

Disablism and Diaspora: British Pakistani Families and Disabled Children

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Abstract: This paper explores the intersections of diaspora, disability and family. Drawing on qualitative interviews with the parents of three British Pakistani families we draw out three lines of enquiry. The first, *disability and disavowal in Pakistan*, explores parents' relationship with 'home' and how this is complicated by the presence of disablism. The second, *disability and the fight for care in Britain*, explores the ways in which British Asian families are grounded not only in the cultures and traditions of their parents and the Asian subcontinent, but also in the social practices of Britain. The third, *disability and diaspora - from isolation to ensembled caringscapes*, examines the limits and possibilities offered through diaspora. One key affirmative element of this is the support of an extended family, which brings with it, the chance to look to the future with hope and possibility.

Introduction

This paper explores the accounts of three British Pakistani families who include a disabled child. Their accounts intersect a number of key concepts. Our first consideration is *diaspora*. The families represented in this paper merge important cultural, familial and subjective elements of Britain and Pakistani. By recognising that both nations boast complex forms of multiculturalism the mixing of these cultures resonates with the postcolonial concepts of cultural hybridisation (the mixing of cultures and heritage) and diaspora (the geopolitical spread of groups of displaced and in some cases exiled people, see Grech, 2011 for an excellent discussion of these concepts). Brah (1996) characterizes diasporic identities as those that cut across and displace national boundaries, creating new forms of belonging and challenging the fixing of identities in relation to place. As Anthias (1998) observes: the etymological basis of diaspora relates to the Greek word for 'scattering of seeds'. Dwyer (2000, p. 483) argues that while cultural theories of diaspora have celebrated 'cultures of hybridity' found particularly in music, sport or fashion, there has been a tendency to ignore the everyday, mundane and, therefore, complex negotiations of diasporic identities. British Pakistani families, following Dwyer (2000, p. 475), can be readily assigned membership of the 'new diasporas' created by postcolonial migrations. The concept of diaspora:

enables an unraveling of the nexus between (and relative significance of) place(s) of 'origin' and place(s) of 'settlement' and allows us to comprehend how the identities of second- and third generation British Asians are subject to both global and local, or, ... 'glocal', influences. (Burdsey, 2006, p 23)

This raises questions about how people live in a culture of hybridity and how they articulate diasporic identities that cut across fixed notions of belonging. Diaspora is thus often used to describe 'groups of displaced and exiled people who feel they possess a shared ethnicity, culture, (imagined) community and traditions but at the same time, have a relationship, whether real or imagined, to a perceived homeland' (Mavroudi, 2007, p. 469). The heuristic potential of

the concept of diaspora is therefore as a descriptive typological tool and as a social condition and societal process (Anthias, 1998, p. 557).

The postmodern versions of diaspora ... denote a condition rather than being descriptive of a group. Not only is the condition one structured through the trajectory of movement but it is one which seeps into the very fabric of the modern (or postmodern) condition itself. This condition is put into play through the experience of being from one place and of another ... Here the issues around the destabilizing effect of transition and movement of the individuals' cultural certainties may be explored and the ontological and epistemological effects researched. (Anthias, 1998, p. 565)

In considering the experiences of these families we need to be mindful of how we theorize their identities. Any exploration of family life evokes considerations of the kinds of social theories that we draw upon. We are guided by the great Stuart Hall, (2003, p. 222) here who argued that:

Identity is not as transparent or unproblematic as we think. Perhaps instead of thinking of identity as an already accomplished fact, ... we should think, instead, of identity as a 'production', which is never complete, always in process, and always constituted within, not outside, representation.

Diasporic identities are 'those which are constantly producing and reproducing themselves anew, through transformation and difference'. (Hall, 2003, p. 235). Hall's concern 'has been to reconstruct an approach to cultural identity and 'race' which avoids the pitfalls of essentialism and reductionism' (Anthias, 1998, p. 560). Like Hall, we do not consider identities to be fixed in time and place. Instead, we understand identities as constantly evolving and changing as a consequence of a host of relational, cultural, political and material factors. Bhabha's (1985) work on hybrids emerged out of writing about postcolonial contexts. He suggested that it is best to understand the postcolonial subject as a subject who fuses pre/present/post colonial practices through 'mimicry, hybridity and sly civility' (Bhabha, 1994, p. 21). Following Goodley (2011), the Indianized gospel, a British-born Pakistani identity, the glocalization of a South East Asian youth each exemplify, in their own way, the appropriation and imitation of colonial *and* traditional cultural practices (see also Spivak, 1985, p. 253). The postcolonial subject is always hybridised. For Sherry (2007, p. 19), Bhabha's (1994) model of hybridization 'stresses those in-between moments that initiate new sites of identity, new collaborations and new conflicts of one's identity'. 'The hybrid draws attention to the weaving away, making sense of, experimenting nature of human subjectivity and relationships' (Goodley, 2011, p. xx). We adopt this dynamic constructionist view of identity in relation not only to diasporic identities of the British Pakistani families but also, crucially, in relation to our second area of consideration, *disability*. Just as critical race and postcolonial theories have historicized and politicized 'race' and ethnicity – moving it from a fixed, pathological and essentialist position – critical disability studies scholars have also recast disability as a socio-political phenomenon (see Goodley, 2011 for a contemporary overview of the field). Following Dwyer (2000, p. 483), we seek to provide new ways of theorizing disability and identity that recognize differences and avoid essentialism. To this we could add the avoidance of cultural determinism which overplays national context and fails to capture the cultural hybridity of British Pakistani

mothers and their families. Similarly, from a critical disability studies perspective, by advancing a socio-cultural model of disability then we seek to challenge a lapsing back into traditional pathological notions of impairment. How impairments are understood, responded to and treated depends hugely on their cultural location. The word 'disability' hints at something missing either fiscally, physically, mentally or legally (Davis, 1995, p. xiii). Disability affects us all, transcending class, nation and wealth (Goodley, 2011). Critical disability studies respond to the emergence of impairment in society and dominant socio-cultural responses. Thomas (2007, p. 73) provides a definition of *disablism*, as 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being'. This is helpful because it permits disablism to sit alongside other forms of oppression including hetero/sexism and racism. And because disablism is a fundamentally environmental response to impairment then, just like diasporas, it is prone to shift, mutate and change according to a multitude of external factors. The dynamic nature of diaspora and disability interact with a third concept; the *family*. In recent years there has been a plethora of research, particularly in Western Europe and North America, about disabled children and their families that have tended to emphasise the experiences of white, middle class, Global North families (e.g. Kittay, 1998a, 1998b, 2002; Traustadóttir, 1991, 1999; McKie et al, 2002; Watson et al, 2002; McKeever and Miller, 2004; Hughes et al, 2002; McLaughlin *et al*, 2008). We know from this work that families, as a whole, experience disablism (hence the term disabled families). Parents have to fight for basic services, support, and recognition of their children as valued members of society. These families face more socioeconomic hardship than non-disabled families. Communities fail to support them by including their children in day-to-day activities, ranging from education to leisure, and mothers are often pushed to take the lead role in care for their children. We aim to explore in this paper what this research has failed to uncover: how the phenomena of diaspora, disability and family intersect in the accounts of three British Pakistani families who boast a disabled child.

There are currently approximately 1.2 million British citizens who were either born in Pakistan or whose ancestors came from there (Nabassi, 2010). Here we want to think carefully about the hybridisation of local and global meanings. In considering the global place of the families, we seek not to fall into the trap identified by Rattansi (2004, p. 614) where 'sociological analyses have been wont to smuggle in unacknowledged normative considerations ... on the basis of simplistic and common-sensical assumptions about 'human nature' and 'group dynamics'. In similar ways to Lloyd (2000) we want to explore the ways in which the parents we interviewed criss-crossed and renegotiated material and imaginary boundaries between countries and cultures in caring for their disabled children. Moreover, following Anthias (1998), we explore these diaspora by paying more attention to 'intersectionality', in this case, across disability, family and diaspora.

Methodology

This paper draws on a number of accounts of disabled children and their parents collected as part of a project funded by the Economic and Social Research Council¹ *Does every child matter, Post-Blair: Interconnections of disabled childhoods*. Our over-arching aim was to ask what life is like for disabled children/young people in contemporary British society. The research was

carried out over a period of 32 months from September, 2008 – May, 2011 and had the following empirical phases included:

- (i) Pilot Study – to explore approaches to interviewing and ethnography;
- (ii) Narrative inquiry – retrospective interviews with 6 parents of disabled children aged 14 + to reflect on their experiences with their disabled children;
- (iii) Children’s accounts: Interviews with two groups of children: 4-11 and 12-16yrs old;
- (iv) Focus group interviews with professionals;
- (v) Longitudinal narrative case studies of 7 parents with disabled children (ages ranging from 4 – 16);
- (vi) Growing up – 50 days of ethnography of children’s social worlds.

Our participants included disabled children aged 4-16, their parents/carers and professionals who work with disabled children, including teachers, third sector workers, health workers and social workers. Children had a range of impairment labels including autism, cerebral palsy, developmental disability, Down’s syndrome, achondroplasia, profound and multiple learning disability and epilepsy.

Despite contacting nearly 40 organisations supporting children and parents, we originally failed to recruit any families from a British Minority Ethnic background. We were very lucky to be able to work with Uzma, one of the authors of this paper, and a Pakistani international postgraduate student, to contact families. We eventually found three families who were happy to participate. Uzma and Katherine interviewed the families once in the family home. At times Uzma acted as both interpreter and interviewer and at other times, in the same interview, participants spoke in English. It is beyond the scope of this paper to speculate on why we were initially unable to recruit diverse families to the study, despite our attempts to contact a myriad of organisations. However, it is important to acknowledge that ‘minority’ families are often excluded from the research process and that their engagements with disabling society often remain untold. Furthermore, we feel it important to acknowledge the white positionalities of Dan and Katherine and follow Burdsey’s (2006, p. 12) stance that:

‘it is essential for white researchers in the field of ethnic and racial studies to examine not simply how hegemonic ‘whiteness’ and notions of white privilege permeate the structures and institutions in our areas of research, we must also examine how these issues enter and affect the research process’.

One key reflexive point for us was not to homogenise nor essentialise families in terms of their presumed cultural capital. We know from Anthias (1998), amongst others, that the concept of ethnicity fails to be articulated in the relation to whiteness though always rears its head in the company of diaspora. Our work with Uzma and the families detailed below has revealed the ways in which much disability studies research on children and families – like a lot of social science – remains broadly Eurocentric and ignores political, cultural and social factors associated with ethnicity, culture and globalisation (see Wakeling, 2007 for a broader discussion). We hope to address this lacuna both empirically and theoretically through reading the accounts of a few British Pakistani families:

The Families

Saira is a second generation British Pakistani. She lives in a borough in a city in the North of England with a high proportion of British Pakistani residents. She lives in a semi-detached house on a quiet cul-de-sac. Saira is in her early forties and has four daughters aged from eight to fifteen. She is married but her husband is currently a resident in Pakistan because of visa difficulties. Saira and her children have British passports, but her husband does not. Saira's extended family all live in Pakistan. She told us she has one friend in England who lives around the corner, but who is currently on an extended visit to Pakistan, and does not know the other families on her street. Saira works part-time at the local primary school as a multi-lingual teaching assistant. Two of Saira's daughters are disabled. Asiya is 12 and has the label of ADHD and challenging behaviour and Aamira, who is 15, has the label of severe learning difficulties. Asiya attends a local mainstream secondary school and Aamira attends a local special school. The family lived in Pakistan for a while when Aamira was younger.

Yusef is a second generation British Pakistani. Shanaz, Yusef's wife, was born in Pakistan and came to England after their arranged marriage eleven years ago. Yusef and Shanaz live in a city in the West Midlands of England. They live in a borough with a high proportion of British Pakistani residents. They live in a small terraced house, which has recently been extended to provide a ground floor bedroom for their disabled daughter. They are both in their late twenties and have two children: Habiba who is 9 and has the label of profound and multiple learning disabilities and Fatima, her little sister, who is 2. Habiba attends special school. Shanaz and Yusef are very happy with the education Habiba receives there. Shanaz's family are in Pakistan, but Yusef's parents, brothers and sisters all live nearby and are very supportive of the family. Both Yusef and Shanaz care full-time for their daughter. Yusef gave up his job shortly after their daughter was born.

Mysha is second generation British Pakistani, her husband Asif came to Britain some time after their arranged marriage. They live in a small terraced house in a town in the South East of England in an area with a high proportion of British Pakistani residents. Mysha and Asif are in their early forties. They have three children, but only Farhan lives with them, two older children have left home. Farhan is sixteen and has the label of learning difficulties. Asif has his own business and Mysha has no paid work outside of the home. Mysha's mother also lives with the family. She is the main cook in the family, however, there are no other members of the extended family nearby to help care for Farhan.

Our sample size could be viewed as too small to allow us to tease out any recurring themes of relevance to many other British Pakistani families with disabled children. In defence we are able to mine a rich seam of disability studies research that have attended to the rich qualities of a few lives to tell us much about social, cultural and political conditions faced by disabled people and their families (Bogdan and Taylor, 1976, 1982; Humphreys et al, 1987, Groce, 1992, p. 175). While our sample is not big enough for wide analysis of a population we believe that it is narrow and deep enough to tell us much about living as a family with a disabled child.

Analysis

We all define ourselves, at least in part, by where we are from. Yet this was not a straightforward process of identification for the parents in our study (see Valentine and Sporton, 2009: 741 for a similar discussion). Saira (and her daughters) were geographically separated from her husband. Other families exhibited less direct forms of distinction: as they had to juggle distinct cultural and welfare contexts of Britain and Pakistan. These tensions were further magnified by the presence of a disabled child as families fought for the rights of their children. Where you are from, of course, is complicated by a hybrid identity. Following Valentine and Sporton (2009) we understand identity not just to be about commonality or belonging; but also to be defined by difference. The discourse around disabled children utilized and promulgated by families reflected the differential aspects of being British (born or based) Pakistani. We follow Valentine and Sporton's (2009) interest in the multiple, shifting and sometimes contradictory ways that individuals both identify and dis-identify with other groups; and with their fluctuating emotional investment in different subject positions. We do not uncover essentialist interpretations of ethnicity and culture – differentially related to Britain and Pakistan – but instead are drawn to the complex ways in which location, culture and disability intersect.

Disability and Disavowal in Pakistan

Parental interviews led us into discussions of Pakistan. Alongside the more practical discussions such as, in the case of Saira, the difficulties associated with her husband being away from the family home, Pakistan appeared to be framed as an 'imagined community' (Anderson, 1991). Burdsey (2006, p. 17) explains this in terms of forming 'a symbolic link with the subcontinent, enabling the celebration of tradition and feelings of belonging with the nation from which they or their forebears migrated'. For Clarke (2009, p. 229), Anderson's (1991) work allows us to consider the ways in which communities are constructed through a variety of symbolic forms (from marking borders to flags, from everyday ceremonies to the little linguistic ways in which a common identity is assumed). Having a disabled child, however, added a further layer of complexity to this imagined community:

Shanaz: I was listening yesterday ... to the radio and there's a family in Pakistan there that's got three blind children and ... it's a terrible country and families are brought to that position that they don't want anything to happen to their kids so they keep them in the house and all three children they were blind and mum and dad had to go to work to feed them and that.

Saira had a similar experience, as noted here.

Saira: Yeah, because of Aamira we can't go there because ... in Pakistan it's different... these are special needs children and I think even for normal children... if you are very, very rich then it's alright. He's [my husband] saying you have to come home. I keep saying 'How can I come home, my daughters, they don't want to go and what will happen with Aamira and she just staying there and sitting and nothing to do' ... Her behaviour is very, very terrible in Pakistan ... she will not go to school, she will just sit down, because when I came in this country before she used to go to school and there are no any special need school just mainstream school ... here they realised that she's special need ... In Pakistan they didn't realise that she is special needs and then she didn't listen to the

teachers. They [the teachers] really badly, really badly beat her he used to beat her very badly ... she came home with bruises all over her legs...

Both families had a similar and dramatic experience with their children's experience in Pakistan, the nation with which they have a symbolic link.

According to Dwyer (2000, p. 483) metaphors of 'home' remain significant in diasporic discourse. All of the parents we spoke to had strong ties to Pakistan. Such metaphors of home are also gendered, and thus women are reconnected to Pakistan both symbolically, as guardians of familial cultural values, and, sometimes in practice, through ties of intermarriage (Dwyer, 2000). For Shanaz the 'home' of Pakistan is imagined as exclusionary and disablism in terms of the reactions to her daughter. Her account supports the findings of Dwyer (2000, p. 483) in her study of young British Pakistani women. She found that while some individuals enjoyed greater freedoms when visiting Pakistan, the majority found the expectations of normative gender roles in rural Pakistan more restrictive than their lives in Britain. For Dwyer (2000, p. 477) diasporic identifications are always configured through gender because women occupy a symbolic place, sometimes as the guardian of family honor and integrity. Identities are shaped by familial expectations of 'appropriate femininities', which ensure that the behaviour and attire of young women are strictly monitored. These practices are upheld through patriarchal discourses, often given new emphasis within the diaspora context, which define young women as guardians of religious and cultural integrity. We found similar expectations of 'appropriate femininities' in our accounts but these were complicated – or crippled (McRuer, 2006) – by the presence of disability.

Saira: Because of her [Aamira's] condition because of her religion I want her to settle and everything like normal [arranged marriage]. When she is a nineteen or twenty, I'm trying to go to Pakistan and you know do everything normal like normal daughters. I'm trying to find partners ... I am thinking because I don't have any boy and y'know my husband lives in Pakistan so it's really hard for me if ... if she's stayed with me all the time, I do work at the school and I want to do more work, not just for two hours ...

Hence while Saira has powerful emotional investments in the traditions of arranged marriage there is a risk of disinvestment because of her daughter's impairment. In this sense then we could argue that the embodied realities of disability (Edwards and Imrie, 2005) framed familial perspectives on Pakistan in particular ways.

Yusef: I'm glad that she's born here ... Pakistan is a nice country. They could make it even nicer if they did some things different. Because [in England] she has like problems going to the toilet some of the time and in Pakistan she had *no* problem, as soon as we come back to England we had to give her the medicine...

Shanaz: She had constipation here from the medicine that they give to us and... we never used it in Pakistan, because .. the heat is good for her [in Pakistan]

Uzma: There are some other problems that you don't have [in England]?

Yusef: I used to take the wheelchair out there [Pakistan] and I'd have the whole village following me thinking 'What's this?'

Here Pakistan is imagined as a community with varying responses to disability. For some, Pakistan was a place associated with difficult talk about their disabled children:

Uzma: And what about Pakistan society as compared here?

Shanaz: [in Urdu]

Uzma: Can you explain in English? Because, uh ... she's saying very good things.

Yusef: What she's trying to say is ...uh... in Pakistan, people do talk especially the elders. They say, 'What's the reason they have a disabled child?' 'Why?' or 'I feel sorry for her'. They don't y'know look at how beautiful she is, y'know there are people that are in the world with worse conditions. But you can't stop people from talking you can't, so, I just let them talk and I just say 'Thank you very much' You can argue as well but arguing just makes things worse. Families talk, you can't stop them.

Whereas Valentine and Sporton (2009) found that different diasporic histories of mobility infected people's self-identifications, as in this case of British Somalian young people, we found evidence for the impact of different histories of disablism on the identities of our participants. Specifically, we can view the accounts of our families as histories of psychoemotional disablism (Thomas, 1999; Reeve, 2008): which refers to the in/direct responses of (non-disabled) others (such as staring, ignorance, voyeurism) which threaten to engender negative emotions in disabled people. Families face a further layer of dis-identification with Pakistan: associated with the cultural disavowal of their *disabled* children in which children are subjected to contradictory responses of fear and fascination. This might explain why not all diasporas sustain an ideology of 'return' to an imagined community (Burdsey, 2006, p. 23).

We want to be clear here that neither our families – nor we – are suggesting that disability is disavowed only in Pakistan. As we shall see below; Britain offers more than enough of its own examples of disablism. Instead, what we are suggesting is that a diasporic relationship with Pakistan is influenced by the disabling processes around children that shift families perspectives on the imagined community. Hence, as with Anthias (1998: 557), a reliance on a notion of 'deterritorialised ethnicity which references the primordial bonds of homeland' – whether imagined or not – is problematised by disability. As Valentine and Sporton (2009, p. 748):

While as individuals our identities might be multiple and fluid, within the spaces within which we [imagine we] live and move, power operates in systematic ways to generate hegemonic cultures and spatial orderings that define who can claim a particular identity, where, and who cannot, who is in place and who is out of place.

This question of who can claim an identity is apposite for our families. We know that disabled people are denied opportunities to claim a valued identity and are very often placed in spatial positions of 'outsider' or 'stranger'. Bauman (1997, p. 14) argues that not everyone is

welcome in the postmodern sphere of fluidity and consumerism; new strangers are created, 'flawed consumers' who are 'objects out of place' (see also Hughes, 2002). Feelings of home and belonging are increasingly being seen as affected by the processes of migration, globalization and we can now add disability (Mavroudi, 2007, p. 472).

Hardt and Negri (2000, 2004) describe migration and nomadic forms of labour as possible forms of resistance to strict national requirements around employment status. The migrant worker, they suggest, moves across national boundaries and stretches concept of work from something done in the same country as one resides to forms of work that permit flows of capital from one country to another. Yet, they also acknowledge that nomadic forms of work create difficulties and tensions for workers and their families. The absence of a father (due to being denied a visa to live and work in the UK) made day-to-day living difficult for Saira and her children. The lack of support from neighbours and friends conspicuous by their absence and the challenge of seeing two daughters off to mainstream school while meeting the needs of her disabled daughter pushed Saira near the edge:

Saira: It's really hard, I need my husband ... nobody can help like my husband ... Everyone is in Pakistan. Just me and my children are here. They say, if you want to live with your husband you should go to Pakistan, but why should I go to Pakistan? Because my children, they don't want to go, they erm...

Uzma: They born here?

Saira: We have British passport, and everything. And my youngest daughter was crying and I asked 'Why you cry?' 'I want my Daddy now, I want my Dad now.' I said 'I can't give you your Dad now' so she y'know ... I said if you want to stay with your dad you can stay you live with him. She said, no, I want you and him, Mum and Dad together.

Not only does literature on diaspora risk romanticizing the hidden referent of home and point of origin (in our case Pakistan) it also fails to apprehend the differentiated forms of transnational movement and settlement that occur as a consequence of diaspora (Anthias, 1998) and, in Saira's case, complicated by disability.

Disability and the fight for care in Britain

Diasporic British Asian families are grounded 'not only in the cultures and traditions of their parents and the Asian subcontinent, but also in the social practices of Britain and beyond, with increasing reference to globally mediated spheres' (Burdey, 2006, p. 23). Unsurprisingly, caring emerges as a key social sphere for families of disabled children. Kittay (1999b, p. 205) views parents, especially mothers, as being nested in sets of reciprocal relations and obligations. Watson *et al* (2004, p. 333) note that caring work is often assumed and silently demanded from mothers and women more generally. Most meet these demands, embracing them in an active fashion, as demonstrations of their femininity and presumed social and economic roles.

Attending to care is an important part of recognizing labour outside of the normative material paid sense of the word. Across cultures wives and mothers are ideologically and practically associated with unpaid care-giving often in the home. The various positions that

parents, occupy from day to day, perhaps hour to hour, highlight Traustadóttir's (1991) concept of the extended caring role of parents. On the one hand, caring can be extremely hard, tiring work that limits parents in pursuing other roles and activities. On the other hand, caring can provide for more opportunities than normally associated with the traditional parenting role (Pratesi and Runswick-Cole, forthcoming). We are reminded here of Kagan et al's (1998) call to find ways of valuing the caring work of parents. After all, we know from previous research that parents occupy 'positions of 'reserve army' care provider or 'para—professional' in health and social care through being almost single-handedly responsible for performing skills such as physiotherapy, suctioning, urinary catheterizations, administering medicine, spoon or tube feeding, lifting and positioning' (McKeever & Miller, 2004, p. 1188). Following Hardt and Negri (2000, 2004) we can consider parenting and care as key elements of what they term immaterial labour. These forms of labour are traditionally banished from malestream notions of meaningful labour – such as service work, care and support – are revisioned as some of the most significant forms of labour of contemporary societies. The immaterial labour of mothers and fathers translated into a growing knowledge about, and response to, the needs of their disabled children. This ranged from communication to medication:

Mysha: He can understand us but he cannot speak at all. He can understand a word. We said 'Eat?' he said 'Yes' but he took me to kitchen, and ran some water. I say 'Want to go to sleep?' and he understands that and I say 'I'm going for walk, you come with me?' and he understands that... They've [school] been teaching him to sign haven't they? Because he talked about signing, and they were they were, all the information was about managing his behaviour and trying to stop him from throwing things or whatever and what they did to manage his behaviour.
... so he's taking medicine. And, erm controlled drugs like, y'know? Liquid and capsules, he cannot swallow but we give him the bottle just erm y'know capsule broken up and erm putting them on spoon in bottle and erm then he'll take controlled drugs fine, we give him controlled drugs but then he's calm...

This knowledge extended to the extent that parents' convictions were so strong that they refuted diagnostic suggestions:

Yusef: erm... before she was born the doctor says... they gave us the choice if she want an abortion and they did say that they could see that the baby was going to have some problems but we said no.

Katherine: Did you feel under any pressure?

Shanaz: Uh... not really.

Katherine: Did you feel like they just gave you the information and they gave you a choice?

Yusef: They were saying it could be linked to family first cousins but I said no. My mum and dad were first cousins and in four generations this is the first disabled child in my family so, I don't understand. I don't like being accused, it can happen to anybody. So...

it's alright. I suppose but... they didn't let me... they didn't let me into the room they go you look too young! [laughter] you can't be the daddy.

In some cases parents were called on to manage medicalisation.

Mysha: because medicine we gave to him there, there is no medicine over here because these are special medicines, only these medicines available in Arab country y'know?

This growing knowledge of medicalisation and diagnosis mirrors the findings of McLaughlin *et al* (2008) who found that in a number of cases parents were, seemingly, more up to date about their child's care needs than many of the professionals. One consultant they interviewed happily admitted that parents would often turn up to appointments with 'state-of-the-art' knowledge about treatment and prognosis that the consultant was yet to hear about. McLaughlin *et al* (2008) inform us that parents are active participants in diagnosis. They often seek a label for their child and participate in their own diagnostic processes. Diagnosis is often not an immediate one off event, even if there is evidence that the child is developing or acting differently, defining the source involves a significant amount of medical uncertainty. Medical diagnosis in young children is a comparative process, made against developmental markers, which define both the normal and the distance from it (McConachie, 1995). Often there are mixed messages, generating ambiguity, from different medical practitioners (McLaughlin 2008 *et al*). Confusion, anxiety and concern are common emotions for parents during the stage of diagnosis and these emotions are heightened for parents whose first language is not English.

Katherine: When Farhan started at school, did they give you a diagnosis? Did they give a name to what he has?

Mysha: Erm...

Uzma: She wants to ask, what exactly problem he has? Did they give you that this particular problem he has?

Mysha: No, he had a bad problem of telling me the area y'know? Other thing is err he is err not learning quickly you have to spend a lot of time with him. (.) Other thing is (.)

Katherine: So they didn't give you any particular diagnosis?

Mysha: No, no, no only that he cannot speak. Otherwise (.) so they scan him, whole body almost and said he was normal.

Of course parents find getting a diagnosis helpful. But seeking a name – particularly when it is vague and seemingly pathological as in the case of the vague diagnosis above – may disturb parents' relationship with their children (McLaughlin, 2005; Goodley & Tregaskis, 2006).

For Anthias (1998) a key issue associated with gendering diaspora involves asking to what extent the experiences of diasporic women capture some of the cultural and structural shifts

in relation to their 'labour' which might produce emancipatory and liberating experiences. We could argue that the mothers in our three case studies are empowered in terms of their skills and knowledge precisely because, like other mothers of disabled children, they have to take on the extended role of parenting a disabled child. However, as Anthias (1999) warns, we need to be careful not to romanticise these accounts and remain attuned to entrenched systems of subordination. Indeed, supporting the findings of McLaughlin *et al* (2008), parents (and particularly mothers) of disabled children risk being drawn into disempowering systems of professional governance and surveillance:

Saira: I was at home, making dinner ... and the children were upstairs fighting each other. Asiya was doing her homework and Aamira was messing around with her stuff and Asiya pushed Aamira and she fell down. I didn't know. The next morning she said 'Look Mum, look!'. I asked her 'What happened?'. And she was laughing and she said 'I'll go to school and I will tell my teacher Mum hit me!' I said she's just joking. I was at work and I received a call from the deputy headteacher. I couldn't receive the call and they didn't have my mobile number and he left a message. I couldn't listen to the message because I was working. When I listened to the message at half past three the school was closed. I couldn't call back. So I thought, it's alright, I'll give the call tomorrow morning. Then when Aamira came at 3.45 and at 4.00 social services came they said 'the school called us because you hit your daughter'. I was really shocked because I didn't hit my daughter. So the lady said 'we have to speak with you alone and we have to speak with your daughter alone'. They spoke to me and then they called Aamira she said 'No! I don't want to come with you alone, I want my mum.' Y'know the lady noticed she's really attached with me ... They asked 'What happened?' and I said 'I don't know what happened, because I asked her in the morning and she didn't tell me what happened' so she said 'You have to know about it, what happened' I said 'It's just in the night time I was making the dinner' she asked me 'Did you go anywhere and leave them alone' I said 'No, I didn't go anywhere'. So the lady came from social security she said 'Oh I know [professionals who work with your families] and I will ask them as well about you and we are going at the moment and we have to go to the doctor to find out what happened and everything because Police are involved now in this matter and the Police will come in the school tomorrow.' Then I had to go to Deputy Head and I explained everything and I asked Asiya, 'Asiya please tell me what happened', then Asiya told me in the night time, 'I pushed her because she was messing around in my homework and I was telling her again and again, go away, go away, and she was not listening. I was sitting on my bed because they share a room, and because I was sitting on my bed but she was messing around with my homework and I didn't really push hard I just push her like this and she fell down'. It's only a small bruise, that lady y'know came again making an appointment to the Doctor. When I went to the Doctor, the Doctor knows me very well, she said, this young lady makes up stories. Y'know, her mum can't hit her, I know.

Raghuram (2009, p. 175) argues that diasporic research can at times be so accustomed to thinking that stories of migration are always stories of arrival, from 'there' to 'here', that we rarely stop to think that the UK is also the site of departure and of circulation. We were reminded of the circulating practices of power associated with the care of disabled children undertaken by families in the context of the British welfare system.

Disability and Diaspora: From Isolation to Ensembled 'Caringscapes'

The concept of diaspora is useful because it helps us to understand how people can have continuing attachments to places – or scapes – which cannot be explained if we think of populations as static and territorially bound in nations (Raghuram, 2009: 183). For Anthias (1998) any use of the concept of diaspora should capture some of the trajectories of migration and settlement that then lead to a reconfiguration of ethnic solidarities. A diasporic space is created when it transgresses the boundaries of ethnicity and nationalism (Anthias, 1998, p. 566). We could argue that the articulations presented above are symptomatic of a hybridised identity (offered through the diaspora) which permit critiques of cultural responses to disability and challenges to service provision. The families that we spoke to illuminated some of the ways in which their diasporic positionings left them feeling isolated or, in contrast, supported by ensembled relationships. For Anthias (1998, p. 564) the diaspora is constituted as much in difference and division as it is in commonality and solidarity. One can feel an acute dual sense of loneliness and camaraderie. Like many other parents of disabled children, parents spoke of the difficulties of parenting a disabled child. Mysha's son struggled to sleep at night, which kept her awake, and she complained that he was difficult to control and 'discipline'.

However, as others have suggested (e.g. McLaughlin *et al*, 2008), these difficulties of parenting should not be attributed to the 'burden' of a child's impairment. Instead, and in line with a critical disability studies perspective, we need to excavate the social and relational support enjoyed by families and its impact upon their capacity to care. For example, Saira spoke about the barriers she experienced in accessing health, social care and education when she had to make a 3 hour round trip to pick up medicines from the hospital which her local GP was unable to prescribe. Hughes *et al* (2005) propose that the feminization of care in a phallogocentric culture makes participants in the caring relationship – regardless of gender identity – necessarily subordinate. Saira's account would, perhaps, indicate subordination. Saira told us of the lack of friendships and community support 'I don't have so many friends, just one friend and she knows my children' complicated further by the fact that her husband was refused a visa. On the other side of the diaspora experience were those times when support, care and love was provided to the disabled child (and their parents) by their extended families.

Katherine: Do you get (um) some families get support from people coming to help in the home. Do you have any help in the home or do you just look after Habiba yourselves?

Yusef: No my family does it all the time

Shanaz: She comes back from school to Grandma's house... She plays with Grandma she plays with Grandad when he comes home at half six and then my brothers come and probably play with him if not my sister if she comes back from University she puts her music on. Her Grandma begs us 'Leave her here, leave her here for the weekend, leave her here!'... we're ever so blessed.

This description resonates with Hughes *et al's* (2005, p. 266) notion of care as a 'gift' redolent with positive properties such as 'generosity, trust, confidence, love, commitment, delight and esteem'. How these gifts are offered will, of course, be influenced by social class,

economic and cultural capital. As Anthias (1998) reminds us: the diaspora is a heterogenous phenomenon marked by class, gender and, in our case, disability. Contemporary western parents are often expected by others to play a pivotal role in enhancing their children's 'futuraity': their anticipated value, productivity and well-being as adult citizens (McKeever & Miller, 2004). Similarly all parents imagine what the future will hold for their children. 'These ideas will be influenced by dominant narratives associated with the trajectory of the 'proper family'. The introduction of disability into a family shatters the 'presumed certainty of such possible futures' (McLaughlin and Goodley, 2008, p. 329). It would seem, though, that the presence of an extended family may provide some hope and positivity for the future:

Katherine: Is it okay for me to ask about the future, when Habiba grows up, what do you think will happen for her? Do you think that she will still live with you?

Yusef: Yes, then my brothers will look after her.

Katherine: You're very lucky to have that, very, very lucky.

Yusef: If there's a problem then my sister will definitely take her. If something does happen to us two, and if worse comes to worst then her grandparents, they'd love to take her.

Katherine: So there'll always be a family member who'll look after her? Yusef: Yeah.

The potential offerings of the extended family captured in this account contrasted markedly with the isolated experiences of many white British families that we have worked with. Drawing on the work of McKie *et al* (2002) and Watson *et al* (2004) we could conceptualise the contributions of the extended family in terms of 'caringscapes'. This concept acknowledges the complex and diverse ways in which people deal with the day-to-day challenges of organizing and conducting caring work. Following Watson *et al* (2004) it incorporates the spatial and temporal into an analytical framework that reflects ideas of landscape or terrain. Thus, some of the time people try to realize particular aims and goals by actively selecting their paths through this terrain. But caring pathways can be restricted by the availability of caring resources, income or services or routinized through well-trodden conventional, invariably gendered, pathways. In contrast to the limited caringscapes associated with the isolated mothers and families described above, Yusef and Shanaz depict an ensembled caringscape that boasts interdependency. At their best, caringscapes 'shift in response to the influences of others or changes in mobility, communication, and the institutional organizations which confront individuals' (Watson *et al*, 2004, p. 341). According to Crozier and Davies (2006), British South Asian parents have been variously accused of having too high expectations of their children or not being interested at all. In contrast, they show, parents demonstrate huge parental involvement in their children's lives and that this involvement resides not simply in the hands of the parents but within the wider family. Similarly, we would suggest that there may well be similar opportunities for ensembled support in the wider British Pakistani diaspora. What this points to is a further need to critique diaspora. For Anthias (1998) this involves considering the ways in which men and women are inserted into the social relations of the country of origin. A case unit of analysis for Anthias (1998) is the family and other institutions and discursive formations in the reproduction and

dynamic transformations of central facets of culture. Yusef and Shanaz's extended support capture the productive possibilities for enhancing caringscape through the diasporic family.

Conclusion

Diaspora may be seen as dynamic, 'on the move' and multiple but also subject to power relations, tensions, disconnections and the specific, situated processes that enable (or force) the constructions of shared (and often politicised) notions of belonging, identity and community (Mavroudi, 2007, p. 472)

We aimed to explore in this paper the intersecting nature of diaspora, disability and family intersect. Drawing on qualitative interviews with the parents of three British Pakistani families we drew out three lines of enquiry. The first, *disability and disavowal in Pakistan*, explores parents' relationship with 'home' and how this is complicated by the presence of disablism. We suggested that previous literature on diaspora risked romanticizing the hidden referent of 'home' and 'point of origin' (in our case Pakistan) and had failed to apprehend how diaspora is complicated by disablism. We make a plea, therefore, for researchers of diaspora to include socio-cultural theories of disability in their analyses. The second, *disability and the fight for care in Britain*, explored the ways in which British Asian families are grounded not only in the cultures and traditions of their parents and the Asian subcontinent, but also in the social practices of Britain. We focused on their engagement with services and professionals. We conclude that service evaluation and critiques of professional practice must be sensitive to the diasporic identities of their clients. The third, *disability and diaspora - from isolation to ensembled caringscapes*, examined the limits and possibilities offered through diaspora. One key affirmative element of this is the support of an extended family brings with it the chance to look to the future with hope and possibility. In illuminating the affirmative impacts of extended families on the care of disabled children we hope to extend understandings of caringspaces that view cultural diversity in terms of possibility. Following Raghuram (2009) the families accounts remind us of the diasporic potential for translocalism: simultaneous attachment to the places one might have left and the places one moves into. Translocalism emphasises the many activities that families engage in to maintain these relations across space.

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Endnotes

¹ (RES – 062-23-1138) (see project website: <http://post-blair.posterous.com/>)
