

Social Model of Disability: A Small-Scale Survey of the Bangladeshi Community in the London Borough of Tower Hamlets

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ABSTRACT

This study employs a small-scale survey to investigate the lives of Bangladeshi disabled residents in the London Borough of Tower Hamlets. Survey instruments include individual interviews and focus group discussions with people with disabilities in the Bangladeshi community. The paper also investigates the health and social care activities of Tower Hamlets Council through the lens of the social model of disability. The findings show that there are numerous facilities available for people with disabilities, but there is still a lack of satisfaction with the services provided to the community.

Keywords: Disability, Social Model, Disability Discrimination Act, Bangladeshi Community, Tower Hamlets.

INTRODUCTION

Around one billion people live with disabilities worldwide, accounting for approximately 15% of the global population or one in every seven people. Between 110 million and 190 million of these adults have significant functional difficulties. It is estimated that 93 million children have a moderate or severe disability (WHO, 2015). When family members are included, there are approximately 2 billion people worldwide who are indirectly impacted by disability. This equates to nearly one-third of the global population. (Lightfoot, 2004). With the rise in political activism by disabled people and their organizations on a global scale in recent decades, disability has become a particular focus of attention and a critical development issue. The United Nations has stressed the necessity of defending the rights of disabled persons. It is stated in Article 11 of the UN Convention on the Rights of Persons with Disabilities that:

“States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters” (CRPD, 2006, Article 11, p. 10).

Countries all over the world are taking the lead in paving the way for a more inclusive and sustainable world for the disabled. Following many years of disability activism at the national and international levels, several governments adopted disability-focused legislation in the 1990s. The primary pledge of the 2030 Agenda for Sustainable Development is to leave no one

behind and to reach the most vulnerable people first. The agenda includes 17 SDGs as well as 169 targets that must be adopted by the UN member states by 2030. Disability is mentioned in several targets and as a cross-cutting issue in the 2030 Agenda. Although there has been progress in adopting or harmonizing existing laws and policies in accordance with the CRPD at the national and international levels, implementation of such measures has been slow (UN, 2018). Consequently, people with disabilities continue to be marginalized. According to a 2002 International Labour Organization (ILO) report on 29 African countries, persons with disabilities were either forgotten or kept out of the way of socioeconomic integration (ILO 2002). The Flagship Report of the World Health Organization and the World Bank, published in 2011, found a connection between poverty and disability in both developed and developing countries (WHO, 2011). In this context, the current study examines the lives of disabled Bangladeshi adults living in the London Borough of Tower Hamlets using the social model of disability as a framework. It also discusses disability legislation and policy implementations in the United Kingdom in order to assess the effectiveness of such policies for disabled Bangladeshis in the Borough. The study employs a small-scale survey to determine the true picture of the community and to understand how respondents' perceptions match the policies.

DATA AND METHODS

This study has two segments. The first portion is a review of several institutions' web content connected to disability legislation and functions, as well as Bangladeshi populations in Tower Hamlets. The second is a small-scale survey that employs two instruments: individual interviews and Focused Group Discussions (FGD). Participants in the survey were ten randomly selected disabled Bangladeshis who were receiving services from the NHS's Health and Social Care Unit (previously known as Primary Care Trust) in Tower Hamlets. In-depth individual interviews with respondents were conducted utilizing a semi-structured questionnaire. A focus group discussion (FGD) with a group of disabled people was held to collect group information to supplement the individual information set. Participants in the focus group shared their perspectives on policies and actions taken to assist disabled people. FGD respondents were chosen from the client list of the NHS Health and Social Care Unit. Individual interviews with adult members were conducted at the respondent's convenience in four Unit locations. The questionnaire was developed in compliance with the Disability Discrimination Act of 2005 and is based on the social model of disability. Was ethically approved by three parties: the University of East London¹, the Tower Hamlets Health and Social Care Unit, and the respondents. The confidentiality of the data and the anonymity of the respondents were strictly observed. Data collection took place in August of 2012. Qualitative techniques were used to analyse the data. I drew two intriguing case studies from the dataset.

Social model of disability: The social model of disability served as the conceptual framework for this investigation. There has been substantial advancement in the field of disabilities of several theories and models such as the charity model, medical model, relational model, economic model, human rights model, and social model. However, the social model and the medical model of disability are the most frequently debated. The medical model of disability depicts disability as a personal issue caused by disease, trauma, or other health concerns. Medical care is regarded as the primary concern in the medical model, with health-care policy reform serving as the primary remedy. The social model of disability, on the other hand, sees "disability" as a

¹ The small-scale survey was part of my master's thesis at the University of East London.

matter of complete integration of individuals into society. According to this viewpoint, disability is not a personal trait, but rather a complex set of issues, many of which are created by the social environment (Oliver, 2013; Jackson, 2018; Retief and Letšosa, 2018). The social model of disability highlights that persons with disabilities are frequently impaired as a result of how society is structured. According to the social model of disability, individuals are not disabled by physical or mental disorders; rather, they are disabled by socioeconomic and political barriers, as well as insufficient support services, which they face on a daily basis (Oliver, 2013 and Barnes, 2005). The central theme of the social model of disability is the concept of barriers to participation in society. The removal or reduction of the barrier means that disabled people can participate in society (Oliver, 1990; Barnes, 2000). The Disability Discrimination Act of 1995 was passed in order to prevent discrimination against disabled individuals in employment, access to goods and services, health, and education. The goal of this Act was to move away from a medical model of disability and toward a social model of impairment.

PLANS, POLICIES AND ACTIONS FOR DISABLED PEOPLE IN THE UNITED KINGDOM

The government of the United Kingdom has established an ambitious "Vision" for the protection of the equal rights of disabled persons. It said that by 2025, disabled persons should have every right to improve their quality of life by having full options and choices, as well as being valued and included as equal members of society (PMSU, 2005). The United Kingdom has signed the UN Convention on the Rights of Persons with Disabilities, as well as its optional protocols. A wide range of programs and policies have already been developed and implemented that have an impact on the lives of disabled people, both directly and indirectly. The government adopted the Disability Discrimination Act (DDA) in 1995 (and later revised it in 2005) to protect the fundamental rights of individuals with disabilities (DDA, 2005). The Disability Discrimination Act of 2005, as amended, aimed to include the social model as a devise. Based on this model, various organizations have developed plans of action to assist and support disabled people. However, with all of these initiatives the biggest obstacle the disabled people face in the process of their inclusion in the society is negative attitudes built in the mode of production (Oliver, 1996; Barnes, 1991). The social model of disability has been implemented in the United Kingdom and has become influential in the development of disability practices, having a significant impact in disabled people's organizations and academic circles.

Legislative developments for the disabled in the United Kingdom.

The legislative body of the United Kingdom, Parliament, passed or amended a number of laws and acts to benefit disabled people in the country. The following Acts are noteworthy (GOV, 2021):

Disability Discrimination Act (DDA) 1995: The Disability Discrimination Act of 1995 establishes legal classifications of disabled people in order to protect them from socioeconomic and political discrimination. It began operations in 1996. The Disability Discrimination Act of 2005 repealed the Act.

Disability Rights Commission Act 1999: This Act replaced the National Disability Council for protecting the rights of disabled people. It started operation in April 2000. The Act is repealed by Equality Act 2006.

Special Educational Needs and Disability Act 2001: This Act was introduced in order to eliminate all forms of discrimination against impaired students in educational institutions. It began in September 2002.

Disability Discrimination Act 2005 ("the 2005 Act"): Several parts of the Disability Discrimination Act of 1995 ("the DDA") were changed by the Act. The 2005 Act is a transformation "from exclusion towards inclusion – civil rights of disabled people" incorporating the themes of social model. The Act also changed the definition of disabled people to include people living with HIV, cancer, or multiple sclerosis. It was released in April of 2005.

Mental Capacity Act, 2005: The Act was enacted to assist mentally susceptible persons in gaining control of any hardship, disorder, or impairment.

Equality Act, 2006: The Equal Opportunities and Human Rights Commission has taken over the functions of other equality commissions, including the Disability Rights Commission. It is currently known as the Equality Act, 2006 (Dissolution of the Disability Committee) Order 2014, and It has been in operation since April of 2014.

Equality Act, 2010: This Act intends to harmonize and reinforce discrimination law in order to facilitate progress on equity. The majority of existing legislation will be repealed. The Equality Act of 2006 shall remain in effect insofar as it relates to the establishment and operation of the Equality and Human Rights Commission. The Act has been in effect since April of 2010.

London plan

According to a feasibility study conducted by the Greater London Authority in 2004, disabled residents of London face challenges in finding and obtaining suitable housing. These include a lack of accessible properties that meet full wheelchair standards, a lack of funds for home improvements, and a lack of disability awareness among council officers and developers. They also have issues with assessment delays, a lack of flexibility and choice, and finally having to move. For these reasons, they were unable to consider changing jobs or relocating to a more suitable location for housing. It was difficult for them to move around, especially if they lived in social housing (GLA, 2004). Based on this report, the Mayor of London declared the London Plan in 2004, with the goal of promoting an inclusive environment in London through Supplementary Planning Guidance (SPG). SPG has used inclusive design to adopt the 'social model of disability' and advises the boroughs to do the same. Its inclusive design, unlike the medical model, focuses on the design of the environment rather than the individual's impairment (London Plan, 2004). Over the last decade, there has been a significant improvement in the workplace environment for disabled people in the United Kingdom. As a result, the unemployment rate (as a percentage of the economically active population) for people aged 16 to 64, both disabled and non-disabled, nearly halved between 2013 and 2019. In 2013, the unemployment rates for disabled and non-disabled people were 14.5 and 7.2 percent, respectively. In 2019, unemployment rates fell to 6.7 percent and 3.7 percent, respectively (ONS, 2019).

Tower Hamlets disability activism

Tower Hamlets Council provides care, support, and assistance to the disabled citizens of the borough. The purpose is to assist disabled people in living independently at home and in the

community by offering services ranging from information and guidance to long-term residential care. The following are the major disability programs (LBTH, 2021):

Tower Hamlets Pan Disability Panel (THPDP): THPDP empowers disabled people to shape local services such as housing, transportation, education, training, access to leisure, health and a variety of other services. This follows the inclusion principle of the DDA.

Children's Services: A Children with Disabilities Team in children's services assists families and other caregivers. The team provides practical assistance, personal care in the home, and as well as connect caregivers with other expert organizations.

The Community Equipment Service: This program enables people to be more self-sufficient and live their lives as they see fit. Support might range from simple daily living aids to more complicated equipment.

The Sight and Hearing service: This program works with blind, partially sighted, deaf, hard of hearing, or deaf blind adults in Tower Hamlets to promote independence, equality, and inclusion by providing a tailored service that allows people to have choice and control over their life..

DLA reform and PIP: The Disability Living Allowance (DLA) is a government program that assists children and people with long-term illnesses or impairments. In 2013, the government began phased-out DLA for persons of working age (16-64), replacing it with a new benefit known as Personal Independence Payment (PIP). As they approach the age of 16, children on DLA will be eligible for PIP. Tower Hamlets Council administers DLA and PIP (LBTH, 2015b).

A REVIEW OF DISABILITY STUDIES ON THE BANGLADESHI COMMUNITY

There is a large body of disability research in the literature, but studies on disabled people from ethnic groups in the United Kingdom are rare. Beresford (1996) conducted one such study, which found widespread disadvantages and discrimination against disabled people, particularly those from minority ethnic groups. The unjust behavior of society damaged the family since other members of the family, such as disabled children, were marginalized and discriminated against. Disabled families had to deal with higher material deprivation in the long run, as well as less access to a variety of knowledge and services that could improve their lives. (Beresford, 1996; Ahmad, 2000).

Chamba et al. (1999) carried out a national survey of ethnic minority families with impaired children. Their findings revealed disparities both within and across ethnic minority groups, as well as differences between ethnic minority and majority populations. Families with disabled children of Pakistani and Bangladeshi origin fared the worst in both of the identified key dimensions. According to the survey findings, 65 percent of ethnic minority parents with a disabled kid had a family income of less than £200 in 1997, compared to an estimated £450 for a family of two children and a car. In another study, Modood et al (1997) examined the income of ethnic minorities in the UK and found that more than 80% of all Pakistani and Bangladeshi households had less than half the average income, compared to only 28% of white households. As a result, as Chamba et al (1999) suggest, it is not surprising that disabled households are more likely to have poor wages. However, it is often assumed that having a disabled child increases the family budget. Lower income combined with higher expenditure in families with

disabled children is frequently associated with comparatively low levels of employment and benefit receipt. According to Roberts and Lawton (1998), there are disparities in the distribution of Disability Living Allowance (DLA). Minority ethnic group parents were less likely to receive DLA carer allowance and they were less likely to receive higher rates of DLA than majority group parents. Language barriers and a lack of knowledge about the application process are major impediments to receiving benefits. Parents from minority groups who understood and could communicate in English were more likely to receive higher benefits than those who did not (Chamba et al, 1999). Families with disabled children were more concerned about their living situation. Six out of ten ethnic minority families with disabled children reported that their residence was unsuitable for caring for their child. In comparison to majority ethnic populations, Pakistani and Bangladeshi families were more likely to encounter various issues as minorities. (Beresford, 1996).

Fazil et al. (2002) looked into the lives of 20 Pakistani and Bangladeshi families in Birmingham, England, who had at least one seriously challenged kid. According to the study, ethnic minority families face challenges in gaining access to appropriate services due to disadvantaged circumstances, implying an additional dimension of institutional racism. This study is comparable to the findings of Chamba et al (1999), who reveal that ethnic minority parents with impaired children incur significant additional disadvantages when compared to the white majority. Families of Pakistani and Bangladeshi origin are less likely to receive disability services than other ethnic minority groups because they are less capable of comprehending existing information or processes and effectively expressing their needs. Despite receiving less supports and services, Bangladeshi and Pakistani families report fewer issues with service providers than other ethnic minority groups. This is consistent with the notion that "disadvantage is associated with both poor quality service provision and low expectations" (Chamba, et al 1999, p. 22). The problem of relatively low expectations and low expressions of dissatisfaction with a wide range of services necessitates more research in this area. Fazil et al. (2004) conducted a follow-up study on their previous sample to improve the quality of life for Pakistani and Bangladeshi families with at least one severely disabled child. The study emphasizes the importance of culturally sensitive advocacy in empowering individuals and families to improve access to information and support services.

Bangladeshi community in the United Kingdom

Bangladesh was a part of India until its partition in 1947, and then a part of Pakistan (as East Pakistan) until the 1971 Liberation War, when it gained independence. The study defines the British Bangladeshi community as those who migrated from what is now Bangladesh, excluding 'Bengali' people from India and other parts of the world. To distinguish them from 'Indian Bengali,' they are sometimes referred to as 'Bangladeshi Bengali'. Bangladeshis first arrived in the United Kingdom at the end of the eighteenth century, when lodging houses were constructed in east London for Indian seamen from ships operated by the East India Company. From then on, people from the north-eastern part of Bangladesh known as Sylhet and the British merchant navy developed a special relationship due to the traffic of two specific goods, lime (building material) and tea from Sylhet. Because Europeans were hesitant to deal with the harsh working conditions on uncomfortable ships, such as extreme temperatures in the engine room, 'Sylheti' men found it easy to find jobs (mainly as cooks) on merchant ships. They were usually hired for one voyage at a time and returned to Sylhet with their pay at the end of the trip. Those who became ill and disabled or lost money and were unable to find work on the

outward voyage applied for assistance to the East India Company, which arranged lodging houses near the docks in East London. Some seamen jumped ship in the east London docks and opened cafes in Britain to serve those who could not get back on the ships and were living in seamen's hostels. This established the link between East London and Sylhet, which lasted until the Second World War as trade expanded. Rather than remaining in the merchant navy, some of the seamen chose to work and live in the United Kingdom (Dench, Gavron, and Young, 2006).

Following the War and the partition of India (in 1947), hundreds of East Pakistani men arrived in east London and took jobs in Indian restaurants (mostly owned by Bangladeshis) – a growing industry in response to the developing British taste for curry. During the 1960s and 1970s, a large influx of East Pakistani (now known as Bangladeshi) immigrants arrived in the UK but many of them did not work in London because there was a growing need for cheap labour in the industrial North of England. Despite the fact that the Bangladeshi community has now spread throughout the UK, the eastern part of London, particularly the Borough of Tower Hamlets, has remained densely populated by them. According to the 2011 census, Tower Hamlets has the largest Bangladeshi population in England, accounting for 32% (81,377) of the Borough's total population of 254,096 people (LBTH, 2013). There were a total of 16,379 unemployed people in the Borough. This corresponds to 8% of the adult population or 12% of the economically active population (those who are employed or unemployed but actively seeking work). The Bangladeshi community has the highest unemployment rate (25%) compared to other ethnic groups such as Pakistanis (15%), Indians (7%), and White British (7%) (LBTH, 2015a). In light of the data presented above, the current study focuses on Bangladeshi people with disabilities in the London Borough of Tower Hamlets.

SMALL-SCALE SURVEY OF DISABLED BANGLADESHI IN TOWER HAMLETS

The Bangladeshi community in the United Kingdom suffers from a variety of physical and mental impairments as a result of environmental, cultural, and other factors. This study attempted to understand the current living conditions of disabled Bangladeshis. I chose the London Borough of Tower Hamlets as our field of study to investigate the living conditions of Bangladeshi disabled people there. I randomly selected ten disabled people who were under the supervision of NHS Tower Hamlets' Health and Social Care. Individual interviews were conducted using a semi-structured questionnaire. A Focused Group Discussion was also held to collect respondents' perceptions of current facilities and future opportunities. The study used the social model of disability as a theoretical foundation and the major components of the DDA, 2005 as a backdrop for the information needed for the research.

Major findings

Respondents were completely satisfied with the transportation services provided to them. Housing facilities are reported to be adequate, but insufficient due to family size (average family size 6.5) of the disabled Bangladeshi. They desired to relocate for better living conditions but were unable to do so due to financial constraints. The majority of respondents reported that the disability services they receive are subpar, but they never complained because they did not know how or where to complain. Overall, they preferred to disregard this and express their satisfaction with the services provided to them. One of the most significant barriers they identified was a communication gap between the disabled and service providers. During the interview, it was discovered that one out of every ten people could speak English fluently.

The majority of disabled people were found unemployed but they were not covered by the employment benefit. Even though, they were satisfied with the level of benefit allowance provided by services under the DDA regulation including formal support of health services. According to the findings of this study, disabled people can talk intelligently about their condition, and the barriers they identify are often compatible with the social model of disability. Many of them are aware of how society acts in terms of attitude and how it places barriers to their participation. At the same time, they are satisfied with the services provided to them as compensation. There could be two interconnected reasons for this attitude. Firstly, service providers provide adequate services for the disabled by removing all physical, mental, and environmental barriers; and/or secondly, the expectations of disabled people are lower than the standard normal. The reason for the lower expectations is that the Bangladeshi community is one of the lower income group minorities, with a history of having lower financial aspirations. Furthermore, the majority of them were concerned about losing benefits for a variety of socioeconomic or political reasons. There was also a communication issue in the form of a language barrier that prevented them from demanding what they required. Some of them preferred to blame their own fate rather than the negative attitudes and barriers of society.

Case Study I: *Mr. Mahbubul Anam, age 65, was born in Bangladesh. In 1977, he moved to the UK. He had two children from his previous marriage, but they just divorced. He worked in finance until 2002, when he became ill with an unexplained fever. When he went to the doctor, he was told that he had a problem with his retina as a result of his long-dormant diabetes. The physicians attempted but failed to save his sight. He had been registered blind since then. He also had kidney disease, and he had to go to dialysis every week. He is currently incapacitated due to sensory impairment. Despite his blindness and other hardships, he founded the Dekhte Chy (Bengali for "desire to see") organization to assist other blind people. He is the chairperson of this organization. The Royal National Institute for Blind People and Tower Hamlets Council funded his organization. Dekhte Chy publishes a monthly audio magazine that is free to blind people. He stated that his wife abandoned him due to his condition, but he is still alive because to the disability services offered. Mr. Anam continues to assist other disabled people. His story demonstrates how the social model of disability can supplement the medical model when it fails.*

The fundamental aspect of social model theory is to ensure equal opportunity. Individuals with equal rights have the ability to make decisions and take advantage of opportunities to live their lives to the fullest. The Focus Group Discussion among a group of disabled people revealed that, while there has been significant progress toward ensuring disability equality by the service provided, there is still much more to be done. Because of their impairment, the majority of the participants said they faced barriers to equal participation in society. Some of them have argued that their full participation is hampered not only by their disability, but also by societal attitudes and barriers. One of them strongly argued that attitudes and barriers in society was the main reason why they could not lead their fullest possible life. Others believed that their disability was a natural occurrence and that they had no choice but to accept it. The discussants did not address the fact that their disability was not the only factor preventing them from living full lives. In fact, they were aware of the social attitudes and barriers that prevent them from participating in society on an equal footing. It could be argued that disabled people can articulate the assumptions made in the social model of disability, but they may or may not recognize the underlying limitations in their lives. The social model of disability frequently

emphasizes the changes that must be made in society as a whole, rather than the individual disability, as the medical model suggested.

Case Study II: *Mr. Mafizul Islam, 55, is another crippled Bangladeshi. In 1990, he moved to the United Kingdom. He was married and had two children. He was injured during the Bangladesh war of independence in 1971. His current impairment could be related to that incident. He is now paralyzed and moves around in a wheelchair. Back in Bangladesh, he worked for the well-known NGO Bangladesh Rural Advancement Committee (BRAC) and the UNICEF country office. He came to the UK to study and had part-time experience working in a Bangladeshi restaurant. Following his studies, he and his friends founded a restaurant. His infirmity began when his friends abandoned him and his café. He is presently hampered by heart problems. His wife does not work, and his two daughters are students. With all of his misery and pain, he claimed for disability benefits. He now receives income support, housing allowances, disability equipment, and other benefits. His family is reliant on these benefits because he is the only earner in the household. Mr Islam claimed that his impairment was caused by his hard work in the restaurant and the refusal of his business friends to cooperate. His situation exemplifies the social model of disability, which holds that disability is the result of society's negative attitudes and discrimination toward disabled people.*

According to social model theory, social barriers cause disability and poverty to persist. Physical barriers do not cause a stronger link between poverty and disability; rather, negative attitudes, a lack of understanding, and low expectations do. Group discussion with the disabled Bangladeshi community revealed that a lack of understanding and low expectations were major barriers to their job availability, access to benefits, and other services. Persons with disabilities who are members of ethnic minorities are more vulnerable to disability and poverty than people who are members of majorities. Although the majority of handicapped individuals were aware that policies and regulations were in place to protect their rights, only a tiny number were aware that their rights were protected by the DDA. During the group discussion, it was revealed that there were barriers to accessing goods and services such as parking, taking the bus, and finding disability-friendly housing. Only a few disabled people complained, and the majority did not know where to complain. Disability can lead to poverty by preventing people with disabilities from fully participating in the economic and social life of their communities, especially when appropriate supports and accommodations are unavailable.

CONCLUSION

Through the lens of Social Model theory, this study looked into the lives of disabled Bangladeshis in the London Borough of Tower Hamlets. One of the most significant findings was that ethnic minority communities have a low level of disability awareness. A lack of disability awareness can be caused by two factors: a lack of information and a lack of communication. According to the findings of the interviews and focus group discussions, many disabled people do not know where to go or how to approach disability service providers. Some people are unaware of how much assistance they are entitled to. In this regard, more frequent dissemination of information is required. Every year, Tower Hamlets Council organizes a Disability Summer Camp. Our recommendation is that more funds be allocated to organize larger events, or that steps be taken to organize it more than once a year. Access to disability information is also a challenge for Bangladeshi people with disabilities. There is no systematic

official database for disability services or disabled people, particularly those from ethnic minorities. Communication is a serious difficulty for disabled people from ethnic minority groups. Many of them have a poor command of the English language. This issue may lead to discrimination among recipients of disability services. If the cost of hiring an interpreter is prohibitively high, English language courses for the disabled should be made available. According to the research findings, disabled people were eager to work but their physical conditions prevented them from doing so. They were recommending disability-friendly soft work for them. The majority of them claimed that their health was deteriorating as a result of disability-related diseases. In this regard, proper balance between the medical model and the social model is required for the well-being of people with disabilities. Overall, this study found that there are adequate provisions for people with disabilities, but ethnic minority groups, such as the Bangladeshi community, require more assistance to catch up with mainstream society.

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