ETHNICITY, DISABILITY AND CHRONIC ILLNESS

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Introduction

Waqar I.U. Ahmad

Analyses of health and health care of minority ethnic groups constitute a major industry. However, interest in disability and chronic illness among minority ethnic communities is relatively new. Much of this research is small scale; often it lacks theoretical sophistication. The more voluminous and more sophisticated mainstream literature on disability, chronic illness and caring rarely includes minority groups. Debates on ethnicity, disability, caring and chronic illness usually occupy different discourses and politics. This book aims to make a contribution to both theoretical and policy debates in these areas. It does so by bringing together issues, debates and politics rarely discussed under the same cover.

The debates in the fields covered by this book are complex and contingent. To begin with, notions of impairment and disability themselves lack precision. Impairment is defined as an imperfection or loss of function of an organ or limb. Disability refers to the stigma attached to individuals who have impairments and the consequent marginalization and discrimination experienced by people with impairments (Oliver 1990; Swain et al. 1993). The fundamental argument is that the disability resides in the workings of an unjust society; a more inclusive environment ranging from inclusive employment, education and transport policies would allow people with impairments to perform their roles as citizens. Citizenship, as for those without impairments, combines responsibilities towards the society and the state, with social and political rights of the individual. As a model for conceptualizing the discrimination experienced by people with impairments, the social model of disability is powerful and necessary. Reconceptualizing disability as a social issue rather than a personal tragedy is necessary to ensure that the disablist marginalization experienced by people with impairments is seen in similar terms to racist, homophobic or sexist discrimination, that is discrimination experienced by a whole class of people (with impairments) which systematically disadvantages them compared to the mainstream of society. The loss of independence, lack of control over resources, the
marginalization of personal voice in decisions about personal care, relationships, lifestyle and tasks of daily living are all important markers of experiencing disability.

However, the social model of disability requires a number of qualifications. For many the distinction between impairment and disability remains problematic. The form and severity of impairment have an impact on whether someone experiences disabling consequences. The time of onset of impairment and its severity have distinct consequences for people and their identity. For example, the mobilization around British Sign Language by Deaf people is not shared by many who become deaf in older age or due to an accident. My relatively modest visual impairment is easily corrected by wearing spectacles and would not be regarded as disabling; that is, I do not experience any perceptible stigma or marginalization because of this minor impairment. Many conditions leading to impairments require ongoing medical interventions or make the impaired person dependent on medical technology for survival. Indeed, for some conditions, such as asthma, medicines can help control the symptoms and thus help reduce the stigma and discrimination experienced by the affected individual (Prout et al. 1999; see also later discussion of sickle cell disorders in Chapters 4 and 7).

Political movements, almost by definition, are historically and culturally specific. Thus some of the arguments about loss of control or independence in relation to the social model of disability may seem over-westernized to many for whom interdependence, mutual support and reciprocity are the hallmarks of social and family relationships. This is not to trivialize the discrimination experienced by disabled people within Asian or other non-western societies. The disabled individuals do still experience oppression and marginalization, but their marginalization can be understood only against what is considered ‘normal’ for someone of their gender, age and class in their own cultures. Normalcy is not a given universal; thus impairments require to be seen in their social and cultural context. The discrimination experienced by minority ethnic people in their own ethnic communities may lead to the lack of an ability to reciprocate, to engage in equal or incremental social or economic exchange, or fulfil other obligations normal for their non-disabled siblings. The stigma of impairment, as in the west, may lead to social isolation, infantilization or ‘invisibility’ – in Finklestein’s terms ‘social death’ (Finklestein 1993). Minority ethnic communities live within not only their own social structures but also the structures of the wider society. Some normative values (facilitative or oppressive) may be difficult to fulfil because of their minority status within Britain. This range of issues requires an assessment of impairment and disability among minority ethnic people both in the context of their cultures and their minority status.

I have noted that many of the debates pursued in this volume utilize different discourses; often they are conducted in opposition to each other. For example, the debates on carers and disabled persons are often presented as binary opposites. Both the disability movement and carers’
organizations have fuelled this notional opposition. Disabled people have sometimes portrayed carers as oppressive and colluding with professionals to undermine disabled people’s rights to self-determination. On the other hand, literature on carers, developed from feminist critiques of the gendered nature of domestic labour, understandably highlighted the ‘labour’ and ‘burdens’ of care. These constructs were somewhat uncritically reproduced in research work on carers. The recent emphasis on so-called ‘young carers’ is perhaps particularly problematic for its denial of disabled people’s parental contribution and young people’s contributions to family well-being in families without disabled parents. Arguments about the distinctiveness of being a carer or disabled person have become ossified in an essentialist identity politics fuelled by state welfare policies. Here, carers’ representatives highlight the burdens on them from the failure of the state to provide adequate support to families. And disabled people emphasize their unnecessary dependence on the family because the state marginalizes disabled people from education, economy and other spheres of life.

However, some recent work demonstrates the symbiotic relationship between carers and disabled people (e.g. G. Parker 1993b), emphasizing interdependence and reciprocity rather than the assumed one-way relationship of disabled people always receiving and never providing care. That disabled people do not stop functioning in their own capacity as parents or family members, and thus stop caring for or about others is also noted. The relationship is especially complex when it comes to dealing with disabled people from minority ethnic groups and disabled children. For disabled children, parents are the greatest allies and confront society and services to ensure the best for them. The stigma associated with impairment is often shared by other family members, although the parents and extended families may themselves have disablist attitudes. For minority ethnic disabled people, own families and communities provide vital buffers against a racist society. Perhaps there is a greater tendency for the stigma of impairment to be shared among the family members within the often more communally oriented South Asian communities. Having a disabled family member, for example, may affect the marriage chances of siblings or the social standing of the family. The disablism within the minority ethnic groups is as pernicious as in the white society and must be challenged; but the importance of alliances with their own families and ethnic communities in struggles against racial oppression cannot be overemphasized (Begum et al. 1994; M. Hill 1994; Stuart 1996).

Many minority ethnic disabled people involved in the disabled people’s movement experience racist marginalization (M. Hill 1994; see also Ahmad et al. 1998). Millie Hill (1994) noted this marginalization:

Black Disabled people have often found that they are regularly forced to negate the issue of their race in order to ‘fit in with’ the rest of the Disability Movement. Alternatively, they are compelled to face the ire of white Disabled people when, no longer content with having to lop
of huge chunks of their identity in order to be ‘allowed in’, they go off and set up their own associations. As one Black Disabled person said ‘they always talk of brotherhood but they are not really our brothers’. (M. Hill 1994: 74–9)

That the disabled people’s movement fears recognizing or responding to diversity is not surprising. Parallel journeys have been undertaken within the feminist movement (Carby 1982) and the anti-racist movement (Modood 1994). In the feminist movement, for example, black feminists were critical of racism within feminism and while recognizing the sexism of their own communities, argued for alliances with black men to fight racism. Millie Hill (1994) put forward a similar argument in relation to disabled people’s movement and the need for ‘black’ disabled people to build alliances with the black communities in order to fight racism. In anti-racism, the recognition of religious or cultural diversity was feared to dilute the collective struggles against racist discrimination. Yet many felt that the collective struggle should not require cultural and religious identities to be sacrificed. The inability of the anti-racist movement to deal with struggles for religious respect raised questions of its relevance to those who claimed to experience more discrimination on the bases of religion or culture, rather than necessarily colour. Movements and discourses which do not accommodate obvious diversity risk becoming irrelevant. Yet the fear of fragmentation through ever increasing sub-identities are very real; often such fragmentation is fuelled by the opponents of these movements.

The politics of organization against different oppressions do not necessarily overlap. The social models of disability, on the one hand, and of deafness, on the other, share many common fundamentals, for example, arguments about marginalization and discrimination by an uncaring and oppressive mainstream society. However, their analyses and solutions are often very different. Whereas the disabled people’s movement, quite rightly, argues against segregation – a vehicle of oppression and of ‘social death’ for so long – segregated education is strongly argued by many deaf people. For the latter, a shared culture and language in schools for deaf children allows them to develop strong identities, progress educationally and acquire important life skills. Deafness, so goes the argument, is not an ‘impairment’; deaf people are disabled by a hearing society’s failure to communicate with deaf people through a language that Deaf people are skilled in using. Deaf people are thus a linguistic minority; for some – perhaps stretching a point – they are a distinct ‘ethnic group’ with a unique culture, history and language. Of course, these arguments are not without problem, and among the challenges to this conceptualization of a universal Deaf culture, are those from minority ethnic deaf people. We return to this in Chapter 5.

The literatures on disability and chronic illness occupy somewhat distinct spheres, both theoretically and politically. Yet disability and chronic illness often go hand in hand and show some overlap in terms of consequences and discourses. Many impairments are progressive or episodic, or directly
related to the effects of a chronic condition. For many chronic conditions, the impact on personal biography, lifestyles and identities is not dissimilar to that of relatively stable impairments. Stigma and discrimination are also shared. Disruptions to identities may also be shared between people who become chronically ill or have impairments later in life. However, the relationship with medicine is often quite different. In many chronic conditions, escape from the medical model may not be desired or possible, or at best may be transitory. The use of medicine to control pain, or to halt or minimize the damage or life-threatening consequences of illness is not uncommon. Indeed, as Prout et al. (1999) note, medicine may be used to maintain a sense of normalcy and thus minimize stigma and marginalization. In sickle cell disorders and thalassaemia major, two major chronic conditions affecting predominantly minority ethnic groups in Britain, the link between chronic illness and disability become closely tied. Both are inherited impairments of the haemoglobin. In thalassaemia major, for example, the affected individual does not make enough haemoglobin and thus requires monthly transfusions for life. An important side-effect of transfusions is excess iron, which needs nightly injections of an agent commonly known as desferal in order to be excreted. Complications of thalassaemia can range from failure to enter puberty, restricted growth and damage to various organs, to premature death. The condition is very much technology dependent; rejection of the personalized medical model is not an option; compliance with medical regimens is a condition of continued life and of maintaining some control over the condition. In order to reduce the impairments relating to the condition, and to limit the stigma attached to many of the impairments, compliance with the medical regimes is a necessity. Not only are chronic illness, impairments and disability closely related, but also the discourses on the social and medical models of disability are closely related in case of thalassaemia. The reliance on medical interventions to maintain life and improve quality of life need not be seen in opposition to struggles for dignity and inclusion within a society which discriminates against disabled and chronically ill people and their families.

Finally, minority ethnic groups, disabled people and carers, as distinct groups have criticized the state and welfare services for not recognizing their needs, locating their needs in their own presumed failings and placing barriers in their access to substantive citizenship. For minority ethnic disabled people and carers these barriers are even greater, including questions about their citizenship rights, unwillingness of services to reach out to non-speakers of English, the use of stereotypes of ‘caring extended families’, arguments about ‘low numbers’ to marginalize needs, and keeping users and carers ignorant of their rights. In a recently published national study of minority ethnic parents with severely disabled children, a consistent picture of greater disadvantage is presented (Chamba et al. 1999). Parents with severely disabled children tend to be poorer compared to the general population. Minority ethnic parents with severely disabled children consistently faced greater adversity suggesting that their ethnic minority status was
important in explaining their greater poverty, lack of service provision and access to benefits.

About the book

The contributors to this book are among the leading researchers in the field of ethnicity, disability, chronic illness and caring. The chapters were specially commissioned to provide a coherent package of previously unpublished material based on major research projects. Contributions cover three important but overlapping areas with chapters complementing each other. Chapters 2 and 3 explore how disability or chronic illness is conceptualized and the implications of particular definitions for disabled people and carers. Chapters 4 and 5 focus on living with a disability or chronic illness. The final three chapters engage with the role of services in providing support to disabled people and carers. A brief theoretical and policy context for the chapters is provided below; this demonstrates the complex and contingent nature of debates addressed in this book and relates the chapters to the substantive debates introduced above.

In Chapter 2, Savita Katbamna, Padma Bhakta and Gillian Parker explore perceptions of disability and care-giving relationships among South Asian communities. Their findings are based on the first major survey of Asian carers (and some disabled people). Not surprisingly, they note that like the general population, the South Asian communities carry disablist attitudes which affect disabled people and their families alike. Many parallels with the attitudes of the general population are noted. Impairments carry social stigma. Disabled individuals and their families confront negative comments and social isolation from some relatives. Disabled relatives were often treated as invisible; in social relationships with the family, people excluded the disabled individual. As a father comments to Katbamna and colleagues: ‘They ask about the other kids but they don’t ask about the one who’s disabled . . . Isn’t he a human being as well?’

Carers were concerned about the disabled relative maintaining a stake in society and having a viable social role. Caring was done out of love and affection but the caring responsibilities were gendered, with the female moral identity closely tied to the caring role. Consequently, male carers not only were thought to be deserving of greater support but also experienced ridicule for carrying out tasks associated with the ‘female’ gender role. Not all carers saw the caring role as one sided; the reciprocity within the relationship was important for many and was conceptualized either in the present sense or in a historical sense. Caring for a disabled relative impacts on other family members, not only in terms of having social, emotional and financial consequences but also in terms of chances of finding marriage partners. For some (especially Hindus and Sikhs), association of disability with notions of retribution for past sins created numerous problems. As noted, many of these carers’ experiences are similar to those of white carers.
However, there are some important differences. These carers often care in greater isolation, with little information about the disabled relative’s condition, or about support available for the disabled relative or themselves. Importantly, many faced criticism from wider family and community if they approached services for help, this being regarded as a sign of not being able to cope or of abdicating responsibility to care and thus damaging their moral identity as a ‘good’ wife, daughter-in-law or son. There was only limited support from the extended families. The account provided by Katbamna and colleagues demonstrates the inextricable connectedness of disabled people and their family members, making the often promoted binary opposition between disabled people and carers unviable.

As Katbamna and colleagues note, perceptions of disability and caregiving relationships matter. Perceptions of impairment, however, do not develop in a social or historical vacuum. Societal views of impairment and of disabled people rest on assumptions both about normality, and values attached to being able to perform certain tasks in relation to age, gender and culture. By and large, the limitations experienced by disabled people are thought to reside in their impairment rather than in the disablist assumptions and structures of the wider society. Professionals play an important part in constructing notions of normalcy. In particular, the medical profession has played an important, though far from honourable, part in constructions of women, disabled people and non-white people. Medicine’s legitimization of contemporary discourses and practices of oppression has been much criticized (Doyal and Pennel 1979; Littlewood and Lipsedge 1989; Oliver 1990; Ahmad 1993). Waqar Ahmad, Karl Atkin and Rampaul Chamba have researched in the areas of disability, deafness and haemoglobin disorders. In Chapter 3, they explore attribution of ‘cause’ for haemoglobin disorders and deafness by professionals and parents. Ahmad (1994) has argued that historically, racialized minority groups have been thought in the west to be dangerous to their own health. Their cultures, lifestyles and genetic make-up have all been criticized for their presumed intellectual backwardness, ill-health and premature deaths. Consanguinity, the practice of marrying within one’s own kin-group, has recently emerged as a powerful discourse, combining fears about diseased genes and inferior cultures. Ahmad and colleagues note that professionals overemphasized the role of consanguinity in ‘explaining’ the child’s condition, and the discourse on consanguinity was based less on clinical evidence but more on racist discourses on undesirability of Asian family forms, presumed oppression of Asian women, and the desirability of adopting the British way of life. The unhelpful emphasis on consanguinity meant that parents often remained uninformed about the genetic basis of their child’s condition, and lacked information necessary to care adequately for the child. Parents resented the emphasis on consanguinity; this emphasis damaged professionals’ relationships with parents, engendered feelings of guilt in parents and, at times, undermined their ability to come to terms with the diagnosis. At the same
time, some parents internalized the professional discourse linking consanguinity to their child’s condition, an internalization that they found unhelpful and often contradictory. Chapter 3 provides a powerful case study in the marriage of diverse oppressive discourses, all predicated on assumptions of alienness and inferiority of these families, their cultures and genes ‘causing havoc to their children’. Regrettably, the history of professionals too often being part of the problem facing minority ethnic users is repeated in these accounts. However, the chapter also shows challenges to oppressive discourses both from parents and from some professionals.

Chapters 4 and 5 focus on living with an impairment or chronic illness. In Chapter 4, Karl Atkin and Waqar Ahmad present findings from a qualitative study of young people with sickle cell disorder. (The study also included young people with thalassaemia major but this is not reported here.) Sickle cell disorder is an inherited disorder of the haemoglobin, resulting in the characteristic ‘painful crisis’, and often leading to damage to vital organs and thus secondary impairments; it can be life threatening. Its association with people of African descent gives it a racialized character. Its neglect by the National Health Service (NHS) is often located by the affected people in it being a ‘black disease’. Chapter 4 explores the experiences of young affected people in relation to medical precautions, treatment and lifestyles. Sickle cell disorder (SCD) is episodic and variable, making medical prognosis difficult and allowing affected people and their families greater scope to maintain alternative constructions of the condition, constructions which emphasize their normality and where an undermining of medical discourse in itself is an important coping mechanism (see S.A. Hill 1994). Precautions suggested by health professionals thus carry less weight than for other more or consistently technology dependent conditions where the effects of non-compliance are immediate. With SCD, consequences of non-adherence to medical and lifestyle precautions are both unpredictable and temporally distanced. Yet during the painful crisis, the reversion to the medical model is inevitable and thus alternative constructions of SCD remain vulnerable. The relationship of SCD to personal identity and strategies to maintain a positive self-image and control over one’s life are explored by Atkin and Ahmad. They note that impairments or ill-health are not experienced in a social vacuum; in relation to SCD and young people, age, gender, ethnicity, family relationships and lifestyle choices are all important. These young people’s experiences of living with SCD can be made sense of only against this wider context.

Maintaining a focus on identity and impairments, Waqar Ahmad, Aliya Darr and Lesley Jones in Chapter 5 discuss minority ethnic deaf people. As noted, the Deaf people’s movement constructs deafness as linguistic oppression by an unsympathetic hearing world. The unity of Deaf people and claims to having an independent Deaf culture help sustain this image of being a linguistic minority, separate both from the hearing world and from the disabled people. As in the disability movement and anti-racism, the shared experience of (language) oppression is privileged over ethnic or
religious diversity among Deaf people; it also helps maintain distance from the disabled people's movement. It is this conception of a Deaf culture in which very many South Asian and African Caribbean Deaf people were socialized. However, as Chapter 5 (based on a national study of minority ethnic deaf people – Ahmad et al. 1998) shows, the acquisition and maintenance of a Deaf identity was often at the expense of ethnic and religious identities. Minority ethnic deaf people experienced marginalization from their ethnic and religious communities because of language barriers. Their easier access to the predominantly white Deaf culture made alliances with white Deaf people easier. Yet they experienced racist marginalization within the white Deaf society. Ahmad and colleagues discuss the recent developments in self-organization of minority ethnic Deaf people around cultural and religious identities, a new-found pride in owning and celebrating their ethnicity and religion while maintaining a strong Deaf identity. The experiences of minority ethnic Deaf people mirror those of ‘black’ feminists (Carby 1982) and black disabled people (M. Hill 1994). The alliances with the Deaf community remain important but the racist marginalization shows the lack of acceptance of minority ethnic Deaf people by the white Deaf movement. Ethnic and religious communities remain important in giving Deaf people a sense of belonging and identity, and yet continue to ‘disable’ Deaf people, by their failure to learn to communicate with and continued negative attitudes towards Deaf people.

As noted earlier, substantive citizenship rights are often denied to minority ethnic groups as they are to disabled people. The tools of denial are varied and many, and discourses of ‘race’ and nation, deployed to undermine citizenship rights, go hand in hand with stereotypes of supportive extended families, used to deny needs for state welfare. The non-recognition of need and the unwillingness of agencies to provide services which are appropriate and accessible need to be considered against these twin contexts. The final three chapters explore minority ethnic users’ interaction with state services.

In Chapter 6, Rampaul Chamba and Waqar Ahmad report some findings from the first major national survey of minority ethnic families of severely disabled children. With colleagues (Chamba et al. 1999), they collected data on nearly 600 South Asian and African Caribbean families who had one or more severely disabled children. Their work showed that compared to white families with severely disabled children, there was an added depth and intensity to the problems faced by minority ethnic families. A major problem faced by families is in relation to communication and information. In Chapter 6, Chamba and Ahmad note problems faced by non-users of English, many of whom still rely on informal interpreters; those provided with professional interpreters often find them less than ideal. Information about the condition and about services for the disabled person and the family is a vital resource for both disabled people and their families. This chapter shows that parents remained poorly informed about their child’s condition but particularly about support available for the child and themselves.
Knowledge about and use of support groups remained poor and many parents had a variety of unmet needs for themselves and their children. Within the context of poverty, lack of access to benefits and barriers to services, the importance of professionals functioning as a resource for families cannot be overstated. Chamba et al. (1999), however, note that the variety and strength of barriers faced by minority ethnic parents of severely disabled children act to exclude them from society, leaving too many families ‘living on the edge’. This work is important in that it provides numerical data to back up the increasing qualitative evidence on the poverty of service response to the needs of minority ethnic disabled and chronically ill people, and their families.

Earlier, Chapter 3 focused on young people’s own accounts of living with SCD and demonstrated the symbiotic relationship between young people and their families. Chapter 7, concerned with the perspectives of parents whose children have sickle cell disorder or thalassaemia major, underlines the importance of this relationship both for the affected individual and the family. The personal and clinical consequences of SCD are noted above. Thalassaemia has the same pattern of inheritance as SCD but affected individuals are more technologically dependent and the condition is more stable. Services for these haemoglobin disorders remain patchy in coverage, quality and organization. Karl Atkin and Waqar Ahmad have been researching this field for some time (Ahmad and Atkin 1996a; Atkin and Ahmad 1998; Atkin et al. 1998a, 1998b) and here provide an account of parental experiences of using services. Confirming Chamba and Ahmad’s (Chapter 6) findings, they note problems in information and service co-ordination, non-recognition of parental or children’s needs, and limited language support for non-users of English. Especially importantly, they note variable and often very limited knowledge of the conditions among health professionals. This ignorance was often coupled with arrogance on the part of professionals, who discounted the considerable expertise of the affected children and their parents in relation to the condition. Affected children and their parents persevered with inadequate and unsympathetic care while, from considerable previous experience, knowing the shape and benefits of appropriate care. Not surprisingly, parents distrusted many health professionals. This led to sometimes strained relationships, and in particular made stays in hospital stressful for both the children and their parents. Within the general context of poor services and unhelpful practitioners, they also note the much appreciated facilitative role of specialist haemoglobinopathy workers. These workers occupied a central coordination role for parents, provided accessible information and support, were flexible and usually shared the users’ cultural and linguistic background. Importantly, their performance shows how services can underwrite parental resources and support families and affected children through often trying times.

The problems of coordinating services within health care and across health and social care boundaries have been recognized for some time. Coordination becomes especially problematic when dealing with users requiring complex
care packages needing multi-professional and multi-agency involvement. Problems experienced by disabled children and adults, and their families are noted by a number of researchers (Baldwin and Carlisle 1994; Twigg and Atkin 1994). The concept of a primary health care team was developed to provide, in the words of Padma Bhakta, Savita Katbamna and Gillian Parker (Chapter 8), ‘a comprehensive pattern of services embracing social, psychological as well as physical needs’. Literature on the support needs of Asian carers is scant. Bhakta and colleagues’ chapter is based on a significant research project on South Asian carers’ needs and the role of primary health care teams. Here they focus on carers’ experiences of using primary health care teams. They note that these teams can be supportive and facilitative; indeed some carers found them very helpful. However, they argue that for most carers, primary health care teams remained unhelpful. Consultations with general practitioners and other team members remained problematic. Professionals expressed negative attitudes towards carers and rarely appreciated the carers’ role; their concerns about the disabled relative and the difficulties they experienced as carers were ignored. And carers remained poorly informed about the role of different team members. The chapter shows that the potential of primary health care teams being a key resource to carers remains to be realized, perhaps particularly so in relation to South Asian carers.

This book aims to add to the emerging literature in these fields. In theoretical terms it problematizes distinctions between users and carers, between the social model of disability and more individual medical discourses, and argues that chronic ill-health and impairment can be made sense of only within people’s personal, social and citizenship contexts. Ethnicity and racism remain important aspects of this wider context for minority ethnic people with impairments or chronic ill-health, and their families; however, neither racism nor ethnic culture deterministically structure their attitudes or experiences. In terms of policy and practice the book highlights the continued problems experienced by minority ethnic disabled and chronically ill people and their families. Although many of these users’ experiences are shared with white users, the intensity and persistence of disadvantage that minority ethnic users face can be understood only with reference to their racialized worlds.

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