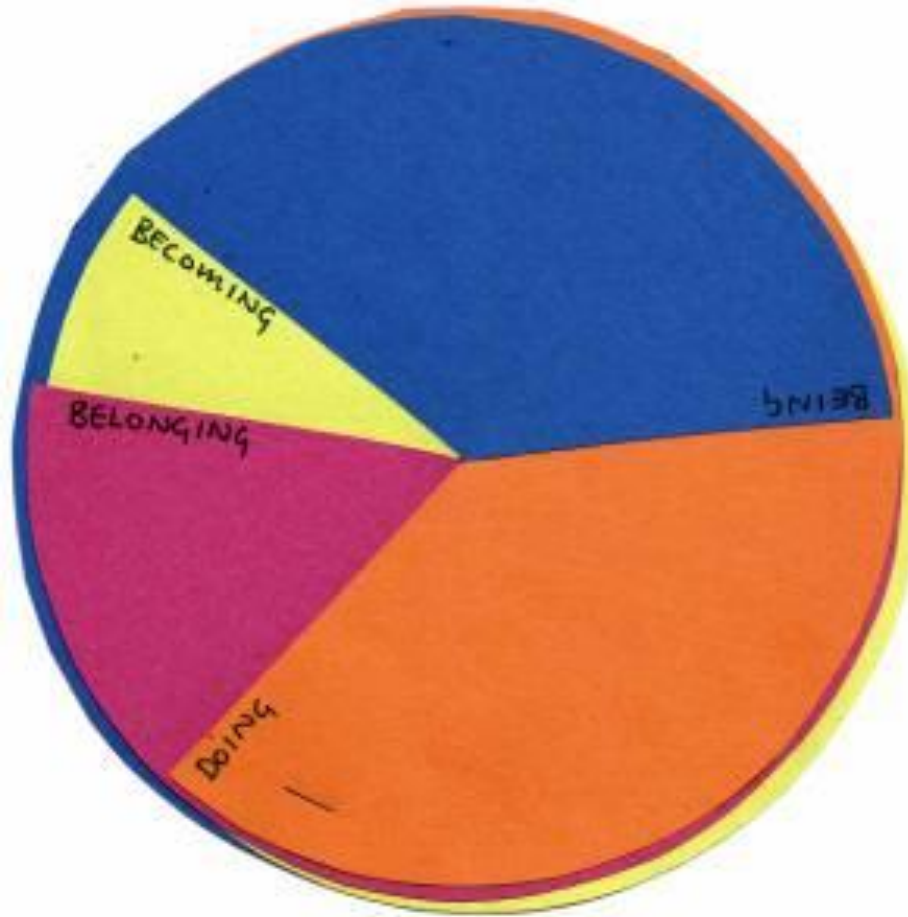
$$d + b^3 = s h$$

I gave them four paper circles cut along the radius, each colour representing the importance of one concept

The women shuffled the circles as they reflected on their lives.

Reference: Wilcock (2006)

Case study: Tahira



Tahira showed how little she felt she was allowed to 'belong', or think about 'becoming' – she felt she was always 'doing' and that that was expected of her.

Sense of 'being' was very important to her and had been influenced by her strengthened faith and resilience through raising her disabled child.

Siblings

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The non-disabled children in the family carried out a variety of caring tasks, e.g. playing with / minding their sibling or helping with personal care tasks.

They expressed strong loyalty to the family, both for the present and for future care

The combination of caring needs and cultural restrictions meant that they had restricted social activities (e.g. after-school and other clubs) and friendships (e.g. visiting friends at school).

The children also reported incidences of teasing/bullying in relation to having a disabled sibling.

For their action research focus they chose: “we want to understand our disabled brother/sister better, so that we can make them happy”.

Conclusion

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Parents of disabled children in the UK struggle to find adequate support so that they can attain occupational balance in their lives.

For Pakistani families the situation is further complicated by the fact that they are one of the most disadvantaged groups in society and because some cultural aspects add further complexity.

The participatory nature of the project and the creative methods used helped the participants to express some of these issues clearly.

Any Questions?

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