

‘All Doors are Closed to Us’: a social model analysis of the experiences of disabled refugees and asylum seekers in Britain

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ABSTRACT *In this article we undertake a social model analysis of the experiences of disabled refugees and asylum seekers, who are among the most socially and economically disadvantaged members of society in the UK today. The statuses of disability, refugee and minority ethnic group are each linked to discrimination and oppression (Oliver, 1990; Robinson 1999; Vernon 1996), yet little consideration has been paid to the particular cumulative constellation of oppressions experienced by disabled refugees and asylum seekers.*

In this article, several models are presented that demonstrate that disabled refugees and asylum seekers experience barriers to health and safety in their country of origin, such as impairment-creation through torture and war. Once in the UK barriers to social services, benefits and social contact prove similarly insurmountable.

Introduction

There is currently no comprehensive source of official data concerning refugees and asylum seekers in Britain, and basic information, such as community size, age and gender structures, are impossible to obtain at a sub-national level (London Research Centre, 1999). In this climate, researchers must rely upon ‘soft’ sources of data (Robinson, 1999). In practical terms, lack of data means that service providers are largely ill informed about refugees and their specific needs, which ‘makes it difficult for them to respond’ (Robinson, 1998, p. 153). More specifically, this lack of data means that the presence of refugees within a community may be ignored or, alternatively, that diversity within the refugee population, be it with regard to age, gender, religion, country of origin, ethnicity or disability may be overlooked. Furthermore, the tendency of some media to confuse the distinctions between refugees and asylum seekers, and to characterise both as illegal migrants, produces an environment in which minority interests within the refugee community can be lost.

Disabled refugees are:

the most invisible ... among the uprooted populations who have fled violence in their own countries ... The massive problems faced by ... national organisations in their efforts to help the ever-growing numbers of refugees tend to eclipse the particular problems of disabled people among them. (Boylan, 1991, p. 4)

At present there is no means of assessing exactly how many of the refugees and asylum seekers living in Britain are disabled. The research that underpins this article into their experiences forms the first attempt to rectify this situation (Roberts & Harris, 2002).

References to disabled refugees are rarely found within disability literature, although in recent years the Disability Rights Handbook (Disability Alliance, 1999) has included limited advice for disabled refugees and the organisations' *Disability Rights Bulletin* has included various short articles about disabled refugees and asylum seekers (Mori, 1998; Roberts, 1999; Datta, 2000; Davis, 2000). Similarly, the recent government white paper *Fairer, Faster, Firmer: a modern approach to immigration and asylum*, the subsequent Immigration and Asylum Act 1999 and both the consultation paper on the integration of recognised refugees in the UK (Home Office, 1999) and the white paper *Secure Borders, Safe Haven: integration with diversity in modern Britain* (Home Office, 2002) largely failed to consider or include disabled refugees and asylum seekers.

In recent years, in the British disability studies literature, a body of work has emerged that identifies the multiple and simultaneous sources of disadvantage and discrimination experienced by minority ethnic disabled people (Stuart, 1992; Begum *et al.*, 1994; Ahmad & Atkin, 1996; Vernon, 1997). However, disabled refugees' experiences as a minority group within the disabled community and a minority group within the refugee community merit separate consideration.

Policy Background

Local authority social service departments have a responsibility to 'carry out an assessment of care needs.. and ensure that care being given was what that person needed' (Department of Health, 1998, p. 13). However, a series of legal challenges have meant that local authorities can claim that they are unable to provide the required services because of resource limitations (Valios, 1997). Therefore, although an individual's service requirements are recognised, legally, they can continue to remain unmet. Although undergoing a Community Care Assessment (CCA) does not therefore mean that an individual will receive the support they need, Blackman (1998) argues that 'at present, social care assessments appear to offer the best approach to identifying need' (p. 193), even if support then has to be targeted at those most in need, leaving some people unsupported. Many local authorities make charges for services (Department of Health, 1998), which further confounds access in situations of insufficient financial resources.

Recent research demonstrates, however, that many disabled people experience

difficulty in gaining access to assessment (Rummery *et al.*, 1999). Research also suggests that many disabled people cannot access benefits to which they are entitled (Corden, 1995; Roberts & Lawton, 1998).

Accessing social and welfare services can also be thwarted because of a lack of information about the services on offer (Chesson & Sutherland, 1992). A further barrier is posed when social services fail to provide information in accessible formats (Harris & Bamford, 2001).

Between 1996 and 2000, concerns were expressed through the media about the expectations placed upon local authority social services departments to provide destitute asylum seekers with housing and subsistence under the National Assistance Act (1949) (Vaux, 1998; Travis, 1999). This requirement was dissolved from April 2000 by the implementation of the Immigration and Asylum Act 1999, which formally ended entitlements to social security benefits for all new asylum seekers and transferred responsibility for destitute asylum seekers from local authorities to the National Asylum Support Service (NASS). NASS provides 'destitute' asylum seekers with accommodation on a 'no choice' basis and subsistence support (currently £36.54 per week, which equates to 70% of Income Support level benefit). The Act also instigated a policy of dispersal, with asylum seekers being sent to areas of the UK that had not previously housed significant numbers of refugees and asylum seekers. Nevertheless, recent court cases (for example, in Westminster) have confirmed that local authorities retain their obligation to undertake assessment of disabled asylum seeker's requirements for services.

Methods

Qualitative interviews were undertaken with 38 disabled refugees and asylum seekers living in England to investigate access to social and welfare services. The interviews were conducted by seven first language interviewers who recruited from Somali, Vietnamese, Sorani (Kurdish) and Tamil communities via media contacts, refugee community groups and by utilising snowballing. All but one of the interviewers had been through the asylum process. Each interviewer recruited adult (over 18 years) disabled refugees or asylum seekers from their own linguistic communities (see Table I). Participants were eligible for inclusion if they identified as a disabled person, and they had arrived in Britain as a refugee or asylum seeker. Two respondents (Rwandan and Algerian), volunteered to contribute their experiences.

While the majority of the interviewees lived within Greater London, four lived elsewhere in England. Interviews varied in length, lasting from less than 1 hour to over 3 hours. Some respondents chose to ask a relative to remain with them during the interviews. Sign language interpreters were present as required.

The immigration statuses held by the participants ranged from asylum seeker to British citizen reflecting all stages of the asylum process. As research with refugees and asylum seekers often focuses on men, the interviewers made a particular effort to recruit both men and women. A total of 15 women and 23 men participated in interviews. The participants were adults of all ages (range 19–75). Twenty people had physical impairments, six people were deaf or partially deaf, three people had

TABLE I. Linguistic groups

Linguistic group	Number of interviews
Somali	14
Vietnamese	11
Tamil	7
Kurdish	4
Algerian	1
Rwandan	1
Total	38

visual impairments, one person had mental health problems and eight people experienced multiple impairments.

In the accounts presented below the participants' country of origin, religion and locations have been removed for reasons of confidentiality, identity and personal safety. Although this detail added context to the accounts, the latter are considered essential.

Barriers to Health

The respondents had undergone extreme life experiences as a result of violent and harrowing incidents in their countries of origin, such as imprisonment, deliberate denial of treatment for acute conditions, witnessing massacres of family and friends, exposure to chemicals and being shot in conditions of war, and impairment creation from undergoing torture.

Figure 1 summarises the barriers to health experienced by the respondents in our study. These barriers were war (effects of being involved as a bystander, being shot accidentally, being poisoned by chemicals used by opposing regimes), imprisonment, torture and impairment creation (having impairments created through torture), witnessing massacre of family and friends (with consequential effects upon mental health), and deliberate denial of necessary treatment (for on-going health conditions). These are outlined in more detail here.

One respondent stated:

In 1984 the government burned our house. Also in 1969 they burned our second house. When I came to [location] to do my exam they arrested me when they saw my identification. After that they put me in jail. Also they beat me and broke two of my teeth. I told them I am a Haemophilia patient; they did not listen to me. I stayed bleeding for three days in jail ... In 1995 after they saw my identification they broke my right knee. I showed my disability identification; still they broke my right knee. The government when they harassed me, put an electric shock in my brain.

Other respondents were injured as a result of civil uprisings and war. Here, we

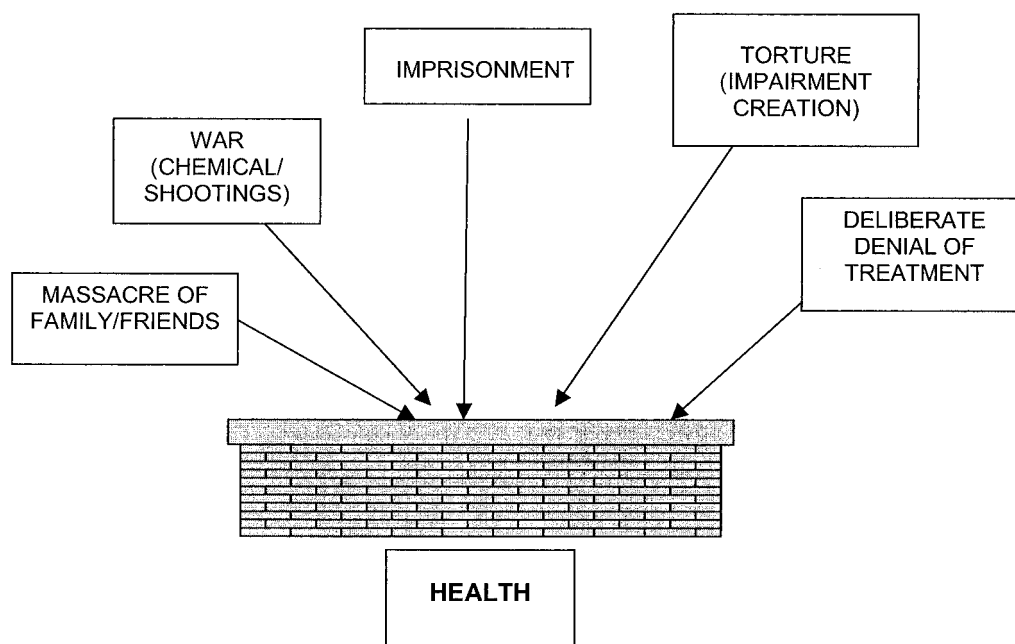


FIG. 1. Barriers to health.

present two respondents' experiences. During an intense civilian struggle between two rival clans, the first respondent had the following experience, which he described as part of 'genocide':

Respondent 1: My father was a [name of tribe]. One night the [opposing tribe] came and shot my father and mother. Also they threw a hand bomb. Because of that, fragments of the bomb affected my eyes. Also I was mentally disturbed.

Interviewer: Can you tell me what caused your blindness?

Respondent 1: Gunshots, fragments went in my eyes. That is why. I became a blind person. Before that I was a sighted person.

Respondent 2: One evening I was on my way home, two people were standing on the road asking for a lift. As usual I stopped and offered them a lift. As we drove towards [location] we noticed some people with machineguns trying to stop us. The two passengers told us to go through to the side road (it looked likely these two persons were wanted by the [name] regime). I tried to go my own way and not listen to them, but they confronted me with their pistol to go the other way. At that point we were close to the road block so I didn't know what to do ... I had my brother and cousin in the car and we carried on not stopping so the [opposing faction] tried to stop us. So we went through the road block and they started shooting at us and I [lost consciousness. When I woke] I was in a room with no water. I did not know where I was. They told me I was in the

hospital prison. My face was smashed, one of my eyes blinded. I had no senses, my nose was smashed, both my legs were broken. My body was a mess.

The experience of undergoing severe hardships as a result of civil unrest affected at least half the respondents and a core group of a quarter of the respondents had similarly intense life-threatening experiences such as this person. One respondent described how he was in the army, then imprisoned for 9 years doing hard labour:

During the war, you did not work for 8 hours a day. You had to work for 24 hours a day because of the situation. Whenever you were needed you had to get up ... I think the chemical used in the war, in the battlefields (to destroy plants in the forest) [affected me. Then in the UK] I had been working one year then one morning when I got up, I felt that half one side of my body had no strength. My body tilted over.

The respondent was sure his impairments (affecting mobility and speech) arose as a result of the exposure to chemicals that occurred during the war. Several other respondents were shot during times of war:

I became disabled when I was in my country. The car I was travelling in was attacked by gangs, who shot and the bullet hit me. My disability is called paralysis (no feeling or movement in lower part of body).

Of the 38 respondents, nine gave graphic accounts of having been tortured whilst in prison. One described his experience as follows:

In 1984 I was in prison and due to the torture, one of my kidneys stopped working which was removed in an operation. [I was freed after two months then] I was arrested again with 3 of my friends. After 40 days they executed (shot with bullets) all my three friends and they gave me 7 years imprisonment during which I was beaten, tortured and thrown about. One time they blindfolded me, pulled and threw me to the wall. My head was injured. They took me to hospital to sew my injuries. After that I was withdrawn, depressed, fainting and my conditions got worse.

As a result of torture, this man developed epilepsy and now has depression. Another respondent received a visual impairment, was burned and had both legs broken during 2 years of torture:

They put me in a room 2M × 2M which was just enough to lie down and gave me only one meal a day which was a piece of cold dry bread and some water. It was very dark, during which I had a very hard time. There was nothing to [commit] suicide with. If there were anything, I could have killed myself with, I would have done. There was only a plastic bucket and they used to push the food under the door for me. They were taking me once a day to the toilets and as my legs were broken, I had to crawl there. This is a very painful memory. It is difficult to talk about it.

The unifying element of these accounts of torture, undergone in different countries

as a result of different political allegiances and struggles, is that they resulted in impairments. One man stated that his impairment was created:

Respondent: As a result of beating and torture, my toes were damaged and twisted as the result of electric shocks. I am limping with my right leg of the same causes and they now have to operate to remove some kind of growth inside my eye.

Interviewer: Has this anything to do with the torture?

Respondent: Yes. Sometimes they didn't let me sleep for three/four days. Also as a result of not being fed properly in prison I suffer from a gastric ulcer and digestion problems.

Another respondent said:

[The terrorists] hit me. Once they took me to their camp and gave me an electric shock. Also the [government] army took me and when I told them I am deaf they did not believe me. Also they said I was lying and hit me.

Several other respondents encountered this reaction to declarations of impairment, especially deafness. These accounts of extreme situations in which the respondents were in fear for their lives, add a further dimension to the experiences of oppression delineated above. Many of the respondents in this sub-section describe effects upon their mental health, which further compound the efforts to regain health once in this country.

Barriers to Safety

All respondents in this study had undergone experiences that posed severe barriers to their personal safety, in order to gain access to this country. Two participants experienced total theft of property, leaving them exposed to the elements and destitute. Several participants described 'harassment'—being psychologically intimidated and receiving death threats from political oppositional members, prior to their decision to flee their country of origin.

The participants gave graphic accounts of desperate escapes from persecution in their countries of origin. They faced persecution in three main areas: political persecution, religious persecution and disability persecution.

Figure 2 summarises the barrier to safety experienced by the participants. These were political persecution, religious persecution and disability persecution (being actively discriminated against on grounds of impairment), destruction of home (often sequential and total), total theft of property (losing all material possessions, including clothes) and the receipt of death threats. These are explained in more detail below.

Following periods of political persecution, several participants described undergoing an exodus in small boats and nearly losing their lives on several occasions:

I didn't like the [ruling political regime] so I ran away. I escaped by boat with my daughter and relatives (nieces and nephews). We were in the ocean for 11 days and eventually picked up by a British ship.

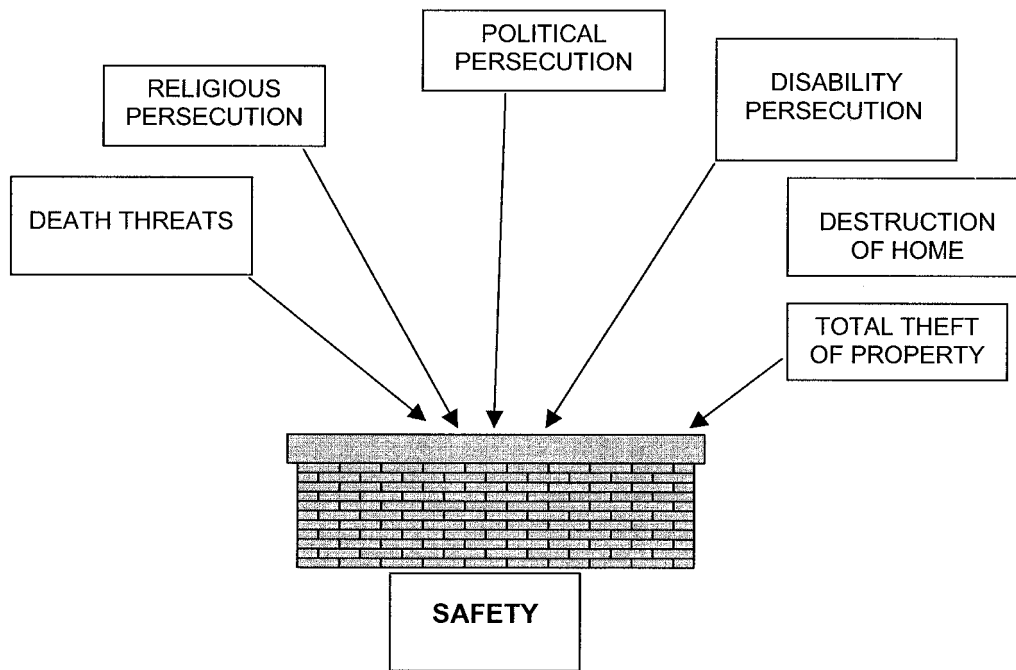


FIG. 2. Barriers to safety.

My family left by boat. I have 3 children. When we planned to escape it was meant for everybody to leave together but it was unfortunate that one got left behind. When we got to [location] the vehicle stopped so passengers could get out. Police came onto the bus to check identification. It was unlucky that they got our daughter, my eldest daughter. She was carsick because the journey is quite far and we had to go through jungles and mountains. We had to avoid the local authority and we travelled by lorry. When the police dashed in she was sitting at her seat and threw up. We were sitting down when we heard the noise, we jumped over the window and ran away. We scattered but they caught our daughter and detained her.

Others had undergone destruction of their homes, sometimes several times, due to the activities of warring factions:

In 1987, the government bombed my house in [location]. Also in 1994, they bombed my [new] house. I lost my one eye ... I came alone ... my family are in [location]. After I left [location] I do not know their details. Because of that I am mentally upset. I do not know what is happening with my family.

Several of the respondents described religious persecution:

Interviewer: Could you tell me about your situation? What led to your leaving there?

Respondent: Because of the killing. The army is killing the population there.

Interviewer: What problems did you face in particular? Was it just because you were a civilian?

Respondent: No. They were killing [religious group] there. It was religious [reasons]. I am a [religion] and have regular [religious] meetings with other people instead of going to [sacred building]. I was unable to go to [sacred building] in [country of origin] because the authorities do not condone any form of religious meetings because they are extremely paranoid and feel that such meetings are a disguise for people that oppose the government to meet together in order to discuss how they will overthrow the government. If we had been found out, we would have been arrested and imprisoned.

Other respondents described disability persecution, which contributed to their decision to flee to the UK:

I returned to [country of origin] in 1996 and stayed there until 2001. The situation was no better than when I left in 1989 and there were so many abuses of human rights. The regime was extremely tyrannical and I was personally discriminated against because of my disability. I was unable to find work and no college would offer me the opportunity to study because of my disability. I did my best to survive but it was difficult. Normally you obtain a work permit to find decent work in [country of origin] but the usual practice is to bribe the police to give you a work permit but I do not have the amount of money. I could not get decent work in [country of origin] and I ended up working on the street. I shined people's shoes on the street but I was often mugged and robbed of the little money that I earned. I was unable to chase after these muggers because I walk with a limp and cannot run. Despite of my condition, police have never helped me to catch the people who robbed me nor offered any help.

These barriers to safety experienced in the country of origin, continued to exert influence once the respondents arrived in the UK. Few could forget the extreme life situations they had experienced and the majority experience severe anxiety concerning relatives who had not escaped.

Barriers to Social Services

Having arrived in the UK all the disabled refugees and asylum seekers then experienced barriers to accessing social services. These comprised three main types of barrier: information requirements, linguistic requirements and forced moves (Figure 3).

In terms of information requirements, the most noticeable feature of the data set as a whole was the consistent response to a question on whether the respondent had utilised social services:

I do not ask for any services, I would like to, but I don't know what to

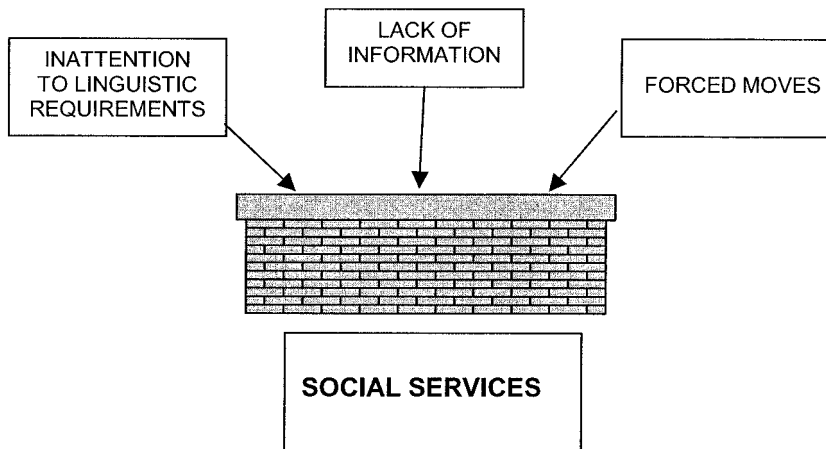


FIG. 3. Barriers to social service provision.

request or how to initiate a request. I do not know who the service providing agencies are. I'm disabled and sitting at home.

Interviewer: Do you get any help from a social worker?

Respondent: No.

Interviewer: Why don't you ask?

Respondent: I don't know who shall I ask?

Interviewer: Do you know if you have a social services assessment?

Respondent: I don't know about this and how to apply for it.

The central unifying feature of these accounts concerned the lack of access to information on what social services may be available. The respondents did not have access to information concerning what services and benefits might be available and, therefore, had no way of asking professionals at these offices about them and initiating discussion about whether they were entitled to apply for them.

A strong generalised feature of the data concerned inattention to linguistic requirements on the part of service providers:

I want to express my illness but I cannot speak the language [English]. I do not know what to do. I think when people work they try their best but it is unfortunate that I do not speak the language.

Inattention to linguistic requirements is an issue the respondents share with some British minority ethnic families with disabled children (Ahmad, 2000). Indeed, Ahmed (2000) claims that provision of accessible information formats is a necessary precursor to successful establishment of service provision.

The policy of 'forced moves' that applies to asylum seekers under the NASS operated dispersal scheme, causes disabled applicants considerable problems, particularly in relation to necessary adaptations to property, due to the temporary nature of stays:

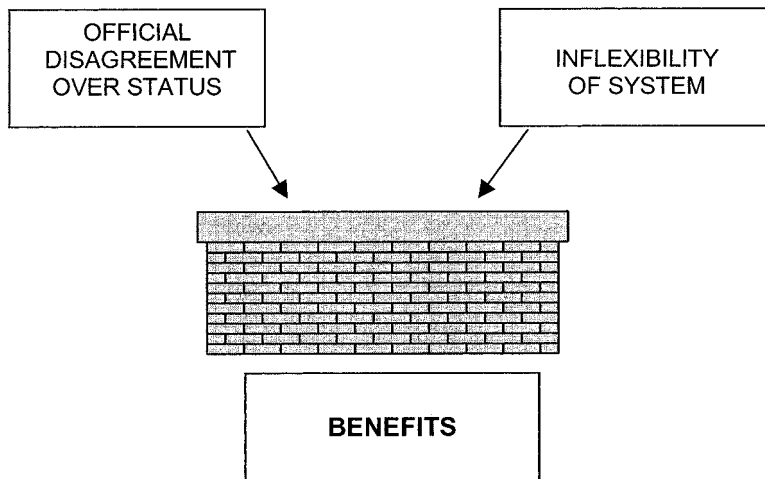


FIG. 4. Barriers to benefits system.

Interviewer: What about other aids such as rails on stairs?

Respondent: We have asked for that but the property was rented from [a landlord] and he didn't like any modifications to his property.

Five respondents were noted by the interviewers to be living in unadapted and unsuitable properties. One respondent's situation was noted by the interviewer in the following terms:

Mrs X is a strong woman, she is trying to find out what is wrong with the system and how she can get support. She doesn't trust the system after the bad experience she faced from the social services and the disease she has is incurable, but she tries to do her best. She needs support and counselling ... She is staying in 3 bedrooms with her 5 children and husband. The situation is overcrowded.

Barriers to the Benefit System

Barriers were also impenetrable surrounding the benefits system, even for those respondents who were eligible, and who had surmounted the linguistic and information barriers detailed above. A lack of knowledge of entitlements and of how to negotiate the benefits system led to individuals missing out on benefits, sometimes for decades. One gentleman had been part of an official refugee programme, but he was not told about Disability Living Allowance. As a result, he missed out on 22 years of disability-related benefits.

Figure 4 summarises the barriers to the benefits system. These comprised two main types of barrier: official disagreements over status and inflexibility of the benefit system. Several respondents were experiencing severe problems with nego-

tiating the social security benefits system and faced a confusing situation in which various officials disputed the extent of disablement:

Doctor gave me medical certificate; I received Invalidity Benefit for 12 months. After 12 months I was examined by the benefits doctor. I got 13 points. I needed 15 points in order to receive Invalidity Benefit. I was told to go to the job centre to sign on. Job centre said I cannot work I have to get Invalidity Benefit. The benefit department said I did not have enough points to receive Invalidity Benefit, I have to sign on at unemployment centre.

The interviewer in this case commented that this respondent had been passed from one office to the next as officials disclaimed responsibility for resolving the situation.

The system of Emergency Accommodation (under which asylum seekers were entitled to only board and lodging) was found to be operating a 'one size fits all' policy, which caused considerable difficulties for our respondents. The first language interviewer recorded the following example of the operation of this policy:

Male asylum seeker aged 25 who has mobility impairment, and also has problems with his chest and back. He has been in the UK 2 months and lives on the first floor in a shared room in Emergency Accommodation. The people he arrived with have been dispersed to [a northern city] he is awaiting a Community Care Assessment (CCA) ... He has to rely on other people bringing his food/drinks to the room and is only occasionally able to obtain cigarette stubs off other Asylum Seekers. He wants to go to [another city] where he has friends. The man had a hard time understanding the bureaucracy around the NASS (National Asylum Support Service) application form and CCA and did not understand why a doctor could not just confirm he is disabled ... He is too scared to move to more suitable accommodation in case the people there do not want to [assist him].

The NASS system was found to be similarly inflexible. At the time of fieldwork (1999–2002) NASS was operating the detested voucher system, in which the respondents were given vouchers, rather than money. This caused multiple problems for the respondents, since the vouchers could only be exchanged at specific shops, some of which were a considerable distance from their accommodation. Descriptions of this type were commonly related to us throughout the project, demonstrating that the practices underlying them, neglect of basic necessities of life and lack of personal assistance, were widespread.

Barriers to social contact

The respondents urgently required access to services of all types; housing, immigration assistance, education and training and sometimes independent living skills training in order to establish their position and secure their futures in the UK.

Figure 5 shows the barriers to social contact experienced. These were forced unemployment (being disallowed from taking paid work), lack of knowledge about

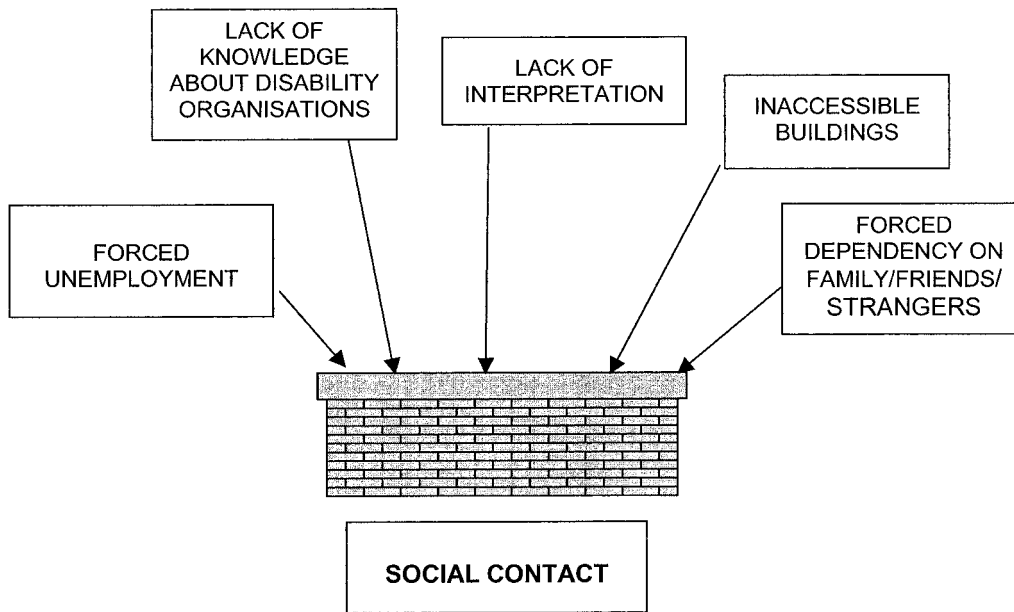


FIG. 5. Barriers to social contact.

disability organisations, lack of interpretation (a necessity to gain access to most forms of social contact), inaccessible buildings and forced dependency on family, friends and strangers (usually in the same accommodation).

Lacking these vital necessities meant that severe social isolation was experienced, resulting in a situation where one respondent described herself as ‘a prisoner in my own home’. At the time of the fieldwork, asylum seekers were debarred from paid work (‘forced unemployment’), and yet many of the respondents wished to work or take up training and educational opportunities. One said to us ‘To me, work is a necessity for life. If you are unable to work you feel there is something missing’ and another stated:

Respondent: I have no problems apart from a few things, which I cannot do because of my disabilities, such as learning English, studying languages and computer courses.

Interviewer: So you cannot work or study?

Respondent: I would like to work and study, but my disabilities prevent me from that, that’s why I spend most of my time at home ... I suffer from the loss of memory that I why I cannot remember many things about last week ... I am not happy because I cannot come and go as I wish and I am not able to work.

Only one respondent reported having contact with a British disability organisation, [1] which further limited opportunities for peer support and possible exposure to a campaigning stance based upon welfare rights. The vast majority of the respondents

found that they could not participate in these organisations usually due to linguistic barriers:

Interviewer: Have you joined any organisations relating to your illness?

Respondent: No, it is for English speaking persons. I do not speak the language, so no.

This finding has resonance with the work of Ali *et al.* (2002, p. 248) who reached a similar conclusion in relation to work with Pakistani and Bangladeshi parents of disabled children. Failure to attend to linguistic requirements has also been found to restrict choice and to limit access to the right to challenge service provision decisions (Shah, 1999).

Q1

Inaccessible buildings prevented respondents' participation in English language courses and computer training, further limiting employment aspirations. Other barriers to social contact were noted in descriptions given of 'forced dependency' on family and friends:

Interviewer: Do you have anyone to help you with personal care, shopping, housework or anything else this week?

Respondent 1: Yes I have my cousin and a friend who comes around every other day and helps me with things.

Respondent 2: Money, in my case it is not enough for food, believe me I eat only once a day with my nephew's help who comes once a day to prepare food for me and spends every day one to two hours helping me with washing, laundry and other things.

The respondents were forced to rely upon very intermittent sources of assistance and to rely intensely upon (typically) one source of support, demonstrating severely restricted access to social contact.

Conclusion

Taken as a whole, the respondent's accounts depict a landscape of barriers to the basic necessities of life. Arguably, many of these barriers also continue to affect British disabled people who are not refugees and asylum seekers (cf. Harris & Bamford, 2001). However, the respondents in this study are far more likely to be confronting all of these barriers simultaneously.

The extreme experiences undergone by the respondents, such as torture, war and the creation of impairment by hostile forces, posed barriers to health. It is not surprising that the respondents, although grateful for a safe haven, found it impossible to regain previous composure. Along with non-disabled refugees and asylum seekers, the respondents experienced severe anxiety concerning family and friends left behind in the country of origin.

The experiences of oppression and persecution undergone in the country of origin (on grounds of religion, politics and disability) presented barriers to safety so severe that the respondents had no alternative but to flee.

Once in the UK, disabled refugees and asylum seekers must surmount con-

siderable barriers if they are to access social services, the benefits system and social contact. Furthermore, many of the respondents faced considerable barriers to accessing the basic necessities of life: food, shelter and warmth. Not surprisingly, satisfaction of these necessities becomes the main priority, eclipsing often pressing requirements related to impairments. The picture that emerges is one of poverty, inadequate and unadapted housing, and failure to render accessible both the social service and benefits system. As one respondent stated:

All doors are closed to us.

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