

Challenging Barriers to Participation in Qualitative Research: Involving Disabled Refugees

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***Abstract:** In this article, the authors discuss the need to consider the potential barriers faced by both interviewers and respondents who wish to participate in qualitative research. Drawing on their experience of enabling disabled refugees to interview other disabled refugees, they discuss their conceptual basis for challenging barriers, and the practical measures they took to address the health, impairment and linguistic needs of both interviewers and respondents participating in the 'Disabled Refugees in Britain' research project. They conclude by encouraging other researchers to identify and challenge the barriers faced by all potential participants in qualitative research.*

***Keywords:** Qualitative interviews, methods, barriers to participation in research, disabled people, refugees / asylum seekers, social model of disability*

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Introduction

Qualitative research involving interviews and focus groups has become a popular means of collecting data in the social sciences (Mason, 1996). Yet literature that discusses the practical aspects of arranging and conducting qualitative research is still relatively rare. With the exception of articles in specialist methodology journals (such as *the International Journal of Qualitative Methods* and the *International Journal of Social Research Methodology: Theory and Practice*), few authors write in detail about how they did their research. Rarer yet is any acknowledgement of the difficulties, or barriers, that need to be overcome to enable both potential interviewer and potential respondent to participate in the qualitative research process; this is despite Croft and Beresford's (1992) call for researchers to explicitly consider the support needs of research participants. Where such discussions are found, they tend to be within specialist publications relating to population groups that are perceived to be 'hard to reach' – for example disabled people (e.g., Barnes & Mercer, 1997) or minority ethnic groups (e.g., Edwards, 1998) – and may or may not go so far as to include strategies for overcoming the identified barriers.

The lack of detailed discussions about the practicalities of conducting qualitative research within the "methods" sections of most mainstream qualitative literature means there is little guidance available for researchers who wish to inform their own methodological practices. Readers are left thinking that arranging and conducting qualitative interviews and focus groups is a straightforward process, and the lack of evidence to the contrary encourages funding bodies to question requests for the resources and time which may be necessary to facilitate participation. Similarly, a lack of consideration of the barriers faced by those who wish to participate in

qualitative research does little to encourage the involvement of those who are least likely to have their voices heard.

Building on the history of addressing these issues within disability studies and minority ethnic studies, this article is concerned specifically with the practicalities of involving disabled refugees and asylum seekers in qualitative research. While methodological literature in the minority ethnic field frequently addresses issues related to overcoming linguistic barriers in research contexts (e.g., Jentsch, 1998; Temple & Edwards, 2002), literature in the disability studies field tends to focus on overcoming barriers associated with impairments and developing research practices based on social and political perspectives of disability (e.g. Zarb, 1997; Humphrey, 2000). The strength of this article is that, by focusing on experiences of engaging disabled refugees and asylum seekers in qualitative research, it transcends the traditional disciplinary boundaries of disability or minority ethnic studies. Considering disability-related barriers alongside linguistic and cultural barriers to participation in research enables a focus on the “polarities, the extreme challenges, the range of diversity and provides the opportunity to get to the essence of the problem” (Stubbs, 1999, p. 257-8).

Specifically, we address the need for clarity about how qualitative research is carried out in the field – the barriers and challenges that researchers face, and the measures required to overcome them. Moreover, we hope that by demonstrating that extreme barriers to participation can be overcome, we will encourage researchers in less challenging research settings to adopt measures designed to facilitate access to the research process.

Background to the research

As part of the *Disabled Refugees in Britain* research project, we arranged and supervised the completion of 38 semi-structured qualitative interviews with disabled refugees and asylum seekers. These interviews were conducted by a team of seven *first-language interviewers*, interviewers whose first language is that of the interviewee, who themselves experienced barriers to their participation in the research. None of the interviewers spoke English as a first language, all but one had claimed asylum in Britain and three had personal experience of impairment. Thus, in order for the interviews to be successfully completed, many of the barriers faced by both interviewees and interviewers had to be overcome, particularly in relation to the health, impairment, and linguistic needs of all the participants.

The *Disabled Refugees in Britain* research project was carried out on behalf of the Refugee Council, the leading campaign organization promoting the rights of refugees and asylum seekers in the UK. It has long been recognized that disabled refugees are “The most invisible...among the uprooted populations who have fled violence in their own countries” (Boylan, 1991, pp.4).

Yet, there is still no official source of data on the prevalence of impairments and chronic ill health among refugees and asylum seekers in Britain. Apart from material that we have written (Roberts & Harris, 2001, 2002a, 2002b; Harris & Roberts, 2003), there is little evidence to suggest that academics engaged in either the disability studies or refugee studies fields have considered the situation and particular experiences of disabled people in refugee and asylum seeking communities. Similarly, disabled people rarely feature in the so-called grey literature

relating to refugees and asylum seekers. This is in part because of the multiple barriers disabled refugees and asylum seekers experience in having their voices heard.

Within a multi-faceted methodology, the qualitative interview phase of the project was carried out with disabled people from four refugee communities – the Tamil, Somali, Vietnamese, and Sorani-speaking Kurdish communities. The barriers to participation in the qualitative interview process and the measures needed to enable all those participating (interviewees, interviewers, researchers) to take part form the basis for the discussion below.

Identifying and challenging barriers

Conceptual framework

The *Disabled Refugees in Britain* research project was informed by the social model of disability – a conceptual framework that stresses that people who have impairments are disabled by the way in which society is organized. The social model of disability argues that individuals are not disabled by their impairments, but rather by the physical, social, political and economic barriers, and inadequate support services, which they encounter within a society which fails to appreciate difference (Oliver, 1990; Barnes, 1991). The concept of barriers to participation in society is central to the social model of disability and provides a practical starting point from which to challenge the discrimination and disadvantage experienced by disabled people. Rather than expecting disabled people to adapt, the social model of disability calls for society to accommodate difference by identifying and challenging the barriers to participation in society as experienced by individuals who have impairments. For example, this might involve the removal of physical barriers that prevent people with mobility impairments entering buildings, or the

provision of support services that enable people with learning difficulties to participate fully in employment, education and leisure pursuits.

Using the social model of disability as a guiding principle, it is clear that as barriers to participation exist within society, we should also expect them to operate within the context of a qualitative research interview. Thus, with a research design that involved interviewing disabled people from refugee and asylum seeking communities, it was immediately evident that people wishing to participate in the research were likely to experience linguistic, health and impairment-related barriers unless measures were taken to specifically address differences in experiences. Given our commitment to involve disabled refugees and asylum seekers in all aspects of project (including as interviewers), we knew we were likely to face problems similar to those that threatened the completion of Zarb's (1997) research when he employed disabled interviewers; notably, staffing problems and shortfalls in meeting the additional costs associated with disability. Forewarned, our research proposal incorporated measures to counter as many barriers as possible, most notably by allowing an extended time for fieldwork and a budget which incorporated funds for meeting impairment-related and linguistic-related requirements.

Practical measures

We begin with a detailed discussion of the practical steps and measures taken within this research project to challenge the barriers to participation experienced by interviewees, interviewers, and the researchers. Following a discussion of the general measures, we present a case study that illustrates the importance of addressing barriers faced by all participants in the interview process.

The interviewees

The aim of the qualitative study was to conduct semi-structured interviews with disabled people (people who had physical, sensory, or multiple impairments) who had arrived in the UK as refugees or asylum seekers.

At project recruitment stage, it was clear that material advertising the project and calling for respondents would need to be produced in a variety of languages and formats to alert people who may find printed English-language material inaccessible. Thus, leaflets in English, Tamil, Sorani, Vietnamese, Somali, and Braille were prepared and distributed to relevant refugee community groups across Britain. Translated advertisements were also placed in minority ethnic newspapers and audio/visual advertisements were played on minority ethnic radio and TV stations. Care was taken in all these advertisements to stress that the interviews would be carried out by interviewers from minority ethnic communities, and that respondents would be able to specify whether they wished to talk to a man or a woman. In addition to these measures, the lead researcher and a number of the first-language interviewers attended various cultural and disability events to promote awareness of the project and to encourage people to participate. In these ways, measures to challenge barriers to participation were integral to the recruitment process and 38 people meeting the recruitment criteria were successfully recruited.

Barriers to participation in research, however, are not limited to the recruitment stage. During any qualitative interview, further barriers exist and must be challenged if the interview is to be successfully completed. Many venues traditionally used for qualitative interviews can be inaccessible and choosing a venue needs to include a consideration of potential social and

physical barriers to participation. All the respondents were offered a choice regarding an interview venue, including their own home or, alternatively, a local community center or refugee community group. We ensured that these alternative venues were culturally appropriate and physically accessible for people with impairments and we covered transport costs incurred by the interviewee (and a carer or personal assistant as required). While the majority of respondents chose to be interviewed in their own homes, interviews were also carried out at two disabled refugee organizations. Linguistic barriers to participation in the interviews were minimized by the use of first-language interviewers and the provision of sign language interpreters for deaf interviewees. As failing to consider the health and impairment related circumstances of interviewees during an interview can also act as a barrier to its successful completion, the interviewers took particular care to be flexible during the interviews themselves. Thus, interviews were sometimes cancelled, or curtailed due to ill health and multiple breaks were offered to interviewees who fatigued easily. When requested to do so, interviewers assisted with the preparation of refreshments during breaks. All the interviewees received a small gift in recognition of their participation in the research, and requests for assistance in comprehension of official letters received by the interviewees were often met at the end of the interviews. Information about entitlements to welfare services was also provided to the interviewees.

In view of the extent of the barriers to participation in society experienced by some of the interviewees, time-limited support was offered after the completion of the interviews. Notably, the researcher and interviewers responded positively to requests to write letters, for instance requesting that service providers correspond with the interviewee in accessible formats. They also frequently provided details of local organizations able to provide ongoing support to the

interviewees. Finally, following the completion of the research, arrangements were made for each interviewee to receive a summary of the research findings in an individually appropriate format.

The interviewers

Central to the recruitment of the first language interviewers was the requirement that they should be fluent in the language in question (Tamil, Vietnamese, Somali or Sorani), have an understanding of the experiences of disabled people, and be familiar with refugee experiences (e.g., persecution, flight from country of origin, the process of claiming asylum). In view of the guiding theoretical framework of the project – the social model of disability - barriers that could prevent suitable candidates from applying for these posts, or from working subsequently as first-language interviewers, needed to be identified and actively challenged.

The first-language interviewer posts were advertised via refugee community groups, minority ethnic newspapers, and university-based job centers. Additionally, individuals already known to the research team were alerted and encouraged to apply for the posts. Further particulars were available in alternative formats (e.g., Braille, on disc, etc.) and the particulars stressed that the researchers would welcome applications from men and women, disabled people, and refugees and asylum seekers. Informal discussions with the researchers were encouraged and individuals selected for interview were contacted to ascertain their particular access requirements at interview. Candidates who required assistance with making travel arrangements were offered support, and in one case a candidate was interviewed by telephone after his travel arrangements broke down. The recruitment process was successfully completed and a total of eight first-

language interviewers were appointed. Of the eight, seven had arrived in the UK as refugees or asylum seekers and three had personal experience of impairment.

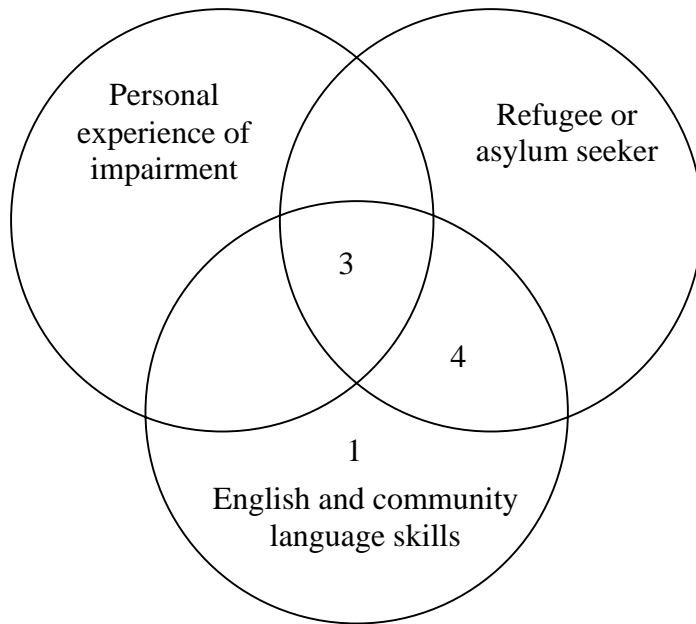


Figure 1. The interviewers

All those appointed as first-language interviewers were invited to attend a two-day training course at the University. Materials used during this course were provided in Braille and on disk as required and the equipment training (tape recorders, microphones, etc.) session was designed to take account of visual impairment and variations in dexterity. The training venue and the hotel in which the interviewers were accommodated were both physically accessible and the researchers joined the interviewers for an evening meal at a restaurant that could cater for both halal and other dietary requirements.

As it was recognized that the interviewers were also likely to encounter barriers when arranging, conducting, and transcribing interviews, support in overcoming potential barriers was offered

throughout their period of employment. Notably, interviewers were encouraged to request assistance in making travel arrangements and the costs of taxis were covered, rather than require those who found public transport inaccessible to take a bus. The researcher accompanied each interviewer (with one exception) on at least one of their interviews for training and support purposes and provided telephone support before and immediately after each interview. This was vital due to the frequently distressing nature of the stories told by the interviewees, which sometimes covered experiences of torture that were shared by the interviewer. Regular contact with the interviewers was also maintained between interviews and workloads were adjusted to take account of changes in both the physical and mental health status of individual interviewers or members of their families. Similarly, requests for extended holidays required for visiting family who had been scattered across the globe following their flight from persecution were accommodated.

The researchers

The two authors of this paper provided each other with mutual support during the course of this research project. Given the distressing stories told by many of the interviewees (often including detailed accounts of torture and consequent permanent impairments), it was crucial that the tasks of supporting the interviewers and analyzing the transcripts be shared, particularly as the researcher experienced an extended period of ill health during the research. This sharing of the support role and subsequent analysis ensured that both authors were able to step back periodically from the material and thus minimize the threat to their own well-being.

Case study

Interviewer A has a visual impairment and contacted the researchers to let them know that he had recruited a number of deaf refugees and asylum seekers to the project. He requested assistance in arranging appropriate sign language interpretation and in preparing for these interviews. A Tamil Sign Language (TSL) interpreter was booked and arrangements were made to meet the interviewee at a refugee community center. However, the TSL interpreter was unable to attend at short notice, and an alternative British Sign Language (BSL) interpreter was provided on the day of the interview. On arrival at the community center, it was noted that the interviewee used a combination of gestures, basic TSL, family-specific signs and lip reading of spoken Tamil to communicate. Her formal language skills were limited due to the barriers she had experienced in accessing education. The interviewee requested that her father be present during the interview; also the BSL interpreter requested access to the project contact who was fluent in both BSL and TSL and the researcher was present to verbally relay visual cues to Interviewer A. Figure 2 illustrates the forms of communication used by each person present at this interview.

Interviewer A conducted the interview with the assistance of the BSL interpreter and the lead researcher who provided verbal cues to indicate the progress of the sign language conversations. The BSL interpreter consulted with the project contact for advice about alternative signs for use with the interviewee. Despite the measures taken, the interviewee continued to experience communication barriers and at times she indicated that questions should be addressed to her father. When this occurred, interviewer A spoke to him in Tamil. Information gained in this way was then translated into English so that the BSL interpreter could use signs to confirm that the interviewee agreed with her father's statements. Thus the interview was conducted in a

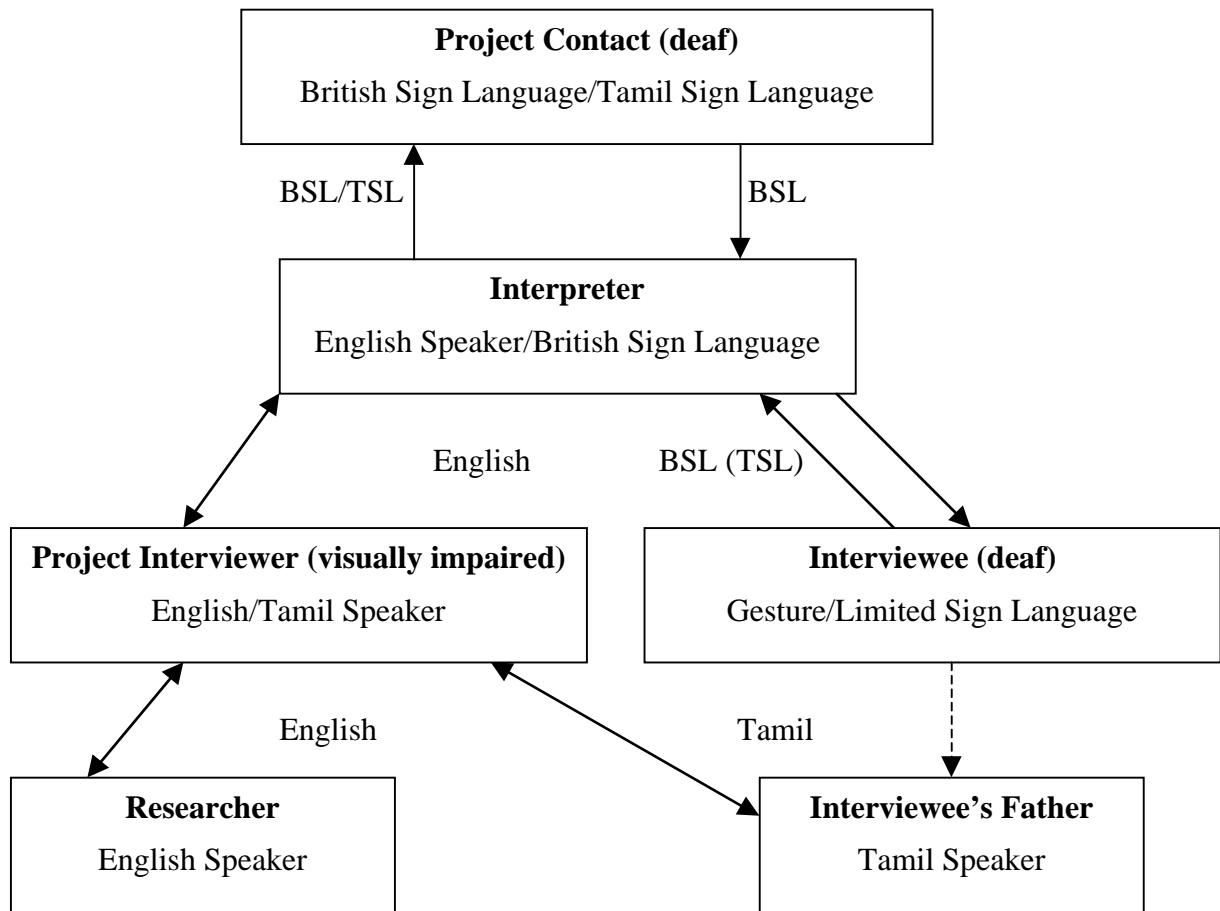


Figure 2. Languages in interview process

combination of English, Tamil, gesture, BSL and TSL. The progress of the interview was extremely slow and discussions with the interviewee were limited to facts rather than abstract concepts. Nevertheless, the interview was successfully completed. This interview provided compelling evidence of the extreme isolation and communication barriers experienced by many disabled refugees and asylum seekers, but also demonstrated the value in attempting to challenge such barriers.

Discussion and conclusions

With the social model of disability as a guiding theory, this research was always going to be conducted in a manner that challenged barriers to participation. Yet, even with awareness of potential barriers, issues arose which had not be foreseen. Certainly at the outset of the project it was not anticipated that a visually impaired interviewer would interview a deaf person.

Nevertheless, a flexible and inventive approach, alongside a commitment to challenging barriers and adequate funding, allowed the research to be successfully completed.

While the circumstances faced in this research were extreme, a willingness to challenge barriers to participation should be incorporated into all qualitative research. Barriers exist throughout society and affect people in different ways. Research staff can become ill; people on low incomes cannot afford to travel to research venues; parents can encounter child care difficulties and employees can face problems getting time off work. Without an awareness of these and other barriers to participation, qualitative research is unlikely to incorporate the voices of those who find it difficult to take part and the voices of “hard to reach groups” will remain ghettoized in specialist literature.

Utilisation of the social model of disability sensitized the researchers to consider the following accommodations. When preparing research proposals and budgets, researchers need to take account of barriers to participation and the measures required to overcome them. Specifically, researchers should allow extra time to recruit respondents such as those in this study. Contacting people who face barriers to participation takes time and energy as well as determination but is clearly possible and adds to the range of experiences highlighted by qualitative research.

The research timetable should allow extra time to cover periods of illness among research staff. During longer research projects, covering 2 years or more, it is almost certain that someone in the research team will experience an illness, accident, or bereavement that requires them to take time off work. Researchers should budget for interviewees' travel costs, including for a proportion of journeys that will not be made using public transport. Many people, including both disabled people and parents with young children, find public transport (in Britain and elsewhere) inaccessible. Additionally, people with care responsibilities (for children or disabled or sick relatives) can have extreme pressures on their time that makes public transport unsuitable.

Recognising barriers to participation in qualitative research involves acknowledging and preempting the specific challenges and taking steps to overcome them. A "can do" attitude is important here.

With more and more research being conducted by researchers on short term contracts, the pressure to present a succinct and sanitized view of how qualitative research is conducted is great. Yet an openness about the realities of arranging and conducting qualitative research is vital if funders are to agree to cover the true costs incurred. Moreover, it should be acknowledged that the process of collecting qualitative data can be as instructive as the data itself. As such, researchers have an obligation to share this knowledge with fellow members of the research community.

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