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THE POLITICS OF SICKLE CELL  
AND THALASSAEMIA

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**Elizabeth N. Anionwu  
and Karl Atkin**

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Open University Press  
Celtic Court  
22 Ballmoor  
Buckingham  
MK18 1XW

email: enquiries@openup.co.uk  
world wide web: www.openup.co.uk

and  
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# The politics of sickle cell disorders and thalassaemia

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Government policy (Department of Health 1997) acknowledges the ‘special health care needs’ of UK’s minority ethnic communities. Yet the two particular care needs of minority ethnic groups – sickle cell disorders (SCDs) and thalassaemia – have received little and belated recognition (Department of Health 1993; Health Education Authority 1998). The National Health Service has been slow to recognize haemoglobinopathies as significant public health issues (Anionwu 1996a). Those endeavouring to improve services, for example, have difficulties competing with the more ‘traditional’ concerns of an NHS, responding to the needs of a predominantly white population (Bradby 1996; Dyson 1998). Recognition among other sectors of welfare provision, such as social services, housing, social security and education, is even more limited (Ahmad and Atkin 1996a). Not only do local authorities have little understanding of haemoglobinopathies, they are also not especially interested in providing support to young people or families affected by the conditions (Atkin *et al.* 1998a). Social security officers regularly confuse SCDs (the condition) with sickle cell trait (carrier status) and benefits are often refused as a consequence of the assessors’ ignorance (Atkin *et al.* 2000). Educational provision is similarly ill equipped to meet the needs of children and their families (Midence and Elander 1994; Atkin and Ahmad 2000a, 2000b).

Mistaken assumptions about the limited relevance of haemoglobinopathies to health and social care debates have helped keep them off the national social policy agenda, effectively stifling any chance of mainstream funds for development and research. There has been a reluctance to allocate regional or national funds for conditions that do not affect the majority population (Anionwu 1993). This is despite statistics questioning the myth that haemoglobinopathies are only relevant for a few urban conurbations (see Modell and Anionwu 1996; Hickman *et al.* 1999).

In the UK it is estimated that there are approximately 12,500 people with SCDs (Streetly *et al.* 1997) and over 700 people with thalassaemia major

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(Modell *et al.* 2000b). The prevalence of these inherited blood disorders is greater than that for cystic fibrosis (Hodson 1989; Dodge *et al.* 1997) and haemophilia (Cowe 1995). The number of carriers is, of course, far larger. About 10 per cent of African-Caribbean people, for example, carry sickle cell trait, whereas 1 in 12 Pakistani people carry the thalassaemia trait (Modell and Anionwu 1996). Generally, the figures suggest that 6 per cent of the UK population and about 10 per cent of all births are in groups at risk for haemoglobinopathy disorders (Department of Health 1993). Hickman *et al.* (1999) have provided estimates of the prevalence of sickle cell and beta thalassaemia in England validated against six community screening programmes (see next chapter).

Arguments about numbers, however, often disguise a more fundamental reason for the neglect of haemoglobinopathies: their association with minority ethnic populations (Black and Laws 1986). Evidence suggests that British welfare services fail to adequately recognize and respond to the needs of people from minority ethnic groups (see Ahmad 1993; Ahmad and Atkin 1996a). Individual and institutional racism means the health and social care needs of minority ethnic groups are often neglected. This failure to acknowledge the existence of a multi-ethnic society has resulted in an inability to respond to haemoglobinopathies in an equitable and timely way (Anionwu 1993), and perhaps explains why community activists, even in metropolitan areas with the highest prevalence, have faced an uphill struggle to convince health authorities of the need for resources to develop provision (Atkin *et al.* 1998a, 1998b). An immediate response has been to marginalize the issue by denying mainstream monies while encouraging voluntary groups to apply for short-term grants (Department of Health 1993). This in itself is an example of institutional racism and does little to alter the response of mainstream agencies, while also leading to inadequate support for the populations concerned (Atkin 1996). More generally, racism can explain the low priority and poor coordination of haemoglobinopathy provision and professionals' negative attitudes (Atkin *et al.* 1998a, 1998b). Haemoglobinopathies, without much doubt, would have higher priority if they were not seen as 'black' conditions (Bradby 1996). This will become an important theme of the book.

Generally, sickle cell and thalassaemia provision have so far received relatively low priority and service development has occurred in response to public action rather than on the basis of routine assessment of population need (Anionwu 1993). Inadequate, ill coordinated and poorly resourced services present major problems for people with a haemoglobinopathy and their families alike (Department of Health 1993; Streetly *et al.* 1997; Health Education Authority 1998). Specific barriers to access include inadequate knowledge of conditions and limited information on the part of families and negative attitudes, as well as limited understanding among service practitioners (Darr 1990; Midence and Elander 1994; Atkin *et al.* 1998a; Atkin *et al.* 2000). Calls for better coordinated services both at a local as well as a national level have repeatedly been made by health workers (Davies *et al.*

1993; Streetly *et al.* 1997), patients' organizations (Sickle Cell Society 1981; Barnardo's 1993) and official working parties (Department of Health 1993; Health Education Authority 1998). As Franklin (1990: 86) notes:

Services for sickle cell disease, although improving, are lagging behind the numbers of cases arising in the UK. Major obstacles to progress are the inadequate education of health professionals, disadvantage within the black community and institutionalised racism. It is unlikely that services will be improved unless there is a very vigorous and active co-operation between those providing services for patients and the self-help groups in lobbying budget holders and health care policy makers.

Franklin's comment regarding sickle cell disorders is equally applicable to thalassaemia.

### **Emancipation, empowerment and struggle**

This book examines the politics of sickle cell and thalassaemia provision in the UK and is timely for a variety of reasons. In the first instance, after many years of neglect, there is increasing policy interest in haemoglobinopathies and how to improve existing provision (Department of Health 1993; Streetly *et al.* 1997; Health Education Authority 1998). This book will directly contribute to these debates and more generally, raise awareness of sickle cell and thalassaemia. In doing so, primacy will be accorded to patients' and their families' views. We will examine delivery and organization of services from users' perspectives. This fulfils another important aim of the book: to provide a detailed evaluation of UK haemoglobinopathy provision.

The book, however, is not just about haemoglobinopathies; it also addresses more general policy and practice interests. There is, for example, growing recognition of the care needs of minority ethnic groups and policy documents emphasize the need for a more systematic approach to planning and providing culturally sensitive services (Hopkins and Bahl 1993; Social Service Inspectorate 1994; Rawaf and Bahl 1998). Such initiatives occur against the backdrop of inaccessible and inappropriate provision (see Ahmad and Atkin 1996a). Haemoglobinopathy provision reflects many of the broader problems that deny minority ethnic communities adequate care and support. These include inadequate language support, inappropriate generalizations, poor quality of care as well as institutional and individual racism (Streetly *et al.* 1997; Atkin *et al.* 1998a, 1998b). To this extent, haemoglobinopathies represent a useful case study in examining the general difficulties faced by minority ethnic groups in having their needs recognized and met by welfare services (McNaught 1987).

More specifically, examples of good practice in haemoglobinopathy provision can inform improvements in more general provision to minority ethnic groups. Nor is this discussion simply about identifying examples

of poor practice. The high regard in which families hold specialist haemoglobinopathy workers, for instance, reminds us that services for minority ethnic people can be sensitive and empowering (Atkin *et al.* 1998a). Another broad policy and practice theme concerns the increasing interest in the genetic basis of disease and the development of provision to identify such conditions (see Marteau and Richards 1996). Haemoglobinopathies are central to such debates (Atkin and Ahmad 1997). Sickle cell and thalassaemia, for instance raise various issues at the heart of the 'new genetics' by illustrating the general complexities of screening and diagnosing recessive and other genetic disorders (Modell *et al.* 1998; Dyson 1999). As part of this debate, three significant themes emerge – explored more fully in Chapter 3. First, general practical problems include poor knowledge of the value and purpose of genetic screening among health professionals; late referral of women for prenatal diagnosis; the lack of coherent screening and counselling policy; and poor interagency collaboration (compare Green and Murton 1996; Atkin *et al.* 1998b; Modell *et al.* 2000a). Second, screening and counselling provision implicates more philosophical concerns such as the tension between 'informed decision making' and 'prevention' (Atkin and Ahmad 1997). Third, evidence suggests a mismatch between professional and lay logic regarding genetics (Richards and Green 1993; Atkin *et al.* 1998b). Individuals do not make simple choices in light of relevant information; a variety of personal and social factors influence their decisions (Michie and Marteau 1996).

Besides its contribution to debates about the 'new genetics', this book will also add to our general understanding of chronic illness and family caregiving among minority ethnic groups. These are much-neglected areas in sociology and social policy, which itself is perhaps a reflection of the institutionalized nature of British racism (Ahmad 1993). We know little about the organization and experience of family caregiving among minority ethnic groups (Atkin and Rollings 1996). There is even less material addressing the experiences of and disadvantages associated with, disability and chronic illness (Stuart 1996). The emerging literature on sickle cell and thalassaemia – when linked to other material – can help make sense of the experience of chronic illness for minority ethnic people as well as the organization of family care.

Finally, empowerment and struggle in improving the lives of minority ethnic communities becomes a fundamental unifying theme informing our narrative. Many of the improvements in the provision of sickle cell and thalassaemia services have occurred as a consequence of community action (Atkin *et al.* 1998b). This reminds us of the importance of informed emancipatory struggle grounded in critical analysis (see Gramsci 1957) and active citizenship (Held 1989). The continuing strategy and struggle faced by minority ethnic groups in ensuring that sickle cell and thalassaemia gain recognition by mainstream agencies provides useful insights into the politics of 'race'. Writings on 'race' and welfare provision tend to focus on the unfair structuring of opportunities (Atkin and Rollings 1993). The critical

emphasis of the literature is perhaps understandable and has successfully highlighted the negative consequences of racism, marginalization and unequal treatment (see Ahmad 1993). Nonetheless by focusing on disadvantage there is a danger of adopting a 'victim orientated' perspective that undervalues the significance and contributions of the struggle of 'black' led organizations. Maulana Karenga described the dilemma:

How does one prove strength in opposition without overstating the case? Diluting criticisms of the system and absolving the oppressor in the process? How does one criticise the system and state of things without contributing to the victimology school which thrives on litanies of lost battles and casualty lists, while omitting victories and strengths and the possibilities for change inherent in both black people and society.

(cited in Jeyasingham 1992: 1)

Constantly highlighting the negative consequences of service provision does little to advance thinking and practice (Levick 1992). Therefore, accounts acknowledging the significance and success of struggles to improve conditions need to supplement work stressing the negative consequences of racism in welfare provision.

Following this, focusing on the needs of minority ethnic groups is not the same as meeting those needs. Action is required. The disadvantages experienced by minority ethnic groups are not inevitable. Despite the overwhelming power of established institutions in Britain, there is frequently scope for successful pressure from the grass roots (Farrah 1986). Policy and practice are made up of contradictory and changeable elements that create 'radical possibilities' (Harrison 1993). Haemoglobinopathy provision in the UK represents a particularly good case study highlighting both the threats and opportunities faced by minority ethnic communities. Despite a constraining and sometimes hostile external environment, community action on haemoglobinopathies offers an example of positive achievement and is a reminder of what struggle and emancipatory activity can accomplish. The emergence of such community action demonstrates that resistance, dissent and grass-roots pressure can empower people from ethnic minorities. In effect, minority ethnic people have to be aware of their rights and the value of taking subsequent action to secure them. The emergence of national and local voluntary organizations in sickle cell and thalassaemia reflects the potential of empowerment and struggle by focusing on strategies, resources and forms of support that African-Caribbean and South Asian people find helpful.

Locating the book in wider discussions about social policy further contributes to this strategy and struggle, by suggesting possible alliances with other disadvantaged groups. Debates about haemoglobinopathies are typically marginalized and divorced from the mainstream concerns of social policy and political philosophy. It is possible for example, to compare the experience of parents who care for a child with a haemoglobinopathy and

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those who care for children with other chronic illnesses (Thompson 1994a, 1994b). Many of the difficulties they face are alike. Their views on accessible and appropriate provision also have similarities (see Ahmad and Atkin, 1996b; Beresford 1996a, 1996b). Screening and counselling for haemoglobinopathies also raises generic problems, faced by those at risk of recessive disorders as well as those providing support. More generally – as we shall see in Chapter 4 – those with a haemoglobinopathy also face many of the disadvantages and discrimination experienced by disabled and chronically ill people in general. Consequently, there are possible links between different groups aimed at improving general service provision rather than piecemeal battles that make limited advances, often only improving the position of small, narrowly defined groups. This is an issue we address throughout the book.

### Structure of the book

The book's structure reflects the broad policy themes described above. At its most straightforward, it offers an introduction to haemoglobinopathies. The book will also address more general policy concerns. As we have seen, these include examining the general difficulties of providing accessible and appropriate welfare support as well as engaging with more specific debates about the 'new genetics' and the experience of chronic illness and family caregiving among minority ethnic communities. Perhaps more importantly, however, the book provides an account of struggle, emphasizing its importance in gaining recognition of the needs of minority ethnic groups. Not only is this a central theme of the book, but in turn, the book hopes to make a contribution to these debates by providing a critical analysis aimed at ensuring haemoglobinopathies receive the attention and support they deserve.

Following this brief introduction, Chapters 2 and 3 provide a clinical introduction to haemoglobinopathies. This clinical description examines the origins of sickle cell and thalassaemia as well as their incidence, identification and consequences. The two chapters aim to present a detailed account of haemoglobinopathies. This is particularly important because the limited understanding of sickle cell or thalassaemia held by many practitioners and managers results in inadequate care and support for affected individuals and their families (Atkin *et al.* 1998a). The description of haemoglobinopathies will also provide the broader context for the remainder of the book and will allow the reader to make sense of the text. Acknowledging these clinical influences, however, is not intended to support a medical model of disability. There is a long-standing critique of the medical model of disability, suggesting that an overemphasis on medical concerns marginalizes an individual's experience of their condition and ignores the way in which the disadvantages they face have social and material causes (Oliver 1996). This book generally accepts this critique and will illustrate

its value when discussing haemoglobinopathies. This is a particular feature of Chapter 4 and as we shall see, those with the illness can find themselves excluded from certain types of social, political and economic activity because of the inflexible attitudes of the wider society. Nonetheless it is also important to accept that the experience of chronic illness cannot fully transcend the origins or consequences of the initial impairment (Morris 1991).

Chapter 4 explores screening and diagnosing within the context of the 'new genetics'. It begins by examining some of the ethical dilemmas in screening and diagnosing haemoglobinopathies, before considering the problems of establishing and managing an accessible and appropriate service. In doing so, it identifies specific shortfalls in current provision and provides philosophical and practical insights into how they can be addressed.

Chapter 5 outlines the general problems faced by those with the illness and their families, as well as the strategies they adopt to cope with their illness on a daily basis. This is not intended to offer a straightforward narrative outlining the relevant literature. This can be found elsewhere (see Midence and Elander 1994). The purpose is to provide an insight into living with a haemoglobinopathy within the broader social context. Such a discussion begins to identify legitimate areas of strategy and struggle, aimed at improving understanding and support for those with the illness and their families. The chapter also draws out similarities with other disadvantaged groups and thereby suggests possible alliances.

Chapter 6 examines present shortfalls in provision, before focusing on examples of good practice which adds to our understanding. For example, rectifying shortfalls in provision as well as building on existing good practice, suggests a possible agenda for community action as well as state intervention. Chapter 6 also reminds us how haemoglobinopathy provision is thus caught up in the general struggle for more equitable provision faced by minority ethnic groups.

The final chapter considers the historical development of haemoglobinopathy services in the UK, bringing out the importance of strategy and struggle. It ends by looking towards the future by identifying both opportunities and threats, while also arguing that haemoglobinopathy services can build on the successes of the past 20 years.

It is not endorsed by the Sickle Cell Society and does not form part of our Information Standard-accredited information. Book Review: The Politics of Sickle Cell and Thalassaemia. Authors: Elizabeth Anionwu & Karl Atkin Publishers: Open University Press, Buckingham, 2001 ISBN 0-335-19607-1. This book is a title in the OUP's series on "Race", Health and Social Care. It addresses specifically the perception of UK policy makers in response to the marginalized concerns of the two most common human blood genetic conditions sickle cell and thalassaemia, together estimated at well over 15,000 s Sickle Cell and Thalassaemia awareness at the Africa Day celebrations May 2013. September Sickle Cell awareness month 2014 at Eurasia Ethnic Super store, Fonthill Retail park Lucan. Representing Sickle Cell and Thalassaemia at the Annual VHI women's mini marathon 2014. Sickle Cell and Thalassaemia represented at the VHI women's mini marathon 2015. SCTI's Mission is to fight the growth of Sickle Cell Disease (SCD) and Thalassaemia in Ireland and create a proper support network between the patients, the community and the health professionals. About SCTI. Sickle Cell, Thalassaemia. Start by marking "The Politics of Sickle Cell and Thalassaemia" as Want to Read: Want to Read. Sickle cell disorder is the name for several related but different inherited disorders associated with the sickling of the red blood cell. Sickle cell disorder alters the shape of the red blood cells from their usual round appearance to something which resembles a sickle, or half moon. The different kinds of disorder are found mainly in people whose families come from Africa. Sickle cell disorder is the name for several related but different inherited disorders associated with the sickling of the red blood cell. Sickle cell disorder alters the shape of the red blood cells from their usual round a