DISABILITY AND KUWAITI SOCIETY: A CRITICAL REALIST APPROACH TO PARTICIPATORY RESEARCH IN CONTEMPORARY KUWAITI SOCIETY

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Abstract

The aim of this study is to explore disability issues in the Kuwaiti context through a participatory research project with disabled people. Six disabled people participated in this project as co-researchers, and a further eight informants (disabled and non-disabled) contributed to this research as research participants.

The thesis initially provides a critical exploration of the dominant conceptualisations of disability, such as the individual and social models and also includes cultural perspectives. The individual model provides an exploration of disability at the biological level, while the social model analyses disability at the socio-economic level (Bhaskar and Danermark, 2006). Cultural perspectives of disability provide an exploration of disability at the socio-cultural level (Danermark and Gellerstedt, 2004).

After this exploration, and in relation to the experiences of the co-researchers, the thesis proposes that each of these singular perspectives can only provide limited conceptual effectiveness. The study then goes on to suggest that, rather than reducing the ‘problem’ of disability to one limited explanation, it is more productive to take an overarching, and more complex and interactional approach to disability that combines the best aspects of individual and social models as well as cultural and societal perspectives.

The findings explore a number of disability issues at different levels. The analysis of the discussions with the co-researchers and interviews with the participants of this study emphasise a number of disability issues related to both the body and society. In relation to the body, both the co-researchers and the participants highlight issues and experiences related to the role of impairment in restricting activity, while at the same time acknowledging the roles of society and culture that play a part in disablement. The findings show the complexity of the understandings of disability and challenge the individual model, the social model and cultural perspectives of disability, and show how ‘impairment’ and ‘disability’ interact in the lives of disabled people in Kuwait. The thesis argues that an appropriate model for understanding disability in Kuwait is rooted in a critical realist paradigm that views disability from multiple levels, including biological, medical, psychological, socio-cultural and socio-economic levels.

The findings also explore the process of participatory research with the co-researchers. In relation to this, the findings highlight the issues of power relations, skills development and reciprocity, decision making processes, sharing the experiences, and the possibility of this research opening the door for further research and changing people’s attitudes on disability.
Declaration

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Chapter One

The Journey into the Field of Disability

1.1 Introduction

There are disabled people in all communities worldwide. As such, it is imperative for societies to provide good services and accessible environments to accommodate them. However, in some countries, there is a lot that still needs to be done in order to provide adequate services for disabled people. Kuwait, for example, is one country in which disabled people, I would argue, are still disadvantaged, and where there is a lack of the facilities required to enable disability accessibility. There are a number of reasons for this state of affairs, which, as I argue in this thesis, include a lack of awareness, specifically among professionals, educators, and the general public, about disability issues, as these groups tend to only conceive disabled people as a vulnerable group that requires medical care and financial aid.

In an attempt to better understand disability in Kuwait, this study gives voice to disabled people by providing them with an opportunity to participate as co-researchers in this study. This research focuses principally upon exploring disability in the Kuwaiti context through participatory research with disabled people. Six disabled participants agreed to participate in this project as co-researchers. The co-researchers and I were able to generate and analyse data from
several focus groups and interviews. The aim of these focus groups and interviews generated from both disabled and non-disabled people was to explore both the process of participatory research as well as disability issues in Kuwait. After such exploration, we were able to create a film to raise awareness of disability issues among non-disabled people in Kuwait, especially in terms of raising awareness of the best ways of supporting and interacting with disabled individuals. The research methodology, processes, the characteristics of the co-researchers, and the other participants in this project will be discussed in detail in Chapter 4. This study also proposes, after the exploration of the experiences of the co-researchers and the participants of this project and the wide reading of the relevant literature, a model for understanding disability in the Kuwaiti context (see Chapter 8).

This subject is of personal interest to me; I had undergone a long journey prior to deciding to work on this topic, which officially started in 2011. I am a non-disabled male in my thirties who is interested in disability studies. Choosing to conduct research into disability has raised many questions for me: Who am I to conduct this kind of research (at that time, I was sceptical of my ability to conduct disability research)? Why am I interested in disability studies? Do I have the right to conduct this research? These ontological questions will be explored in detail in the second section of this chapter. I will then discuss the research questions that I am hoping to answer in this project, followed by the terms and definitions adopted in this project. This chapter ends by demonstrating how the thesis is structured.
In this first section of this chapter, I will first talk about the experiences that eventually brought me to work in this field. Recounting the story of my journey is vital to my thesis for two reasons: it includes logical justification of my choice to work in the field of disability studies; furthermore, it is not merely a journey concerning topic choice but also presents a narrative of the formation of my ontological and epistemological standpoint and underlines the transition from one research methodology to another.

In all likelihood, my interest in disability had been shaped coincidently through a series of various events and encounters. This chapter will highlight the story of my journey through several different stages, which started officially when I designed my first proposal in May 2011, and covers a period of time up to the end of the exploratory phase in August 2013.

1.2 First Proposal

The story begins in 2011 when I was at work. While sitting in my office, one of my colleagues came and sat next to me. I noticed that he looked depressed, so I asked him what was wrong. He replied by telling me that his disabled brother had just left his studies at Kuwait University. When I asked him why, he said it was because of a lack of support and because of the inaccessibility of the buildings; at Kuwait University, a car is sometimes needed to move between buildings. My colleague's brother had difficulty doing this and had to leave the university as a result.
For a person who had just been awarded his Master’s in distance teaching and training and who was looking forward to continuing his PhD, I told myself that I maybe could solve the problems of the lack of support and inaccessibility by providing distance education for disabled students, so that they could learn and study at home without the ‘hardship’ and ‘fatigue’ of attending a university. As a result, I decided to create my first research proposal. The aim of this proposal was to investigate whether distance learning had an effect on physically impaired students. I focused on physically impaired individuals, because I wanted to focus on a particular group that I would be able to access easily. Furthermore, I thought at the time that those who were physically impaired were the only group who faced barriers in higher education because of inaccessible buildings.

The specific target group of this research proposal was physically impaired pupils studying in a special school in Kuwait. Because of my background, as a quantitative researcher, I wanted to make a comparison between two groups, one exposed to a distance learning course, and the other a control group. Thus, my methodology for this proposal was that of an experimental research project to verify the effectiveness of distance learning based upon a comparison between these two groups.

As my previous degree was in distance teaching and training, I have a background in distance learning, e-learning and Virtual Learning Environments (VLEs); however, I had no experience in the field of disability. Therefore, in order to gain a better understanding of this issue, I started to look for literature that combined
both fields. Most of the literature I found was focused on the possibility of building accessible designs for everyone, a process referred to as ‘universal design’ (Burgstahler, 2002; 2012). Additionally, some literature focused on relating the experiences of disabled individuals with e-learning and assistive technology (Seale, 2006; Coombs, 2010).

Following the design of my first proposal, I began to send it to universities. Many universities showed an interest in my topic, but were unable to offer me a place due to the lack of a supervisory team able to cover both fields of interest (i.e. disability studies and distance learning). The only university that made me an offer was the University of Manchester. I accepted their offer and started my PhD with them in September 2012.

1.3 First Meeting with Supervisors

The first meeting with my supervisory team was a turning point in my research. During this meeting, I realised the extent of my lack of knowledge about disability issues. I found myself unable to reply when my supervisors asked me questions related to the topic of disability. For example, they asked me why I wanted to address the topic, and why I wanted to focus on those who were physically impaired. They asked me about the situation of disabled people in Kuwait, and whether they wanted distance learning to be available to them, or whether this would just be another form of exclusion. I could answer the first two questions and tried to justify my choice of this topic and participants, but I do not think I was convincing enough. In terms of the possibility of further isolating disabled
pupils, I tried to address the issue using the notion of blended learning, which would allow disabled pupils to take advantage of both face-to-face and online learning. Most of the questions my supervisors asked concerned the situation of disabled people in Kuwait, but I did not have enough information relating to disability in Kuwait as I had never talked to any disabled person previously beyond my family—my 20-year-old niece is disabled.

This initial encounter was a little disheartening; however, these queries were very useful and inspired me to give thoughtful consideration to the lives of disabled people. My supervisors suggested that I try not to decide on the problem by myself without referring to what disabled people in Kuwait might prefer. In other words, I had to consider whether disabled students would prefer to study using distance learning techniques or to attend university on campus. Based on my supervisors’ recommendations, I decided to go back to Kuwait to explore disability issues in the Kuwaiti context by interviewing disabled students, professionals, educators and other stakeholders. The data I generated from this fieldwork would then be used to guide my understanding of what disabled individuals in Kuwait desire in terms of distance learning.

1.4 The Exploratory Phase

After the meeting, I returned home and began to research disability issues in Kuwait on the Internet. However, I found that little useful information about disability in Kuwait was available. I found a statement by the former Director General of the Public Authority of People with Disability Affairs (PAPDA)
stating that there were no specific numbers for disabled people in Kuwait and that this was because of errors in providing ‘certificates of impairment’ (Alwatan, 2010). However, he revealed that the approximate number of disabled people in Kuwait was estimated to be more than 43,000. However, at a later stage of this journey, I found more information and literature about disability in Kuwait. I will discuss this literature in Chapter 2.

I learned two things from the above statement: (1) there is no accurate census for the number of disabled people in Kuwait; (2) there have been mistakes in diagnosing the impairments of disabled people in Kuwait. These two issues raise certain questions. (1) Why has there been no precise survey of the number of disabled individuals in Kuwait? (2) Why have there been mistakes in providing certificates? (3) Why do disabled people need certificates? These three questions need to be further explored in order to be answered. These inquiries will be explored in detail in Chapter 2 and Chapter 7.

In addition, I found some information about special educational needs (SEN) schools in Kuwait, as the state has provided SEN schools for pupils with every type of impairment. Moreover, the establishment of the Secretariat of Special Education in 1993 gave learning disabled students the opportunity to be educated with non-disabled peers during the early stages of education (Almohtaseba, 2011).

I thought it would be relevant to my research if I could conduct an interview with my sister. In the interview, she discussed several issues related to the rights of disabled people under the new Kuwaiti disability rights law passed in 2010; she
revealed that her daughter now has better protection and recognition of her rights, despite the lack of full implementation of all the articles in the law. She also talked about the financial benefits being implemented in the wake of the new law, and stated that disabled people can now receive a monthly stipend, financial aid for adaptation of houses, and health services and education. However, at the same time, she stated that the medical and educational services are still not as good as they could be and that these services in Kuwait are still poor compared to those in Global North countries. She also mentioned that many public buildings in Kuwait are still inaccessible to disabled people. Meanwhile, when she talked about education, she said that, although her daughter’s school building is accessible, she also thinks that the teaching staff do not have a good understanding of disability and the needs of disabled pupils, and that she has not noticed any significant progress in terms of her daughter’s level of education.

My sister also talked about issues concerning non-disabled people in society and said that she wondered:

**Extract 1.1**

> ‘Why are those people staring at my daughter? Why do children when they see my daughter say to each other “look at the crazed girl”? ’

(Manal, female, aged 49.
Interview date: 10 October 2012.)
She also claimed that non-disabled people sometimes fail to properly respect places allocated specifically for use by disabled people. For example, using accessible toilets, using parking spaces reserved for disabled people, and disrespecting her priority in public places.

Finally, because at this stage my primary interest was in the use of educational technology, I ended the interview with a question about the benefits of using technology in teaching. I wanted to know if my sister, as a parent to a disabled child, thought that technology could facilitate the learning of disabled students. She stated that technology might be helpful for particular pupils with specific types of impairment, such as hearing and visual impairments, and perhaps even for people who are physically impaired; however, she concluded that it would not be of use in the case of her daughter who has a learning disability. By showing the limitation of technology for her daughter, I was able at the time to recognise the differences and the diversity of disabled people, which make it difficult to provide an accessible environment for everyone. In other words, providing a ‘Universal Design’ for all disabled people began to seem an unrealistic goal.

Although I am very close to my sister and my niece, I had never realised that my niece was experiencing this level of discrimination and disrespect from non-disabled people. As such, this interview proved eye-opening in terms of the situation of disabled individuals in Kuwaiti society. The interview also made me realise that my personal interest in disability issues had not begun as recently as I had previously thought; my research may have officially started in 2011, but its
roots had long been developing in my subconscious. Conducting the interview with my sister awoke memories of the time when we all lived together in my family house, and of seeing my niece growing up in the care of the whole family. It also reminded me of a time when I used to take her to school, and when my sister and I took her abroad for treatment. I realised then that my experiences with my niece may have been the main reason that motivated me to conduct this study, and not just the issues raised by the ‘plight’ of my colleague’s brother. However, I do think that the meeting with my colleague shaped my thoughts and may be what made the study feasible.

The experiences and the incidents that I have been through with my niece made me think initially about my position in this project. Although some disability scholars would consider me an outsider researcher because I am a non-disabled person (I will discuss this later in the chapter), I see myself, in some respects, as an ‘insider researcher’. As “insider research is that which is conducted within a social group, organization or culture of which the researcher is also a member” (Greene, 2014, p.1), I am somewhat an insider because I share a culture with the participants as well as some experiences. However, over time, I became aware that sharing culture with the participants is different to having knowledge about the culture, subculture, and the experiences of the participants (Asselin, 2003). Thus, throughout the research process, specifically during data collection and analysis, I have been mindful of these distinctions. However, one should acknowledge that the aim of this process was not to try to achieve neutrality in research, but to maximise awareness, as I believe that:
there is no neutrality [in qualitative research]. There is only greater or less awareness of one’s biases. And if you do not appreciate the force of what you’re leaving out, you are not fully in command of what you’re doing (Rose, 1985, p.77).

1.4.1 Attending a Disability Studies Course

Keeping these issues in mind, I sustained my journey of learning and understanding regarding issues of disability. My co-supervisor, Craig Blyth, offered me the opportunity to enrol in a disability studies course as an audit student. This course enriched my knowledge about the development of disability studies. The focus of disability studies in the UK is currently centred on the social, cultural, and political aspects of disability, rather than on medically focused approaches to understanding disability (Goodley, 2011). I also gained a better understanding of the social model of disability, which is the dominant model within UK disability studies. Oliver (1981) developed this model on the basis of work undertaken by the Union of the Physically Impaired Against Segregation (UPIAS), a UK-based organisation and early advocate of disabled people’s rights. According to Oliver (1996, p.33), disability arises from:

All the things that impose restrictions on disabled people, ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on.

Attending the disability studies course and undertaking extensive related reading was very beneficial to me, as I was able to gain an understanding of the work undertaken in Global North countries within the field of disability studies and
disability research. At the same time, it raised some questions. For example, how can we refer to all of the obstacles and restrictions faced by disabled people as endemic to society without bearing in mind their impairments? If everything in society is well prepared to meet their needs, can disabled people overcome their impairments? From that time, my journey into the field of disability and disability studies was rooted in these two questions.

These inquiries constituted the start of my ‘dilemma’ of disability versus impairment. At this stage, I could begin to see how society could, to a large degree, overcome disability (removal of many barriers) but, at the same time, I was left questioning if ‘impairment effects’ could or should be overcome.

1.4.2 The Two Focus Group Interviews

With all of this new knowledge and many questions running through my mind, I decided to return to Kuwait to discuss these issues with disabled people, as they would be the most important people with whom to engage with regard to the development of this research. I will discuss the issue of methodology in more detail in the methodology chapter of this thesis, but I have also included information here because it is part of the background that formed my thinking with respect to the design and evaluation of the study.

I returned to Kuwait at Christmas, 2012, and began to gather data that could help me to further understand the issues surrounding disability. I began this process with a focus group interview of physically impaired male pupils in a secondary
special school in Kuwait. At this point, I was still considering the issue of providing distance learning courses for disabled students. Therefore, the aim of this focus group was to explore the experiences of the participants with distance learning.

The school principal allowed me to meet with five physically impaired pupils for this focus group. Because the pupils had no prior experience of distance learning, I gave them the opportunity to explore the Blackboard virtual learning environment of one of my MSc units. The aim of this focus group was to explore the advantages of the communication tools available on Blackboard, the difficulties faced by these students, and their desire to use the virtual learning environment.

The participants talked primarily about the advantages and limitations of distance learning. However, the data obtained also touched on several other issues related to the pupils’ attitudes towards disability. Given that the pupils had given their time freely, I felt it would be unethical if I did not give the participants an opportunity to talk about their personal issues and experiences. Thus, I allowed them to talk about anything they chose and to discuss any issue that they found important. Given this opportunity, the participants were keen to talk about the problems they faced and to show their frustration with non-disabled people in society, their schoolteachers, and pupils with, in their opinions, ‘inaccurate’ disability labels (groups of non-disabled pupils who only come to their school because it is easier).
Because all the participants were looking to continue their higher education at Kuwait University, I wanted to know more about their aspirations for the future. Thus, I asked them what they expected from the University of Kuwait and whether they had any particular fears about attending the university. I asked this question to better understand their needs, as well as to gauge whether distance learning would be an appropriate solution for overcoming the obstacles they may face in higher education. However, they were not able to talk about Kuwait University because they did not have enough information about it; they wanted to know more about building accessibility, teachers’ qualifications and the support available to disabled students.

The data generated from this focus group interview was very useful to me, since it was my first time meeting disabled people and discussing issues important to them. However, some parts of the interview required clarification, and it was necessary to ask some follow-up questions to fill the gaps in the data. Therefore, I returned to Kuwait over Easter and conducted another focus group interview with the same participants. This second interview addressed many of the shortfalls of the first.

1.4.3 Second Meeting with Supervisors

After I had analysed the two focus groups, I met my supervisors and showed them my findings. They then asked what I was going to do next. I answered that, because the pupils were looking forward to continuing their education at Kuwait University but expressed concerns about a lack of available information about life
there, it might be helpful to design a distance learning course to provide them with information about life at Kuwait University in terms of building accessibility, teachers’ qualifications, colleges and specialisations, and support allocated for disabled students.

I decided that the best way to approach this would be to have two case studies: one involving disabled pupils in a special school who want to continue their higher education at Kuwait University and another case study of disabled students who are currently studying at university. This would be done in cooperation with the Disability Support Office at Kuwait University, as it would be able to provide access to disabled students, as well as online information and other forms of support. I cultivated my idea based on what had been said by the participants in both focus groups. The following extract is from the data and reflects pupils’ enquiries and fears about life at Kuwait University:

**Extract 1.2**

<table>
<thead>
<tr>
<th>Hamad: I want to continue studying in order to be a teacher in social sciences. But, I have fears about life there in terms of accessibility to buildings.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ali: Yes, me too. I know one friend there [and] he is having difficulties moving between the university buildings.</td>
</tr>
<tr>
<td>Abdurrahman: Yes. I also want to know about special facilities and parking facilities and whether the instructors are well qualified to cope with us.</td>
</tr>
</tbody>
</table>
Additionally, I thought that this research could reinforce the coordination and relationship between the special school where I conducted the focus groups and the Disability Office at Kuwait University. While participants in the focus groups had expressed anxieties about the lack of information available about life in higher education, when contacted, Mona, the Head of the Disability Support Office at Kuwait University, stated:

**Extract 1.3**

We do give information to students in schools by providing them with a lecture about Kuwait University; we do this every year, but it’s not our responsibility to arrange a trip to the University; their school should arrange that.

(Mona, female, aged 43. Interview date: 11 April 2013.)

This led to further questions: if the Disability Support Office gives an induction lecture about Kuwait University every year, why do pupils still lack information? Is the information insufficient? This disparity perhaps suggested a lack of coordination/cooperation between schools and the Disability Office. Thus, I
thought that the implementation of a distance learning course regarding these issues might also enhance the coordination and relationship between the two.

After I explained my idea to the supervisory team, my first supervisor, Gary Motteram, praised the idea. However, I felt that my co-supervisor, Craig Blyth, did not like it, perhaps because he felt that this idea may be underpinned by the concept of segregating disabled people from mainstream society. He may have thought that, instead of fixing buildings and providing good support, I wanted disabled people to stay at home and to offer them online support rather than helping them to integrate. However, my justification at the time was that, as researchers, we are not decision makers that should aspire to fix society; therefore, I thought that there was not much else that we could do beyond making an effort to provide an alternative tool for learning.

Nevertheless, by the end of this supervisory meeting, we all agreed that I needed to generate more data in order to properly acknowledge the different perspectives held by people on the issue of disability. Hence, I decided to go back to Kuwait during the summer to conduct more interviews with educators, professionals and disabled students in higher education.

1.4.4 Interviews with the Two Teachers

I returned again to the same school where I had conducted the focus groups. After meeting with the school principal, I was allowed to interview two secondary school teachers. Both interviews lasted 30 minutes. The aim of these interviews
was to explore the teachers’ experiences of teaching disabled pupils in special education. This objective emerged from the findings of the previous focus groups in which a prominent theme was how the teachers in their school approach working with disabled pupils.

The first interview was with a science teacher (Atia) who had been teaching at the school for ten years. The interview mainly revolved around three themes: working with disabled pupils, working with non-disabled pupils, and the general nature of the work and skills required to be a teacher in an SEN environment.

In the interview, Atia tended to make comparisons between the characteristics of disabled and non-disabled individuals. He revealed that in general education there are typically a large number of pupils in a classroom, and that these pupils are usually quick to understand the content of the lessons. Unlike non-disabled pupils in general education, he claimed that disabled pupils in special education are:

**Extract 1.4**

<table>
<thead>
<tr>
<th>Psychologically tired, not accepting of his studies and his situation, he feels that his body is incomplete, he is like a child, suffering writing difficulty.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Atia, male, aged 47. Interview date: 4 July 2013.)</td>
</tr>
</tbody>
</table>

However, despite this, he also stated that some disabled pupils are clever and can understand teachers merely by looking at their lips. Additionally, Atia mentioned
that all teachers know how to deal with disabled pupils and understand their conditions and said that:

**Extract 1.5**

<table>
<thead>
<tr>
<th>We are dealing with them as God created them like this.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Atia, male, aged 47.</td>
</tr>
<tr>
<td>Interview date: 4 July 2013.)</td>
</tr>
</tbody>
</table>

Atia also indicated that the school uses diverse teaching methods due to the variety of impairments among pupils. For example, when required, the school simplifies information, repeats lessons, and uses different teaching methods such as group work and discussion. Furthermore, he addressed how teachers motivate pupils by using role models and aim to promote psychological wellness by frequently smiling and joking with the pupils.

After I finished this interview with Atia, I felt somewhat frustrated because I suspected that he was holding back and only showing me the positive aspects of the school. Two things that he did say, however, worried me. The first of these was that he had been teaching in special education for ten years and yet had only taken three or four training courses on special education. As he revealed:
**Extract 1.6**

We take training courses if there is something new about disability, and there is nothing new.

(Atia, male, aged 47. Interview date: 4 July 2013.)

The second issue regarded the nature of the language he used when he talked about disabled people, particularly when he said that “he is psychologically tired … he feels that his body is incomplete”, and “we are dealing with them as God created them like this”.

The use of ‘tragedy’ language such as this to describe disabled people requires further investigation, as, for me, it demonstrated outdated attitudes towards disabled people within the education system. I will expand on this issue of the language in Chapter 2 and Chapter 7. Similarly, as this school is only for physically impaired pupils, it seems curious that they feel the need to simplify information to make it easier for them. This was an issue also touched upon by pupils when I conducted the focus groups:

**Extract 1.7**

We have pupils who have fake disability IDs even in our school. They came here because it is easier.

(Hamad, male, aged 17. First focus group: 24 December 2012.)
In this extract, Hamad was talking about those non-disabled pupils who have ‘inaccurate’ disability IDs and who come to the school because it is perceived as being easier. In Chapter 2 and Chapter 7 I will expand on the phenomenon of those, according to the state and disabled people, fraudulently claiming disability IDs. However, if all pupils are physically and not learning disabled, we have to ask why attending the school should be easier than attending any school in the general education system.

The second interview was with a social studies teacher (Abdullah) who had been teaching in special education since 1987. For the most part, Abdullah touched upon similar themes to Atia, including the nature of working with disabled pupils, the psychological care provided by the teachers and the diversity of teaching methods used in classrooms. He also talked about the school’s support systems and problems faced by disabled people in society, such as being stared at by and receiving sympathy from non-disabled people.

Unlike the first interview, the social studies teacher offered information about some negative aspects of the school in terms of how some teachers cope with the challenge of working with disabled pupils. For example, he said that:

**Extract 1.8**

| Maybe some teachers hurt them verbally, but not on purpose and disabled pupils are too sensitive that’s why they get upset. |
| (Abdullah, male, aged 49. Interview date: 4 July 2013.) |
This extract corresponds with what the pupils said in the second focus group interview, as they mentioned that some teachers mock pupils or gloat over their impairments:

**Extract 1.9**

Actually, they do make fun of our impairments by saying, for example, you seem that you have two impairments physically and mentally, you don’t understand!

(Ali, male, aged 17.
Second focus group: 8 April 2013.)

Ali, here, was talking about his friend when he insisted on answering a question in the classroom. The teacher did not want him to answer, then got upset and said the above to the pupil. This extract demonstrates how teachers use the negative discourse associated with learning disabilities as a form of discursive disciplinary power. By saying this, the teacher created a classification system by locating the physically impaired person, if he could understand the lessons, in a better position than a learning disabled person who, in his opinion, could not understand the lessons. However, on the other hand, when Ali’s friend became upset because the teacher said that he had a learning disability, the teacher was also undermining the ability of learning disabled pupils to understand the school lessons. It also reinforced a stance that made Ali’s friend distance himself from learning disabled people. This triplex relationship between non-disabled people, physically impaired people, and learning disabled people will be examined in detail in Chapter 7.
Moreover, the same issue regarding teacher attendance of disability training courses as reported above was also reported in this interview; the teacher revealed that he has not attended any courses in special education since he was recruited in 1987.

Although the responses of these two interviews corresponded with some of the issues raised by disabled pupils in the previous focus group interviews, I believe that the two teachers were slightly reluctant to reveal the negative aspects of life at their school. I am not necessarily assuming here that the pupils were more honest or that the information they revealed was more valid. I felt only that it would be more helpful to the research if the teachers had been more willing to share their experiences and the problems they have faced in order that solutions might be found to overcome these problems.

1.4.5 Interview with the Deputy Director General of the Public Authority for People with Disabilities Affairs

Having met with teachers and disabled pupils, I now deemed it necessary to meet with an official or a decision maker in the field of disability. Therefore, I arranged a meeting with the Deputy Director General of the Public Authority for People with Disabilities Affairs (PAPDA) in Kuwait. The aim of this interview was to explore the plans and policies undertaken by the state to accommodate disabled people in Kuwait. The main theme of the interview was *The Rights of Persons with Disabilities Act No. 8/2010*, the law passed to promote and protect the rights of disabled people in Kuwait. The Deputy Director General argued that this law
promoted the inclusion of disabled people into society by providing them with financial and educational support. He revealed that the financial support varies based on the impairment type and degree: “the more severe the impairment the more money”.

The Deputy Director General also claimed that the state runs and has established special schools for pupils with every type of impairment in order to help disabled people to be included into society. Upon hearing this, I asked him how the establishment of special schools works to underpin the inclusion of disabled people into society. Is it not a kind of segregation from society? Perhaps surprisingly, he said that I was right to ask this, but also revealed that:

**Extract 1.10**

<table>
<thead>
<tr>
<th>People in the past used to hide their disabled children and keep them at home, but after we established special schools they started to take them out and enrolled to these schools.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Essam, male, aged 53. Interview date: 6 August 2013.)</td>
</tr>
</tbody>
</table>

Although this does perhaps demonstrate that the initiatives being taken by Kuwaiti officials are achieving some progress, I think it would be more beneficial if they paid more attention to the attitudes of non-disabled people rather than focusing exclusively on disabled people themselves. Why is it that people used to hide their children? Why did not they want them to mix with their non-disabled peers? Was this a parental decision or the decision of the disabled people themselves?
Questions such as these should have been taken into account before the establishment of special schools that may contribute to the further isolation of disabled people. I, inadvertently, found myself adopting somewhat of a social model of disability mind-set inasmuch as I was becoming interested in how society responded to disabled people.

Furthermore, because of my interest in distance education at the time, I asked the Deputy Director General for his opinion on the idea of providing distance education for disabled students in higher education. He praised the idea and stated that it was compatible with PAPDA’s vision towards the inclusion of disabled people into higher education, especially for those who have severe impairments.

I found this interview very useful, as it helped me to identify the policies and laws implemented by the state in relation to the issues of disabled people in Kuwait. However, it also indicated that I would need to source more information about how such political decisions regarding disabled people are made and what role disabled people have in the process. Additionally, it became apparent that I would need to conduct a more in-depth exploration of the concept of inclusion in Kuwait.

For instance, when the Deputy Director General was talking about including disabled people in society, he mentioned that:
Based upon this, I was not really sure of what he understood by the concept of ‘inclusion’. According to Nolan (2014, p.14), “social inclusion is generally taken to mean being in a position to participate fully in the life of the society one lives in”. This definition would obviously not be inclusive of the idea of a ‘sports club for disabled people’, and as such an organisation may deprive disabled people of the opportunity to fully participate in society and undermines the concept of social inclusion, since all club members are disabled people.

In addition, in terms of education, the UNESCO Salamanca Statement principle suggests that schools should accommodate all children regardless of any impairment (UNESCO, 1994). Based on the standards set forth by the Salamanca Statement, special schools are not inclusive at all, as disabled students mix exclusively with other disabled students and are, it could be argued, left isolated from wider society. The State of Kuwait’s notion of inclusion, therefore, seems somewhat limited, as its aim seems to be merely to encourage disabled people to spend more time with other disabled people. While this is an improvement upon a situation in which disabled people were kept in isolation, it seems to do little to promote inclusion.
1.4.6 Focus Group with Students in Higher Education

In order to try to understand different perspectives of the issues faced by disabled students in higher education, I thought that it was vital that I meet disabled students in higher education in Kuwait. Thus, I organised another focus group, the aim of which was to explore disabled students’ experiences in higher education. I was not able to access students attending universities at the time because the universities were on their summer break, so instead I went to a sports club for disabled people. There I met the administrator responsible for moderating sporting activities, and he allowed me to meet with five participants: one male and four females.

The experience was particularly interesting for me, as it was the first time that I had the opportunity to discuss disability issues with female interviewees. The participants in this focus group raised similar issues to those prevalent in previous focus groups such as society’s attitudes towards disabled people and disability, building accessibility, inclusive education, and teachers’ qualifications in schools and universities. In relation to people’s attitudes towards disabled people, the participants talked about how they reacted when a non-disabled person displayed negative attitudes in staring or making a harsh comment about their impairment:
**Extract 1.12**

Salma: One time me, my sister and her friend were walking together … we saw a disabled girl with a severe impairment, then my sister’s friend said: ‘Mammy, mammy! I afraid’.

Saja: Why didn’t you slap her face?

Salma: Do you think I kept silent? First I cried, then I went to her and asked ‘why did you say that?’. ‘She looked scary’, she answered. Then I said to her, ‘you are scary’.

(Higher education students’ focus group. Focus group date: 14 August 2013.)

The above extract recounts an exchange between two female participants in the focus group. In this extract, Salma recalled an incident that happened while she was out with her sister and sister’s friend, and shows how she reacted when her sister’s friend made a harsh comment about a disabled girl with profound impairments.

Moreover, the participants in this focus group also touched upon other issues related to equality in society, such as the absence of disabled people in leadership positions in society, their right to choose where to study, and marriage rights. I think that part of the reason they were keen to talk about these issues was because the participants in this focus group were older than those in previous focus groups. Therefore, the participants in this group had a greater understanding of the issues faced by disabled people, and were more aware that they should have the same
rights as non-disabled people. The participants also emphasised the issue of the lack of awareness about disability issues on the part of non-disabled people and suggested potential solutions to this problem. For example, they suggested that it could be possible to raise people’s awareness about disability issues through a number of channels, including the school curriculum, the media, training courses, workshops, and conferences.

During this focus group, I also sought the participants’ opinions about providing distance learning for disabled people in higher education. They stated that it sounded like a good idea, especially for people with severe impairments and other people who have medical conditions that prevent them from attending lessons on campus. However, they also suggested that distance learning might only serve limited categories of disabled people, and that it is preferable for disabled students at university to be on campus as much as they can. This stems from their beliefs of the importance of the presence of disabled people in society.

Conducting this focus group interview was helpful as it allowed me to gain new knowledge and insight into disability issues in Kuwait. In this focus group I was able to begin to see differing constructions of the concept of ‘normality’ and how it contributes to the ‘realities’ of the participants. For example, Salma recalled an incident in which a non-disabled colleague used a common Arabic proverb, ‘a healthy mind, in a healthy body’. This proverb means that a ‘healthy mind’ can only be placed in a ‘healthy’ body. In common with other co-researchers as I will show later in the thesis, Salma believed that her body could be considered
‘unhealthy’ but she was unique in thinking that she was being referred to by this proverb and took this orthodoxy as a ‘fact’ in her life. The issues of ‘normality’ will be revisited throughout this thesis.

At that stage, I felt that I now had a somewhat deeper understanding of disability issues in Kuwait; however, I increasingly came to recognise that my mission to provide learning services for disabled people would not be easily accomplished, as I realised that the matters surrounding disability and disabled people in Kuwait are complex.

I wanted to do something useful and effective for disabled people in Kuwait, but at this point I was still entertaining a number of possibilities between which I was not yet able to decide. I had been exploring the issues related to disability for a year (September 2012 to August 2013) and still I could not solve the problem. Therefore, I had to consider whether more exploration was required, and whether I should make a request for the exploration phase of my research to be extended, or inform my supervisors that I wanted to stick with my first topic (i.e. distance learning for disabled students). I also had to consider the justifications for my choice: was my choice based on the data gathered throughout the exploratory phase? What was the evidence upon which I was basing my research?

1.5 My Final Decision

Upon returning to Manchester in September 2013, I began to prepare myself to meet with my supervisors to inform them of my final decision about my research
topic. As I had been driven at the time by the data set of the exploratory phase and not by any theoretical commitments, it was likely that I would let the data speak and decide on my behalf. Thus, this process of analysis was data-driven (Wolcott, 1994), whereby the process of coding the data occurred without linking it to any theoretical interest (Braun and Clarke, 2006). However, as will be shown later, as the development of my conceptual framework generated (see Chapter 3), I became more driven by my analytic interest rather than the data. I would be looking specifically at some interesting details and aspects in the data rather than providing a rich description of the data overall (Braun and Clarke, 2006).

While I was preparing myself for the meeting, I looked again through all of the data that I had gathered during the exploratory phase and found that the themes that had most commonly arisen centred on the societal barriers and obstacles faced by disabled people, whether these were problems with schoolteachers, the general public, or inaccessible buildings and a lack of services.

This realisation brought me to consider directing my research towards what appeared to be the disabled participants’ main focus, raising awareness of disability among non-disabled individuals. The idea of distance learning for disabled students promised certain benefits, but the pupils and students interviewed suggested that it was a scheme that had certain limitations and would only be beneficial for individuals with specific types of impairment. They also expressed the belief that distance learning is not a suitable approach for the teaching of all subjects, and that it may reinforce the isolation of disabled people
from society. On the other hand, I found that they all agreed that the problems they face are issues with society and not with their impairments per se, as they stated that they have different abilities and can, in their opinions, perform many tasks even better than many non-disabled peers.

As a result of the journey described above, I decided that the most meaningful approach I could take with my research was, in partnership with disabled people, to investigate how to raise awareness about disability issues among non-disabled people. This led me to the conclusion that the best course of action for my research would be to design an open learning course that aims to raise the awareness of non-disabled people about disability issues (later, the idea of an open learning course changed to a disability awareness film). Furthermore, because these issues can have such a profound influence on the lives of disabled people, I decided that it was vital to include a group of disabled people as co-researchers and to collaborate with them in the creation of the course, the analysis of the data generated by the research, and in the evaluation of the experiment. In Chapter 4, I will discuss the identity of this group and how I have brought them into this research. Also, in Chapter 4, I will show the details of the research process, constructed methods and practicality, and how our (the co-researchers and myself) aim directed towards designing an open learning course changed over time to the creation of a disability awareness film.

However, although exploring the process of participatory research is an aim of this project, it is not the only aim. This project will be focused more on exploring
disability issues in the Kuwaiti context through participatory research. Thus, to summarise my research, the focus lies on two sides: exploring the experiences of the co-researchers and the other participants (disabled and non-disabled) with disability, and exploring the process of participatory research through creating the disability awareness film.

The exploratory phase of this project not only helped me to specify my research topic but also enriched my knowledge about disability issues in Kuwait. I found that the findings of my research into the experiences of disabled people in Kuwait thus far were consistent with the ‘social model of disability’. However, given that further exploration of the model occurred and deeper analysis of the data was undertaken for the main study, I will show in Chapter 2 and Chapter 7 how, in relation to this study, the social model of disability solely provides only limited usefulness as a tool for conceptualising the experiences of disabled people in Kuwait. This realisation led me to think about developing a model that is more appropriate when seeking to explore and analyse disability in Kuwait.

In the meeting with my supervisors, I explained my idea and they both agreed that it would make a good project, but also emphasised that I should give due consideration to my position as the researcher, the methodology to be used, and the practicality of the research. As stated above, the issues of research methodology and practicality will be discussed in detail in Chapter 4, while the issues regarding my position as researcher will be the core of the next section.
1.6 Bringing the ‘Self’ into the Research

In this section, I consider it vital to discuss the questions raised at the beginning of the chapter in relation to my position as a non-disabled researcher with an interest in disability studies. This will include “ontological narratives” (Somers, 1994, p.618) regarding identity and the political dimension of conducting research into disability: am I able to conduct this kind of research? Why am I interested in disability studies? Do I have the right to conduct this research and to speak for disabled people?

I am a non-disabled male in my thirties with an interest in disability studies. Some disabled academics have addressed the kind of concerns outlined above and some have questioned whether non-disabled researchers have the right to conduct disability research and speak on behalf of disabled people (see, for example, Oliver, 1992). These concerns were, fairly extensively, discussed during the 1980s and 1990s. The main influence for the emergence of this kind of debate was the hegemony of disability research conducted by the non-disabled researchers that resulted in the alienation of disabled people from research production. Oliver (1992), for example, criticises the social relation in traditional research that perceives disabled people as ‘passive subjects’ controlled by academic researchers. He argues that academic researchers use the knowledge of disabled people, interpret it, and make recommendations without referring to them. This kind of alienation from research production led Oliver (1992) to call for research strategies that are both empowering and emancipatory (see Chapter 4). Oliver and other disabled academics believe that, as referred to by Kitchin (2000, p.26), “it is
only disabled people who can know what it is like to be disabled and so only
disabled people who can truly interpret and present data from other disabled
people”.

Accepting this statement would mean that I am not in a valid position to conduct
this research. However, other researchers, such as Finkelstein (1996) and
Shakespeare (2006), have challenged this claim. Shakespeare (2006, p.195) states
that:

… just because someone is disabled does not mean they have an
automatic insight into the lives of other disabled people … The idea
that having an impairment is vital to understanding impairment is
dangerously essentialist.

With the development of disability studies and the creation of the social model of
disability, the disability rights movement and the work of academic researchers
now focus primarily on the social and political barriers faced by disabled people
(Goodley, 2011). It is the experience of living in a ‘disablist’ society rather than
the experience of living with specific impairments that interests them. The social
model of disability conceives these barriers and obstacles as socially created.
Thus, in “a society in which all disabled and non-disabled people live … it [is]
possible for any non-disabled researcher to analyse and comprehend the nature of
disability” (Finkelstein, 1996, p.32).

As Shakespeare (2006) and Finkelstein (1996) argue, there is nothing that
fundamentally prevents me, as a non-disabled researcher, from conducting
research into disability issues; whether disabled or non-disabled, we all live in
society together and the issues surrounding disability affect us all. However, I am aware that the degree of perceiving the effects of disability issues differs as it depends on whether the person perceiving the effects is disabled or non-disabled. Additionally, it has been argued that cooperation between the movement for disabled people’s rights and academic researchers may enrich the scientific research on disability issues, especially where “the movement can provide direct experiences, [and] academics working from a disability studies perspective can provide a logical and consistent political analysis” (Barnes, 2007, p.138), while, at the same time, working to improve the situation of disabled people within society.

However, the most directly relevant perspectives to explore and integrate within this research are those of disabled people in Kuwait. During the exploratory stage, similar ideas regarding the respective abilities of disabled and non-disabled people to understand disability issues were expressed. In the focus group conducted with disabled students in higher education, for example, the participants discussed issues related to their right to access leadership positions in society; for instance, they wondered why there are no disabled people in parliament. The students taking part in the focus group expressed the belief that it would be an important step if a disabled person could become a member of parliament, as he/she might have a better understanding of disability and would thereby be better placed to defend their rights and campaign for legislation to meet their needs. Moreover, by the end of the focus group, the participants explicitly expressed the belief that disabled people are best placed to conduct research into issues related to disability:
Extract 1.13

Who can know about disability issues more than a disabled person?!

(Saja, female, aged 22.
Focus group date: 14 August 2013.)

Nevertheless, even if the focus group participants believe that disabled people are best placed to understand the experiences of other disabled people, they are not talking here about limiting the possibility of conducting research on disability issues to disabled people so much as they are expressing a desire for the state to empower them to share their ideas about impairments and disability.

It is also possible to approach this issue from the other direction if we accept the assumption that disabled people in Kuwait are the only group with the right to explore the issue of disability. However, if we accept this assumption, we may encounter some of the limitations to research posed by the current reality of the situation of disabled people in Kuwait, i.e. that disabled people currently have only a very marginal presence in the research conducted and initiatives being developed to meet the needs of disabled people in Kuwait.

All associations in Kuwait that are concerned with the issues of disabled people are public benefit associations that provide services to disabled people. For example, the Kuwaiti Blind Association seeks to represent and promote the interests of blind people in society by using all available means, such as parties, seminars, organising occasions that allow visually impaired individuals to
demonstrate their abilities, advancing the spread of culture among the blind community by using talking books and Braille, and working to overcome the obstacles and difficulties faced by blind people (Kuwaiti Blind Association website, 2013). While the first two of these stated objectives is general services for blind people (i.e. the organisation of events and provision of resources for visually impaired people), the final objective focuses on fixing wider societal problems. However, it was not clear from the information on the website how this would be achieved. How, then, does an organisation such as this work to overcome obstacles faced by blind people? And what are these obstacles?

In order to find answers to these questions, I went to the Public Authority for People with Disabilities Affairs (PAPDA) in Kuwait and asked for information on research or studies conducted in to the field of disability; unfortunately, I did not find any. I also went to the Studies and Research Centre, and, although I did not find any studies available, I was told that I might find some research about disability at Kuwait University. I went there and searched the university database, but found only one study (AL-Shamayleh, 2005). However, this study was not geared towards disabled people directly; rather, it was about the skills required by teachers in special schools in Jordan. Eventually, I found a few other studies related to disability and disabled people in Kuwait, but these studies exclude disabled people’s voices. I will talk about these studies in Chapter 2.

This reflects the current dearth of research into disability issues in Kuwait, and, likewise, a lack of researchers working in the field (whether disabled or non-
disabled). Thus, arguments made regarding whether non-disabled people have the right to conduct research about disability in a Western context are not necessarily applicable in the Kuwaiti context, as the situation in these two contexts is very different. Additionally, I agree with Finkelstein (1996) and Barnes (2007) who emphasise the importance of cooperation between disabled people, who can provide insight based upon their personal experiences, and academic researchers (including disabled and non-disabled), who can contribute a systematic and theoretically grounded approach to researching disability issues. One way in which this cooperation can be realised is by inviting disabled people to contribute to participatory research. By conducting research of this kind, I hope to address some of the concerns raised in this chapter regarding my position within this research, while still acknowledging that this research gives rise to issues and complexities.

1.7 Research Questions

The focus of this study is primarily to explore disability in Kuwait through participatory research. The participatory research processes here involve the exploration of the nature of the relationship between the co-researchers and myself as the main researcher (e.g. power relations and the extent of participation in construction research methods and analysis). In this thesis, I present and discuss the findings related to the nature of participatory research in Chapter 6, while I present and discuss the findings related to disability issues in Chapter 7. However, although reflecting on research experience and the exploration of the nature of the
relationship between disabled people and the academic researcher is vital, I am more interested in exploring disability issues. In fact, my interest, to a large extent, was derived from the co-researchers’ interests. The main drive that motivated them to participate in this project was not learning how to conduct research, but rather to share their personal experiences of disability, hoping to bring about social change. I believe, along with the co-researchers, that, by opening up the issues of disability and providing in-depth exploration, disabled people in Kuwait can take a step towards emancipation and social change.

By the end of the journey described in this chapter, a number of research questions had developed. In relation to the research nature and the process, this thesis endeavours to answer the following research questions:

1) What are the co-researchers’ motivations behind participating in this research?
2) Do the co-researchers believe that they will benefit from this process and if so, how?
3) What are our (i.e. the researcher and the co-researchers) experiences of the process of participatory research?

In relation to the exploration of disability issues, one general question has emerged:

4) What are the most significant issues facing disabled people in Kuwait?

Moreover, other questions emerged as a result of a thorough exploration of the literature concerning both disability studies in Kuwait and the disability
perspectives in Western societies. These questions may contribute to the development of the field of disability studies:

5) Which disability perspective/analytical tool is more suitable for adoption in Kuwait?

6) To what extent is the state ready to consider a disability perspective/model rooted in critical realism?

1.8 Definitions and Terminologies

The first issue that I want to raise here is what I mean when I say ‘disability issues’. Disability issues are all issues related to disabled people’s lives from biology, psychology and physiology to society, culture, politics, and economics. Perhaps the definition of ‘disabilities’ by the World Health Organisation (WHO) is the best to express this meaning:

Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.

Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives (World Health Organisation website).

In this thesis, I adhere to the social model’s differentiation between the terms ‘disability’ and ‘impairment’. For example, when I use the term ‘disability’, I
mean obstacles/barriers in society, and, when I use the term ‘impairment’, I am referring to disabled people’s bodies. However, at the same time, I want to recognise the impairment effect in restricting disabled people’s activities in society and the interaction between body and society (I will elaborate on this issue in Chapter 2).

Generally, although it is common in people working in inclusive research to use the terms preferred by the disabled participants who are working in the research (e.g. Chapman, 2005; Greenstein et al., 2015), I do not find myself complying with this principle. This is because the people who worked with me in this project as co-researchers had no terminology preferences. They used different and various terminologies at the same time. When referring to disabled people, for example, they sometimes used the term ‘disabled people’ and used ‘people with disability’ or ‘people with special needs’ at other times. Thus, I found it more appropriate to maintain the most acceptable terminologies in the UK, despite the divergence of views on the subject. I use, for example, the term ‘disabled people’ when referring to disabled people in general. Also, it has been argued that the term ‘people with learning difficulties’ is the preferred term among disabled people in the UK (Blyth, Chapman and Stronach, 2016), despite its verbal connotation that locates the ‘problem’ of disability in the body. Thus, since all my discussions regarding terminologies are consistent with the social model of disability, I find the term ‘learning disabled people’ is more appropriate to be used in this project. This term is preferred by learning disabled researchers who work on the Learning Disability Studies programme at the University of Manchester (Greenstein et al., 2015).
In fact, it is difficult to ensure that every individual uses acceptable terminology, but at least people in the UK generally agree with a minimum level of acceptance and rejection of language in relation to disability. Table 1 shows an example of the sort of language that should be avoided and the type that is preferred in relation to a social model of disability. Although the importance of language as a basis for emancipation took a great deal of attention through the work rooted in the social model, it peaked through the work rooted in poststructuralism (see Chapter 2). For example, poststructuralism sees the use of the term ‘non-disabled’, which was introduced “to reverse the stigma of ‘otherness’ and throw it back at the oppressor” (Hughes and Paterson, 1997, p.333), as an important step that helps disabled people to find their way towards emancipation. The change of terms relating to disability and disabled people was subjected to various stages through different eras. For example, “the shift from idiot to mental retardation to mental deficiency to intellectual disability, to learning difficulty, or from mongol to Down syndrome … signify different eras, different frames of reference” (Shakespeare, 2014, p.55).

In addition, I want to clarify here the differentiation between ‘co-researching’ and ‘participating’. When I use the word ‘co-researchers’, I am referring to the disabled individuals who worked with me in the process of conducting the research, while the term ‘participants’ refers to the disabled and non-disabled individuals who participated in interviews and the disability awareness film. However, the term ‘co-researching’ does not “imply an equal partnership” (Walmsley and Johnson, 2003, p.148) in this study. This is because as I believe it
is not possible to equalise the inherent power relations that are in operation within all research; whatever the principle researcher does to equalise the partnership it is, inevitably, led by them. I will further discuss this topic in Chapter 6.

Finally, throughout this thesis, I use the term ‘attitude’, for example, when I say ‘attitudes towards disabled people’. According to the Cambridge English Dictionary, attitude is “a feeling or opinion about something or someone, or a way of behaving that is caused by this” (Cambridge English Dictionary website, 2016). Thus, attitudes in this thesis are composed of ingrained thoughts and emotions and, as such, they are invisible until displayed in words (language) or deed (behaviours). Some would argue that measuring or testing attitudes is pointless as it is actions that matter. This is because attitudes are notoriously tricky when trying to connect them to people’s actions. In other words, sometimes people’s attitudes and their actions contradict, especially when their actions do not reflect what is ingrained in their minds. This discrepancy can be referred to as “human dialectic” (Shahrur, 1990, p.251). Human dialectic occurs when people’s actions contradict with their attitudes. For example, some have the attitude towards smoking that it is dangerous, anti-social, and filthy, yet, at the same time, they smoke. The recognition of this kind of human dialectic is important in this study as it will help to understand how the co-researchers and the participants in this project make sense of their experiences.
Table 1: The social model and language—preferred terms relating to disability and disabled people

<table>
<thead>
<tr>
<th>Avoid/Offensive</th>
<th>Preferred</th>
</tr>
</thead>
<tbody>
<tr>
<td>Victim of</td>
<td>Person who has/person with/person who has experienced</td>
</tr>
<tr>
<td>Crippled by</td>
<td>Person who has/person with</td>
</tr>
<tr>
<td>Suffering from</td>
<td>Person with/person who has</td>
</tr>
<tr>
<td>Afflicted by</td>
<td>Person who has/person with</td>
</tr>
<tr>
<td>Wheelchair-bound</td>
<td>Person who uses a wheelchair/wheelchair user</td>
</tr>
<tr>
<td>Invalid (= not valid)</td>
<td>Disabled person</td>
</tr>
<tr>
<td>Mental</td>
<td>Disabled person</td>
</tr>
<tr>
<td>Handicap</td>
<td>Disabled person</td>
</tr>
<tr>
<td>The disabled</td>
<td>Disabled people</td>
</tr>
<tr>
<td>The handicapped</td>
<td>Disabled people</td>
</tr>
<tr>
<td>Spastic</td>
<td>Cerebral palsy</td>
</tr>
<tr>
<td>Deaf and dumb</td>
<td>Deaf or hearing impaired person</td>
</tr>
<tr>
<td>Cripple/crippled</td>
<td>Disabled person/mobility impaired person</td>
</tr>
<tr>
<td>The blind</td>
<td>Blind or visually impaired person</td>
</tr>
<tr>
<td>The deaf</td>
<td>Deaf people</td>
</tr>
<tr>
<td>Mentally handicapped/backward/dull</td>
<td>Learning difficulties/learning disabilities/learning disabled person</td>
</tr>
<tr>
<td>Retarded/idiot/imbecile/feebleminded</td>
<td>Developmental impairment/learning difficulties/learning</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>disabilities/learning disabled</td>
<td>Person with a mental health impairment/survivor/user of the mental health system</td>
</tr>
<tr>
<td>person</td>
<td></td>
</tr>
<tr>
<td>Mute/dummy</td>
<td>Speech impairment</td>
</tr>
<tr>
<td>Crazy/maniac/insane</td>
<td>Person with a mental health impairment/survivor/user of the mental health system</td>
</tr>
<tr>
<td>Mentally ill/mental patient</td>
<td>Person with a mental health impairment/survivor/user of the mental health system</td>
</tr>
<tr>
<td>Abnormal</td>
<td>Different/disabled person</td>
</tr>
<tr>
<td>Patient</td>
<td>Person</td>
</tr>
<tr>
<td>Special needs</td>
<td>Individual needs</td>
</tr>
<tr>
<td>Special</td>
<td>Everyone is special!</td>
</tr>
</tbody>
</table>

Source: Adapted from Carson, 2009, pp.22–23.

1.9 Thesis Structure

This thesis consists of nine chapters. This introductory chapter has narrated the story of my journey into the field of disability and discussed ontological questions regarding my political position. Chapter 2 discusses my journey into the exploration of a wide range of literature in the field of disability. The chapter starts with a discussion of disability in Kuwait, and then explores the dominant disability perspectives in the Global North in an attempt to reconcile a model/conceptualisation that is appropriate when seeking to critically consider and analyse disability in Kuwait.
Chapter 3 talks about the conceptual framework adopted in this study to analyse disability issues in the Kuwaiti context. The conceptual framework is rooted in critical realism. Chapter 4 discusses the research methodology, data collection, and analysis methods, both in the construction and practicalities. Chapter 5 shows the analytical process and the themes and sub-themes emerging from the data set. Chapter 6 presents and discusses the findings related to the process of the collaborative work with the co-researchers. Chapter 7 presents and discusses the findings concerning disability issues in Kuwait. Chapter 8 discusses the development of a model to understand disability issues in the Kuwaiti context. The last chapter (Chapter 9) demonstrates further discussions, conclusions and recommendations for further research.

1.10 Summary

In this chapter, I have presented how, based on the data generated during the exploratory phase, I have transmitted from one area of interest to another. I showed how my focus changed, from providing distance education for disabled students to focusing on social attitudes and societal structure. By wanting to develop distance education strategies at the beginning of this journey, it can be argued that I was viewing disability from an essentialist/individual perspective, but with the recognition of the importance of structural barriers such as building inaccessibility. However, by the end of this journey, my perspective could be described as that of almost a purist social modellist. However, the following chapters of this thesis will show how engaging with a wide range of literature
continued to shape my thoughts and enabled me able to develop a conceptualisation rooted more in critical realism to analyse and understand disability in Kuwait.

In this chapter, I also discussed the ontological/political questions regarding conducting this project. I then talked about the research questions that emerged as a result of the data generated from the exploratory phase and the wide reading of the literature. I also tried to clarify the definitions and terminologies used in this thesis. The chapter ended in a description of how the thesis is structured.
2.1 Introduction

During my journey investigating the field of disability studies, my reading of the literature over time has significantly influenced my understanding and conceptualisation of disability and has made me think about what kind of model or inquiry tool or perspective might be useful in shedding light on disability issues in Kuwait. Are the predominant models in the Global North relevant to a country such as Kuwait? How can these be modified to suit the situation in Kuwait?

However, although exploring a variety of perspectives on disability is not an easy task, it is crucial in developing an understanding of which analytic tool is more appropriate to be adopted in the context of Kuwait and the extent to which the state is ready to embrace this approach. The second section (Section B) of this chapter will involve an exploration of the dominant Western conceptualisations of disability, including the individual model, a social model of disability, and cultural approaches to disability.

The main driver that made me think of embracing a model from the Global North was the lack of disability research in the Arabian region. However, it is vital to state here that I am not suggesting that I will simply import a Western model/conceptualisation without subjecting it to scrutiny. Importing a Western
model without taking into consideration its appropriateness to the Kuwaiti context can reinforce the process of postcoloniality (Bazna and Hatab, 2006). Thus, before the exploration of the Western perspectives on disability takes place, it is crucial to take a primary step, a comprehensive study of the Kuwaiti situation in general and regarding disability in particular. In the first section (Section A) of this chapter, I will explore disability in the Kuwaiti context, hoping to develop a better understanding, thus enabling the identification of the most appropriate current disability models in order to begin to understand and think about disability in Kuwait.

However, before commencing with the discussion of disability in Kuwait, I would like to give the reader (especially native English speakers) a general sense of the nature of Kuwaiti society.

Section A: The Kuwaiti Context

2.2 The Study Location: The State of Kuwait

“Kuwait is an Arab, independent, fully sovereign State. There shall be no surrender of its sovereignty nor cession of any part of its territories”

(Kuwait's Constitution of 1962, Article 1).

2.2.1 The Kuwaiti Population

Kuwait is located on the north-western shore of the Persian Gulf, and covers an area of 17,818 sq km (BBC News, 2015). According to BQ Magazine website
(2015), the total Kuwaiti population is approximately 4.2 million people, of which 30.9% are Kuwaiti nationals while 69.1% are non-Kuwaiti nationals. The non-Kuwaiti population comprises different ethnic groups, including Arabs, Asians, Africans, North and South Americans, Europeans, and Australians. It also includes those known as ‘Bidun’ or ‘stateless’ residents.

According to the Human Rights Watch report (2016), there are at least 105,702 ‘Bidun’ or ‘stateless’ residents in Kuwait. The report states that the authorities in Kuwait claim that these groups of people are ‘illegal residents’ who have deliberately destroyed evidence of any other nationality in order to receive the benefits that Kuwait gives to its citizens. The phenomenon of the ‘Bidun’ residents has historical roots related primarily to the Kuwaiti Nationality Law of 1959. There are a number of interpretations of the causes of the phenomenon of ‘Bidun’, most of which refer to the chaotic legislation and non-application of certain provisions of the Kuwaiti Nationality Law promulgated in 1959, not applying for citizenship, or hiding their original identities (Aljazeera.net, 2015). Thus, according to the state of Kuwait, there is confusion between the ‘legal stateless residents’ who did not apply for citizenship in 1959 and remained stateless and the ‘illegal stateless residents’ who have hidden their original documents, hoping to be granted Kuwaiti nationality one day and receive the benefits of citizenship.
2.2.2 The Kuwaiti Political System

Since the Anglo-Kuwait protection agreement of 1899 was officially cancelled in 1961 (Scott, 2016), Kuwait declared its independence and formed the Kuwaiti Constitution of 1962. According to the Kuwaiti Constitution, the political system in Kuwait is based on the separation and cooperation of powers (legislative power, executive power, and judicial power) (Article 50). The legislative power is represented in the Amir of Kuwait (head of state) and the National Assembly (Kuwaiti parliament) (Article 51). The executive power is represented in the Amir, the cabinet, and the ministers (Article 52). The judicial power is vested in the courts in the Amir’s name (Article 53). Thus, it can be seen from these articles of the Kuwaiti Constitution of 1962 that the Amir of Kuwait holds all powers (often called the ‘father of powers’) and practices his power through these different outlets, in the sense that any law passed by the legislature cannot take effect without the agreement of the Amir. His consent must be written in the form of an Amiri decree.

All rulers in Kuwait must be descended from the Al Sabah family. However, according to Article 4 of the Kuwaiti constitution, the ruler must be a direct descendant of Sheik Mubarak Al Sabah (an early ruler of Kuwait). Given the presence of an elected parliament, Kuwait is identified as a partially democratic country. Anyone who is Kuwaiti by origin, who is at least 30 years old and able to read and write Arabic well is qualified to be a member of the Kuwaiti parliament.
Parliamentary elections in Kuwait are held every four years. All Kuwaitis (men and women) who are at least 21 years old are allowed to vote. However, people who, for example, serve in the army and members of the ruling family are not allowed to vote in the elections.

Furthermore, according to the constitution, political parties are officially prohibited in Kuwait. However, unofficially, many parliaments members belong to different political blocs in the state. For example, some members of parliament represent Islamists, whether Shia or Sunni. From Shiism there are political blocs such as the National Islamic Alliance and the Justice and Peace Alliance. The Sunni sect, the Muslim Brotherhood, is represented by the political bloc Hadas, while the Salafi movement is represented by the Islamic Salafi Alliance. Also, some liberals in parliament belong to political blocs such as the National Democratic Alliance.

2.2.3 The Economic Resources

“National economy is based upon social justice; its mainstay is a balanced cooperation between public and private enterprise; its aims are the realization of economic development, the increase of production, the raising of the standard of living, and the substantiation of the citizens' prosperity, all within the limits of the Law”

(Kuwait's Constitution of 1962, Article 20).

In the past, the entire economy of the state was based on pearl diving, sea trade, and shipbuilding (Meleis, 1979). However, with the discovery of oil in the 1930s, many changes occurred at the economic and political levels and within society in
general (Bazna, 2009). Internationally, oil resources and the strategic location of Kuwait have drawn the attention of world, whereas, locally, oil revenues have fuelled the development of a new economic structure, welfare, and prosperity for Kuwaiti citizens (Crystal, 1990).

Today, Kuwait is considered one of the most powerful countries in the world in economic terms. According to the Sovereign Wealth Fund Institute, the size of assets of the Kuwait Investment Authority (KIA) is USD$592 billion (Sovereign Wealth Fund Institute, 2016). Moreover, compared to the UK, according to 2016 statistics from the International Monetary Fund examining purchasing-power-parity (PPP) per capita GDP, Kuwait earned fifth place in the world rankings with USD$70,166, while the UK was in 25th place with USD$41,159 (International Monetary Fund, 2016). In Kuwait, the inflation rate was last recorded at 3.1% in July 2016, while the UK GDP growth rate rose from 0.4% in the first quarter of 2016 to 0.6% in the second quarter of 2016 (Ieconomics, 2016).

Economic prosperity and welfare in Kuwait is certainly reflected in the people’s lives in general and Kuwaiti citizens in particular. Kuwaiti citizens enjoy a good standard of living and welfare, including a governmental educational system and healthcare, both of which are free of charge. Water and electricity are also available for Kuwaitis at low cost. Additionally, all married Kuwaitis are eligible to receive a free house after 10–15 years of marriage. These are privileges granted by the state solely to Kuwaiti citizens.
There are differing views on whether the economic system in Kuwait is socialist or capitalist. Some would argue that the state is following a socialist approach, mainly for three reasons. The first reason stems from the state ownership of many public organisations such as co-operative societies and sport clubs as well as water and electricity companies. The second reason they believe that Kuwait is considered a socialist state is because revenues from oil production are shared with all citizens. The last reason derives from the fact that 75.8% of Kuwaitis are working within the governmental sectors (Alrayalaam, 2015) where their jobs are secured by the government. Thus, the government is responsible for guaranteeing the salaries of this significant number in its various sectors.

Nevertheless, the preponderant view is that the economic system in Kuwait is based on a balance between capitalism and socialism. It takes a middle position between extremist socialist and extremist capitalist and thus is an expression of what is known as ‘moderate socialist’ (Tayar-Taqadomi, 2013). This claim stems from the provisions of the Kuwaiti Constitution, which are based on protecting citizens from the economic domination of the capitalist (as in Articles 20, 21, 22, and 24) as well as protecting the economically marginalised groups (as in Articles 11, 13, 15, 25, 40, 41, 42, and 48).

The Kuwaiti government is currently facing a budget deficit of 12.2 billion Kuwaiti dinar (USD$40.2 billion) as a result of the drop in oil prices (Reuters, 2016). The Kuwaiti finance ministry has announced that the expenditure of the upcoming budget will be 18.9 billion dinar (about 10.4 billion for salaries), while
revenue will total only 7.4 billion dinar (Mubasher Aljazeera, 2016). This significant budget deficit will position the ‘rentier state’ in a bind, as it will create difficulties in paying the salaries of the governmental employees in the case of the continuation of the decrease in oil prices. Until now, the government has not provided a clear plan to demonstrate how this problem will be faced (for example, a plan to reduce expenses or to search for alternative financial resources).

Later in this chapter, I will show how Kuwait’s economic prosperity and welfare are reflected in disabled people’s lives. Thus, I find it useful at the beginning of this chapter to provide a glimpse into the Kuwaiti economy and its current challenges in order to monitor whether these changes have had/will have an impact on disabled people’s lives.

I have, so far, given a preface to the Kuwaiti context in general. I began by exploring the general policy of the state before providing an overview of Kuwait’s economic resources. It is also important to give the reader a general overview of Kuwaiti culture and religion. However, this is not a simple task as the topic of culture and religion is very broad. Thus, I find it more useful to narrow my search and focus on the prevalent language that is connected to the construction of the notion of ‘normality’. However, because the dialogue in relation to ‘normality’ will eventually lead to a discourse on disabled people and disability, I find it more beneficial to conduct the discussion around the culture/religion in the next section (i.e. disability in Kuwait).
2.3 Disability in Kuwait

As I contend that the issues of disability are too complex, I could either explore disability from a broad view or narrow down my research by taking one or two aspects of disability and exploring them in depth. In other words, should I look at disability on various levels, including medical, political, economic, cultural, etc., or take one or two aspects and provide a deeper analysis? After long reflection, I decided to explore disability in Kuwait broadly, for three main reasons. The first reason can be derived from the reality of the complexity of disabled people’s lives (see Chapter 7). This will be shown as the thesis progresses through the adoption of an approach that seeks to explore the complexities of disability (see Chapter 3). The second reason is the uniqueness of this study. I will show in this chapter that there is a lack of research in Kuwait and in the wider Arabian region and that the voices of disabled people are totally absent from the small body of literature that does exist. Thus, by exploring different aspects of disabled people’s lives, this study may be taken as a foundation that can pave the way for further disability research in Kuwait or a similar Arabian context. Also, by exploring participatory research strategies (see Chapter 4), this study aims to encourage researchers to think about how best to involve disabled people in research. The final reason can be deduced from one of my research aims: developing a model for understanding disability in Kuwait that aims to bring about social change. I believe that the development of such a model would not be possible without exploring the complexities related to disability and, specifically, disability in Kuwait. However, despite these arguments, the reader will notice that, on a number of occasions, I
delve deeper in my analysis of some aspects that I find thought-provoking to my research questions and my theory. I will amplify this point in the methodology chapter.

In the first part of the next section I will talk about the Kuwaiti culture and the role of religious discourse in constructing the prevalent language and its link to disability. I will then move on to explore the link between Islamic religious discourse on disability with other cultures and civilisations. The first part ends with an exploration of how disabled people are depicted in Kuwaiti media. In the second part, I will explore disability in Kuwait at the political and economic levels, before moving on to explore the nature of disability research in Kuwait.

2.3.1 Kuwaiti Culture: The Influence of Religious Discourse

“The religion of the State is Islam and Islamic Law shall be a main source of legislation”

(Kuwait's Constitution of 1962, Article 2).

Kuwait is a conservative Arabian Islamic state featuring a mix of tribes with different origins that fled from different regions of the Arabian Peninsula and Iran. Adherence to Islamic values that are well cultivated in Muslims’ religious books are reflected in daily behaviours and discourses. For example, the Arabic word ‘inshallah’, which means ‘if Allah/God wills’, is present frequently in day-to-day language. However, the frequent usage of this word should not necessarily be seen as having a religious overtone; rather, this issue can be related to the influence of the context in which individuals live. Thus, one can similarly hear foreigners who
come from non-Muslim societies using this term when they live in an Islamic context. This phenomenon can be likened to atheists spontaneously using phrases that are correlated to God’s existence, such as ‘thank God’, ‘for God’s sake’, or ‘I swear to God’. This again should not be perceived as having religious connotations, but is a natural impact of the context in which individuals live.

Likewise, the phrase ‘praise and thanks be to God’ is common among local people in Kuwait. In fact, this phrase can be used either as an expression of gratitude or to express sarcasm, when someone, for instance, does a ‘foolish’ or ‘weird’ thing. However, this phrase, in its first meaning (i.e. gratitude), can be seen transparently in the speeches of Islamic spiritual leaders and Imams as well as among the general public. This phrase is correlated with the notion of ‘health’ and ‘normality’ as people are required, according to the teaching of Islam, to be thankful for ‘God’s grace’ of having a ‘healthy’ and ‘normal’ body. It is common to notice how this issue is constructed within society since the question first arises once a baby is born: is he/she healthy/normal?

This issue of ‘health’ and ‘normality’ has religious and cultural dimensions and is well emphasised within Muslims’ holy book. The Quran clearly emphasises the importance of humans praising and thanking God for giving them all graces. For example, God should be praised for his guidance to the ‘right path’ (see, for example, Surah Al-A'raf, 7:43; Surah Al-Mu'minun, 23:28). Another issue that is stressed is the importance of being thankful to God for the creation of a ‘perfect’ body:
Say, "It is He who has produced you and made for you hearing and vision and hearts; little are you grateful." (Surah Al-Mulk, 67:23).

Therefore, any loss of hearing or sight would be perceived as a deviation from ‘perfection’ or ‘normality’. This makes religious people constantly thank and praise God for having a ‘healthy’ body, especially when they see ill or disabled people. Some Muslims believe that God creates disabled people as a ‘reminder’ to non-disabled people of God’s grace for giving them a ‘perfect’ body.

Generally, people in Kuwait, believe in God’s will, fate and destiny, as do many religious people; anything (good or bad) that happens to a person has been written and predestined by God, and objection is forbidden, so that a person must accept matters as they are, thank God, and be patient. From this idea, some believe that God can either plague or punish people by giving them an impairment once they deviate from his guidance. However, Imams and Islamic scholars differentiate between the terms plague and punishment. For them, a plague, or a test, is a word to be used inclusively for any Muslims, including ‘good ones’, to test their belief, while punishment can refer to ‘disobedient Muslims’ and to those considered atheists, polytheists, or infidels by Muslims. This may be the reason why the notion of impairment as ‘God’s punishment’ is not widespread among Muslims, but it is not, as Turner (2015) believes, because of the absence of ‘ancestral sin’ that is cultivated in Christianity. The notion of ‘original sin’ also exists in Islam and is stated in a number of verses in the Muslims’ holy book and in the Hadiths (see, for example, Surah Al-Baqarah, 2:35–38).
The notion of plague in the Muslim Hadiths\(^1\) is highlighted, as Muslims are required to be patient in order to receive God’s rewards and gain his forgiveness:

> Never a believer is stricken with a discomfort, an illness, an anxiety, a grief or mental worry or even the pricking of a thorn but Allah will expiate his sins on account of his patience (Book 1, Hadith 37).

> Allah, Mighty and Sublime is He, said: 'For whomever I take his sight, and he is patient and seeking a reward, I shall not be satisfied with any reward for him less than Paradise (Book 36, Hadith 99).

These two hadiths confirm the concept of trials and patience to receive rewards from God in the life after death or hereafter. However, many disabled people may consider these hadiths as inappropriate, removed from the contemporary lives of disabled people. Urging disabled people to be patient and reminding them of heaven does not yield practical solutions to their problems. Rather, the question that may remain for many disabled people is why God chose them in particular to be subjected to this experience. This may lead disabled people to have negative attitudes towards God’s will. I will explore this issue in later pages.

Another view on disability in Islam is discussed in Hasnain, Shaikh, and Shanawani (2008, p.31) who state that “Islam views disability as morally neutral, neither a blessing nor a curse: It is considered an inevitable part of the human condition, one that Muslim society and individuals must address”. In the Muslims’ holy book (and even in any other book from that period), there is no term that could equate to the modern term ‘disability’; rather, there are other specific Arabic

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\(^1\) Hadiths are the books containing the sayings and deeds of the Prophet Muhammad. They are also called ‘Alsunnah’.
terms referring to disability. Among them, the book uses the words ‘blind’, ‘deaf’, ‘lame’, and ‘leper’ to describe disabled people (Hasnain et al., 2008) as well as other terms that could be related to disabled people and disability, such as ‘orphan’, ‘weak’, ‘sick’, ‘indigent’, and ‘needy’ (Bazna and Hatab, 2005). The book concentrates on disadvantaged people who do not possess the social, economic, and physical qualities that are valued by society, as well as on the responsibility of Muslim society to improve their lives (Bazna and Hatab, 2005).

It can be concluded from the above that Islamic religious texts deal with disability as ‘God’s creation’ whatever the believed reason behind it (e.g. blessing, curse, plague) and provide ways and means to deal with disabled people ‘kindly’. How to deal with disabled people kindly is emphasised in the Quran through the famous story of the Prophet Muhammad with the blind man:

The Prophet frowned and turned away. Because there came to him the blind man, [interrupting]. But what would make you perceive, [O Muhammad], that perhaps he might be purified. Or be reminded and the remembrance would benefit him? As for he who thinks himself without need, To him you give attention. And not upon you [is any blame] if he will not be purified. But as for he who came to you striving [for knowledge] While he fears [Allah], From him you are distracted. (Surah Abasa, 80:1–10).

Additionally, the Quran gives hope of healing for disabled people by showing the miracles of Jesus in healing disabled people such as blind people and lepers:

And [make him] a messenger to the Children of Israel, [who will say], 'Indeed I have come to you with a sign from your Lord in that I design for you from clay [that which is] like the form of a bird, then I breathe into it and it becomes a bird by permission of Allah . And I cure the blind and the leper, and I give life to the dead - by permission of Allah .

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And I inform you of what you eat and what you store in your houses. Indeed in that is a sign for you, if you are believers. (Surah Ali `Imran, 3:49).

However, the presence of disabled people is not restricted to Muslims’ holy book; they are addressed in the Bible as well. The Bible, similar to the Quran, demonstrates Jesus’s miracles of healing disabled people (e.g. Matthew, 9:1–8; Mark, 2:1-12; and Luke, 5:17-26). Nevertheless, it also expresses negative attitudes towards disabled people by showing them as an unwelcome group in houses of worship (see, for example, Leviticus 21:16–23).

From these historical standpoints, the literature treats the terms ‘disability’ and ‘illness’ as synonymous and provides an understanding of how the understanding of disability has, in part, been socially constructed through these religious texts (Selway and Ashman, 1998). As a result, it is evident to see how religious texts have contributed to contemporary notions of ‘difference’ and ‘normality’.

**Disability Across the Cultures**

As Islam is considered a relatively nascent religion (compared to other religions) that emerged in the seventh century, it is axiomatic to find overlaps and influences from other cultures and religions. More broadly, it seems that the beliefs that result in a perception of disabled people as receiving ‘God’s plague’ or punishment is not limited to Islamic culture—it is historically/culturally ingrained in different societies (Treloar, 2002). For example, the idea of perceiving a disability as a punishment for sins or ‘God’s plague’ is embedded in different
times and civilisations, such as Greek and Roman, as well as in different religions, such as Judaism and Christianity (Barnes, 1997; Snyder and Mitchel, 2001). Henri-Jacques Stiker (1999), for example, states that disabled people were portrayed as a sign of the gods’ dismay in Ancient Greece, while Huet (1998) argues that they were depicted as a punishment for parental wrongdoing during the Renaissance (cited in Snyder and Mitchell, 2001).

Although there are similarities and connections between cultures, people, at the same time, can have distinctive perspectives on disability across different cultures. Selway and Ashman (1998) cite Buscaglia (1975), who notes that, while Masai tribesmen killed disabled children, the Azard tribe admired them. He also reveals that, while the Chagga of East Africa used disabled people to defend against evil, the Jukun of Sudan believed that evil spirits caused disability.

Selway and Ashman (1998) suggest that people of different religions have varying attitudes towards disability. A study conducted by Westbrook, Legge, and Pennay (1993) examined the different attitudes of various societies towards disabled people. The study indicates that the German community express the greatest acceptance of disabled people, followed by the Anglo, Italian, Chinese, Greek, and Arabic groups. The results also address the degree of stigma experienced in relation to the type of impairment. In all communities, people with asthma, diabetes, heart disease, and arthritis were the most accepted groups, while those with AIDS, learning disabilities, psychiatric illness, and cerebral palsy were the least accepted disabled groups.
Furthermore, people’s attitudes toward their own bodies can vary. Based on the strength of their belief in God, some people show satisfaction with ‘God’s creation’, while others show anger with ‘God’s fate’ for creating them disabled. A study by Treloar (2002) on how disabled people and their families use spiritual beliefs to find meaning in their impairments recounts some stories related to disability and punishments. Treloar reveals that disabled people can have both positive and negative attitudes towards God for making them disabled. One participant, for example, showed satisfaction with having a disabled child:

Some people have asked, ‘What have you done in your past that would make God give you a child with a disability?’ Basically, ‘What terrible sin did you commit?’ Even though it shocks me when somebody says that to me, it gives me an opportunity to say, ‘Let’s talk about why there is sin in the world … Because sin is in the world, there will always be darkness and hate and hurt and disability … here on earth’.

One person said to me, ‘Don’t you hate God if He would do this to you? That He chose you to have a child with a disability?’ Very strong words. Why, who am I? I don’t have a right to say to God, ‘Who are you to do that to me?’ I’m His child, so is Michelle. He’s doing what He sees best for us, even though we don’t necessarily see the big picture. Most of us have a limited perspective of who we are in relation to God, even people that go to church regularly (Treloar, 2002, pp.597–598).

This extract indicates that, despite the negative attitudes exhibited by non-disabled people towards Megan and her child, her belief in God led her to be satisfied with having a disabled child. Megan remained patient and calm when people asked such questions. Although some people like Megan report positive attitudes and satisfaction with ‘God’s will’, others may show anger with God for making them
disabled. This discontent with ‘God’s will’ may lead them to feel despair, hopelessness, and resentment (Pargament and Brant, 1998).

Accepting impairment as ‘God’s will’ resulting from ‘punishment’ or ‘sins’ may be seen problematic for disabled people. Moreover, the notion of Jesus’s miracles of healing (see, for example, the Bible: Matthew, 9:1–8; Mark, 2:1–12; and Luke, 5:17–26; and the Quran: Surat Ali `Imran, 3:49) may be seen as problematic for some disabled people as it can develop confusion between accepting a positive disabled identity and rejecting the negative effects of impairment (Allen, 2010). Thus, exploring both the positive and negative aspects of religions from the perspective of disabled people (religious and non-religious) is needed and is an area that needs expansion in disability research (Selway and Ashman, 1998).

I began this section discussing disability in Kuwaiti culture and religion, but it was difficult to remain focused on Kuwait without looking at the ‘big picture’. Although I looked at the Kuwaiti context initially, the discussion moved to Islamic values in general and their roles in constructing people’s discourse about ‘normality’. This section ended with an exploration of other cultures and religions. After this exploration, one can notice that there are connections and interferences between Islam and other religions/cultures in relation to how these different beliefs perceive disabled people. In terms of similarities with Islam, it can be noticed how the idea of perceiving a disabled person as ‘God’s plague’, or a ‘test’ or a ‘punishment’ is constructed in other cultures, signifying that:

Disability is interpreted as punishment for one’s own sin or for the sin
of one’s parents, a test of faith, an opportunity to build character or to
inspire others, an occasion for the power of God to be made manifest, a
sign that one lacks faith, or simply a mysterious result of God’s will
(Creamer, 2009, p.50).

However, at the same time other cultures can differ in dealing with disabled
people. For example, perceiving a disabled person as an outcome of evil spirits
(Rozario, 2009) is not common in Muslim societies. I would suggest that one’s
discourse, ideas, and beliefs cannot avoid the influences of the “big D Discourse”
(Gee, 1999, p. 6) (see discussion below).

**Media Representation of Disabled People in Kuwait**

“Organizing awareness campaigns through media motivating media to create a
positive image for the people with disabilities”

(Law No. 8 of 2010 for the Rights of People with Disabilities, Article 22 (3)).

Because the media is a mirror for any society, and a tool contributing to discourse
within society, I find it crucial to explore how disabled people are depicted in the
Kuwaiti media. Generally, disabled people in Kuwaiti media are shown in a
negative light. However, Kuwaiti society has no specificity or uniqueness in
showing disabled people as such, as many Western societies present disabled
people in the same way. In these societies (whether in the Global North or Global
South), disabled people are portrayed as ‘pitiable’, ‘tragic’, ‘sinister’, or as a ‘tool
of ridicule’ (Barnes, 1992; Harnett, 2000; Clark, 2003).
People who work in the Kuwaiti media have produced a number of TV shows that portray disabled people as “representatives of many of the things they most fear—tragedy, loss, dark and the unknown” (Hunt, 1966, p.155). An example of tragedy can be taken from a Kuwaiti TV show named Hebr Aleyon. In this TV show, the actress Heya Abdulsalam plays the role of a disabled character who cannot hear, speak, or see. The disabled character is kept in a locked room, isolated from her family, rarely going out or integrating within society. This TV show provides an example of the negative portrayal of disabled people.

Moreover, a number of Kuwaiti TV shows and plays refer to learning disabled people as ‘crazy’ or ‘demented’. For example, the 39-year-old TV show Alagdar showed an unknown learning disabled character wearing torn and dirty clothes, wandering around an old neighbourhood by himself. He had the humorous name ‘Maroob’, which means ‘frightened’. The people in the neighbourhood oppress him, and often insult him by calling him ‘crazy’ or ‘demented’. Children throw stones at him as he runs away.

These and other similar scenes with learning disabled characters are still represented in many Kuwaiti TV shows today, especially comedies. In addition, real learning disabled people are sometimes shown on TV and used as a ‘tool of ridicule’ in order to make the audience laugh. This applies not only to TV shows but also to comedy plays, as the cast summons learning disabled people or people with restricted growth in order to make jokes about them, thereby making the
audience laugh. Famous actors who frequently follow this kind of farce comedy in their TV shows and plays in Kuwait include Dawood Hussain and Tariq Al-ali.

However, as mentioned above, the distortion of the identification of disabled people in the media is not restricted to Kuwaiti culture. It can be also seen in Western societies in the production of Hollywood films such as *Me, Myself & Irene*, *Tropic Thunder*, *The Hunchback of Notre Dame* and many other Disney films. Barnes (1992) and Clark (2003) explore how disabled people became a ‘tool of ridicule’ in many TV shows and films. For example, Clark (2003), who explores comedy around disability in British TV and films, found that non-disabled people often create jokes from the existence of certain physical, speech, and visual characteristics of impairments. Today, many comedians have built their careers on ‘disablist humor’ (Barnes, 1992).

The genre rampant in Kuwaiti media is mainly around portraying disabled people as ‘pitiable’ and ‘tragic’ through the focus on the medical side of impairment, as well as using the disabled body as an ‘object of ridicule’, while some television and theatrical works show disabled people as ‘sinister’ in Kuwait. Other genres include the notion of the ‘supercrip’, which addresses the success of disabled people in spite of their impairments (Silva and Howe, 2012, p.174), though this does not seem to be constructed in Kuwaiti media. Supercrip stories flourish more in Western societies through the production of Hollywood films (see, for example, the series of *X-Men* films). These supercrip films show a disabled person as
extraordinary, someone who can overcome his/her impairment with miraculous abilities and become successful in his/her life (Barnes, 1992; Harnett, 2000).

Moreover, the offence that disabled people in Kuwait are exposed to is not restricted to the presentation of disabled people in TV shows and plays, but is constituted through the nature of the language used. Alanizi, secretary of the Kuwaiti Society of Blind People, reported to the *Alwatan* newspaper (2013a) that the use of the phrase ‘spend on blinds’ is offensive to blind people and can cause a negative effect on their psychology when they hear it on TV. This phrase, popular in Kuwait, is frequently used when a person spends money on something without getting anything in return. Moreover, in an interview, Tariq Al-ali, a famous comedian in Kuwait, used a ‘disablist’ term when referring to disabled people, saying ‘God keeps this evil away from you’. This phrase is usually used to refer to illness, for example, chronic or incurable diseases. This popular Arabic term means to send hope to people by praying that God keeps evil/illness away from them. However, Tariq used it coupled with disabled people, as if to say that disabled people (because of their impairments) are evil and he hopes that God will keep the evil/disabled people away from ‘normal’ people. In other words, he replaced the word *evil* and used it as a synonym for disabled people: ‘God keeps disabled people/evil away from you’.

Although, there is an explicit article in the Kuwaiti disability rights law that emphasises the portrayal of disabled people in a positive way (see Article 22 (3), Law No. 8 of 2010 for the Rights of People with Disabilities), the media in
Kuwait still shows them in negative ways. There is no explicit law in Kuwait that criminalises abuse against disabled people in the media, but, as I will show in the next section, Kuwait has signed international conventions that protect the rights of disabled people. By remaining silent to the abuse that disabled people are exposed to in the media, Kuwait is explicitly violating the international conventions on disability and human rights.

Portraying a disabled person in the media as ‘pitiable’, ‘pathetic’, an ‘object of violence’, ‘sinister’ or ‘evil’ has had a negative impact on modern discourse relating to disability and has led people to perceive disabled people in a negative way in reality (Barnes, 1992). Shakespeare (1999) argues that the media representation of disabled people has nothing to do with the identities and the experiences of disabled people in real life:

The use of disability as character trait, plot device, or as atmosphere is a lazy short-cut. These representations are not accurate or fair reflections of the actual experience of disabled people. Such stereotypes reinforce negative attitudes towards disabled people, and ignorance about the nature of disability (Shakespeare, 1999, p.165).

The media generally portrays disabled people through a medical lens, by showing their inability to interact ‘normally’ in daily life because of their physical impairment or learning disability (Pirsl and Popovska, 2013). This negative portrayal reflects how, in reality, disabled people are perceived in such a ‘tragic’ way, restricted by their impairments.
2.3.2 Disability at the Political and Socio-economic Levels

The economic prosperity and welfare in Kuwait are reflected in disabled people’s lives. For example, according to the Rights of Persons with Disabilities law No. 8/2010 established by PAPDA, disabled people in Kuwait have the same rights and access to services as non-disabled people. However, disabled people in Kuwait, according to the law, can take priority and access additional services based on their needs. For example, according to Article 34 of the law, disabled married people can access a house provided by the state five years earlier than a non-disabled person. Also, disabled people in Kuwait can receive a monthly welfare benefit payment based on the type and the degree of their impairment, in addition to other services and allowances. There is little dispute that, financially, disabled people in Kuwait enjoy a good standard of living and access to a comprehensive welfare system.

However, the disability rights law in Kuwait supports only Kuwaiti citizens and those with Kuwaiti mothers, with some provisions applicable to the other non-Kuwaiti nationals (with non-Kuwaiti mothers):

Provisions of this law are applicable to the Kuwaiti disabled and the children of the Kuwaiti women from a non-Kuwaiti, within the bounds of medical and educational care and employment rights stated in the Law herein.

The Authority is entitled to consider some of its provisions applicable to non-Kuwaiti disabled according to the terms and regulations it deems appropriate after the consent of the general assembly (Law No. 8 of 2010: C1 (2)).

Based on Kuwaiti nationality law, unlike Kuwaiti men, Kuwaiti women married
to non-Kuwaitis cannot obtain citizenship for their children or spouses. Thus, the law differentiates between citizens with purely Kuwaiti parents and non-Kuwaiti citizens with Kuwaiti mothers. It is clear from the article above that the provisions of the law support disabled Kuwaiti citizens and disabled non-Kuwaiti citizens with Kuwaiti mothers. It is not clear from this article and other articles in the law, however, how some of its provisions are applicable to disabled non-Kuwaitis and what these provisions are. In other words, it is not clear how disabled non-Kuwaiti nationals are supported by the state: are they eligible for the same services as disabled Kuwaitis? Or does the Kuwaiti disability rights law exclude the majority of the Kuwaiti population (disabled non-Kuwaiti nationals) and leave them without support?

Nevertheless, as my sister works in private education in Kuwait, she stated that there are a number of disabled non-Kuwaitis who have been granted approval from the Public Authority to receive financial support from the state for their education. This is because free education in Kuwait is available only to Kuwaiti citizens. Yet, it is not clear how these disabled non-Kuwaitis were able to receive these exceptional decisions from the Public Authority, or why only these people were specifically eligible to be granted these decisions. Why does the Public Authority not support all disabled non-Kuwaitis? Another question to be raised here is whether the support of the Public Authority is restricted to education or includes other services. Indeed, these inquires need further exploration in future research.
However, generally, disabled people in Kuwait enjoy a good standard of living and access to welfare services, unlike in the UK, which is currently struggling with the storm caused by the welfare changes that have swept British society in general and their impact on disabled people in particular (Duffy, 2013; Grover, 2015; Roulstone, 2015; Beresford, 2016; Dodd, 2016). However, although the recent large drop in oil prices has not yet seemed to have an impact on people’s prosperity, this issue needs to be monitored to see whether such changes will have an impact on disabled people in particular. Generally, the Kuwaiti government is currently taking austerity procedures to reduce the general expenditure of the state, including removal of subsidies on petrol, diesel and kerosene, cancelation of projects that are not a priority, and allowing foreign companies to invest and have full ownership in Kuwait (Kuwait News Agency, 2016). All of these are precautionary procedures to tackle the crises related to the drop in oil prices. However, the government has not provided a clear plan outlining how such procedures will be achieved.

PAPDA is a governmental political body that is responsible for ensuring the state is applying the disability law in various entities as well as meeting the required needs and services of disabled people. It is also the task of PAPDA to ensure that disabled people are treated equally to their non-disabled peers.

Furthermore, Kuwait is one of 160 signatories of the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations). The purpose of the CRPD “is to promote, protect and ensure the full and equal enjoyment of all
human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (UN, 2006, Article 1). Kuwait announced accession to the convention on the 22nd August, 2013. However, Kuwait has also expressed some reservations concerning articles such as 18 and 23 of the convention, and has added interpretative declarations to other articles such as 12, 19, and 25. For example, Kuwait has shown reservations concerning the provisions of Article 18, subparagraph 1(a), related to the liberty of movement and nationality, as the issues related to nationality are fundamentally a sovereign right of the state. Also, in relation to interpreting declarations, Kuwait indicated that Article 19, paragraph (a), concerning the right of a disabled person to choose the place he/she wishes to live shall not be interpreted to permit illegal relations outside legitimate marriage. In other words, a person is not allowed to live with his/her partner unless they are married. Obviously, this view by the state stems from Islam forbidding any relationship outside legitimate marriage.

However, since the disability law was implemented in 2010 and the CRPD was signed in 2013, it seems that disabled people in Kuwait are still struggling to have their needs realised and their rights respected. In *Disability and Human Rights: Global Perspectives*, Iriarte, McConkey, and Gilligan (2016) aimed to verify the application of the CRPD in specific local contexts through the interaction between disabled people, their families, and professionals. The authors believe that advocacy, research, and evaluation are three tools that can enhance the interaction between these stakeholders and thus improve the quality of the lives of disabled people. However, it does not appear that collaboration between these three entities
has been achieved in Kuwait. In the following section, I will explore the first two strategies by exploring the role of advocacy and disability organisations in Kuwait, mainly represented by PAPDA and scientific research on disability.

Advocacy and Disability Organisations in Kuwait

In the Global North, “disability advocacy is acting, speaking or writing to promote, protect and defend the human rights of … [disabled people]” (Daru, 2016, p.1). The work of disability advocacy is centred around supporting and giving disabled people opportunities to demand their civil rights through different types of advocacies, including self-advocacy, peer-advocacy, citizen-advocacy, and so on (Chapman, 2005; see also Bild, 2016). These kinds of advocacy are not present in Kuwait. Instead, PAPDA sets itself as the main governmental political body, along with non-profit organisations such as the Kuwaiti Society of Blind People and the Kuwaiti Society of Special Needs and Disability Rights, to play this role and speak on behalf of disabled people. It is impossible, from a Global North perspective, for a government body to act as an advocate. Advocacy has to be provided by an independent body (because, often, they will need to advocate on behalf of the person against the government).

In Kuwait, there is no overt and active disability movement led by disabled people themselves. Rather, all organisations in Kuwait are governmental and are led by non-disabled people, with limited participation by disabled people. Furthermore, all disability organisations in Kuwait are considered new entities as many were established in the 1990s. In contrast, the disability movement in the UK formed
earlier, with organisations such as the Physically Impaired Against Segregation (UPIAS) in the 1970s (see Shakespeare, 1993; Thomas, 2004a; Watson, 2004; Finkelstein, 2007; Barnes, 2012).

Politicians and decision makers in Kuwait are coordinating between the Kuwaiti parliament (the National Assembly) and PAPDA. The job of the National Assembly is to legislate laws and amendments in relation to, among other things, disabled people’s issues. PAPDA is the government agency that is responsible for implementing the disability rights law and ensuring that the rights of disabled people are upheld and that they have access to appropriate services. PAPDA has a general manager as well as a board specialising in setting goals and general policies for the Public Authority. The board of PAPDA is formed by the first deputy of the prime minister, and members of the Ministry of Labour and Social Affairs, the Ministry of Health, the Ministry of Education, and the Ministry of Higher Education, and the Director of the General Authority for Sports and Youth Board. Additionally, the board includes members from non-profit organisations and sport clubs working in the field of disability. The board holds at least two meetings a year with the attendance of the majority of members, including the president or his deputy.

Kuwait now has a disability rights law and all authorities described above are available to ensure the application of this law. However, laws, words, and ink on paper do not necessarily mean action (Iriarte, McConkey and Gilligan, 2016). The Kuwaiti disability rights law confirms the rights and services for disabled people
in different domains and levels, including education, health, social inclusion, and financial aid. However, since I officially started researching disability policies in Kuwait from 2012, and until now, all of the information I found was predominantly focused on the financial benefits provided to disabled people. Indeed, based on the discussion above, policies pertaining to welfare benefits and services, etc., do not represent advocacy.

**Conflict over Welfare Benefits**

When the former general manager of PAPDA, Altammar, took his position and the disability rights law of 2010/8 was established, his stated prime mission was to audit the files of the disabled people who were registered with the agency when the old disability law of 1996 was in action (*Alwatan*, 2010). As a result of this process, many people were found to have claimed fraudulently. It was believed that these people only registered as disabled in order to receive financial aid from the government because Kuwait, as Altammar stated in *Alwatan* (2010), provides strong economic support for disabled people. Altammar found himself at war with those who claimed fraudulently and their families because he deprived them of many benefits. His political decisions also affected those who had falsely registered as severely disabled ‘to get more money’ (*Alwatan*, 2010). He stated that the unjustified attack to which PAPDA was subjected by the newspapers and social media occurred because of the process of re-examining the files of disabled people by medical committees, which resulted in the elimination of aid to many
people who did not meet the international standards of disability (\textit{Alwatan}, 2013b). This reform placed Altammar in confrontation with critics.

Among the critics was the head of a Kuwaiti society of special needs and a disability rights activist, Ayed Alshameri. He stated that disabled people have faced many problems since the application of law No. 8/2010 (\textit{Alqabas}, 2015). He revealed that these problems emerged after the cancelation of aid to many ‘real disabled people’. He also mentioned that PAPDA justified, for example, the cancelation of aid to people with one impaired eye because it was applying international standards; but, in fact, PAPDA was depriving disabled people of their rights.

In addition to the disability activists in Kuwait, disabled people and their parents constantly criticise the work of PAPDA. Abu Mishel Alhajiri asserted that PAPDA and its medical committees have diagnosed his daughter incorrectly and changed her impairment from long-term, moderately visually impaired to long-term, mildly physically impaired (\textit{Alqabas}, 2015).

Generally, the views of the former Director General and his opponents show that serious political problems are associated with those who have, according to the state, claimed fraudulently or been incorrectly labelled. Disabled people and their parents and PAPDA have acknowledged the reality of this problem (\textit{Alqabas}, 2015), but they disagree on who ‘the real disabled persons are’ and the diagnosis of impairments.
The issue of welfare reform is likewise currently happening in the UK (see Duffy, 2013; Grover, 2015; Roulstone, 2015; Beresford, 2016; Dodd, 2016), and the same question has been raised around who are the “genuine and ‘faux’ disabled people in the United Kingdom” (Roulstone, 2015, p.677). However, the economic structures of the two countries are very different. As mentioned earlier, under socialism, the Kuwaiti people generally enjoy a high standard of living, unlike English society, which is claimed to be struggling under the current capitalist system. As a result, the target groups who are most likely to be affected by the welfare reforms in the UK are people in poverty and disabled people (Duffy, 2013). A report by Demos (2013) indicates that 3.7 million disabled people in the UK will lose £28 billion in disability benefits by 2017/2018.

I want to conclude here that, although the welfare reforms are concurrently happening in both Kuwaiti and British societies, the motives behind them and consequences may be not the same. PAPDA in Kuwait took this step as a corrective procedure to resolve the problems that occurred when the old disability law of 1996 was in action. These problems were mainly around medical diagnosis. Kuwait is a small, wealthy society; thus, welfare benefits may not be a big burden on the state budget, whereas, in the UK, welfare benefits may be seen as a burden resulting from the expansion of industrial society:

The expansion of the disability category occasioned by liberal and social democratic projects, the ubiquity of media, an ageing population, deindustrialisation and globalisation are all important and longer-run social developments that challenge state constructions of the ‘disability category’. Social policy … was asked to reconcile increasingly difficult challenges – either to expand, legitimate and fund disability welfare or
to define and shrink the disability category to make it much harder to access (Roulstone, 2015, p.675).

Furthermore, it does not seem that the Kuwaiti reform that started in 2010 had an impact on disabled people’s lives financially. Poverty is somehow non-existent in Kuwaiti society, as the Kuwaiti government supports all Kuwaiti citizens, including those who are without jobs. Similarly, non-Kuwaiti citizens, although they are not eligible to receive the same support and services as Kuwaitis, have secured work contracts whether with the Kuwaiti government or companies in the private sectors. However, in contrast, many disabled people will, it is claimed, be dramatically affected by the ongoing welfare changes in the UK (Demos, 2013).

However, due to the dearth of relevant literature, it is difficult to determine the motives that have caused disabled people, their parents, and disability activists to criticise the work of PAPDA. Was it the cuts to the financial benefits of some disabled people that made those people to criticise the work of PAPDA (since the state allocates financial support based on the degree of the individual impairment, so that ‘the more severe the impairment the more money’)? Or was it the intention of the state to reduce the budget allocated for disabled people? Indeed, such inquiries need further exploration, and this was the gap that I found in the literature through my research: the absence of the role of academics and scientific research in the field of disability in Kuwait.

**The Domination of the Individual Model in Kuwait**

According to Oliver (1996, p.31), the individual model is underpinned by what he
calls the ‘personal tragedy theory of disability’, and includes psychological and medical aspects of disability, or what he calls ‘medicalisation’:

The individual model for me encompassed a whole range of issues and was underpinned by what I called the personal tragedy theory of disability. But it also included psychological and medical aspects of disability … In short, for me, there is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalisation is one significant component.

Given the former general manager of PAPDA’s statements and those of his opponents discussed above, one would argue that the individual model (see definition above) is rooted in the Kuwaiti context. For example, re-assessing disabled people files and re-categorising their impairments brings the notion of the individual model that defines people by their biological characteristics (Oliver, 1990a). The roots of the individual model are apparent in the statements discussed above of the former general manager of PAPDA. This was clear especially when the former general manager noted that his desire to re-evaluate the conditions of disabled people stemmed from the so-called ‘international standard of disability’.

The international standard of disability was essentially imported from the USA by American professionals and experts who are working in Kuwait (Bazna and Hatab, 2006; Bazna and Reid, 2009; Bazna, 2009). The US approaches that have been imported are, in my opinion, based clearly upon an individual model view.

In fact, Maysaa Bazna is one of few scholars interested in exploring disability in Kuwait. The work of Bazna (e.g. Bazna and Hatab, 2006; Bazna and Reid, 2009; Bazna, 2009) centres on the criticism of the Western medicalisation imported in
the Kuwaiti context without any consideration of context or cultural sensitivity. Bazna and Reid (2009) and Bazna (2009) suggest that the Western medicalisation is not consistent with Kuwaiti culture, Arabic traditions, and Islamic values. The authors consider these imported Western norms to be a form of colonisation that carries specific norms/standards to determine the relationships between the West and the East (Young, 1995). However, the authors have not provided sufficient evidence on how these Western norms contradict with Kuwaiti culture, Arabic traditions, and Islamic values specifically. Moreover, Bazna and Reid (2009) fall into the same trap (i.e. cultural sensitivity) when suggesting the importation of other models such as the social model or the models built in social constructionism or postmodernism into Kuwait. The authors suggest that these alternative models are more consistent with Kuwaiti culture than the individual model, but they have not provided evidence to support their argument. In other words, without exploration of these models, the reader is left empty-handed. Therefore, it is my intention in this project to develop a suitable model for understanding disability in Kuwait. In the second section of this chapter, I will explore these models in detail, whereupon I should be able to form a clearer picture of whether these models or any other models are appropriate to analyse disability in Kuwait.

Other evidence of the presence of the individual model in Kuwait can be discerned through the nature of the language usage in the field of disability. For example, the word ‘suffering’ is often used by advocates of this model (Iriarte, 2016). This word is repeated constantly in the disability law in Kuwait. For
example, Law No. 8 of 2010 (C1 (1)), concerning the rights of disabled people in Kuwait, defines disabled people as follows:

All those suffering from permanent, total, or partial disorders leading to deficiencies in his/her physical, mental, or sensory abilities that may prevent him/her from securing the requirements of life to work or participate fully and effectively in society on an equal basis with others.

Generally, Kuwait is a wealthy country, adhering to the individual model to determine welfare benefits (Iriarte, 2016). Some disability scholars in the UK, on the other hand, argue that applying medical norms when claiming these benefits would reinforce the issue of ‘normality’ and affect disabled people’s psycho-emotional well-being (Reeve, 2002; Thomas, 2004). Additionally, using people’s differences or impairment category to determine welfare is contradicted by the social model of disability (Oliver, 2013). Thus, a number of disability scholars in the UK would see that:

Much of the latest round of reforms plays down notions of pain and fatigue and relies on performativity criteria that in rewarding the inability to stand assume wheelchair use or severe psycho-social fears (fear of walking). That these reforms are focused on the minutiae of bodily performance suggests that little has been learnt in importing social model ideas into state policies (Roulstone, 2015, p. 685).

In this section, I have provided political statements of the former Director General of PAPDA and his opponents. Through examining these few statements, I sought to understand the Kuwaiti political context. Furthermore, I want to emphasise that, in my research on disability in Kuwait, I found that most of the statements of the former Director General and PAPDA staff members concerned the financial
benefits, such as monthly allocations, home adaptations, money allocated for private drivers, and so on. However, I found a few statements related to the social inclusion and employment of disabled people. For example, Altammar reveals on his website that the government is uncooperative and unjust, failing to employ disabled people, as the proportion of disabled employees in the government is below 4%, which is against the law (Jassem Altammar website). Nevertheless, these statements remain short and sketchy, and it is not clear how PAPDA will address this problem.

2.3.3 Disability Research in Kuwait

As previously stated, there is a lack of academic interest in scientific research in the field of disability in Kuwait. Because one of the aims of this project is to employ participatory research strategies in collaboration with disabled people, I want to explore the current nature of disability research in Kuwait. To date, most of the disability research in Kuwait has been quantitative and medically focused (e.g. Shah, Badr and Shah, 2011; Al-Hashel, Ahmed, Behbehani and Alroughani, 2014; Al-Temaimi, Alroughani, Jacob and Al-Mulla, 2015). Moreover, a number of studies can be classified as cultural/social and educational. These studies were conducted by a disability lecturer in the College of Social Sciences at Kuwait University, Hayfaa Al-Kandari. In her quantitative research, Al-Kandari aims to provide a cultural/social analysis of a particular phenomenon as having an effect at the political level (see Salih and Al-Kandari, 2007; Al-Kandari and Salih, 2008; Al-Kandari and Al-Qashan, 2010; Al-Kandari, 2014). For instance, Al-Kandari
(2014) explored the differences in the perceptions of professionals and families of learning disabled children in relation to services that are needed for the families of learning disabled pupils in special education schools. The findings of her study would be useful in helping social service providers and professionals in Kuwait to identify and apply laws that meet the needs of the families of learning disabled children and give them chance to be part of their children’s educational decisions.

In addition, Al-Kandari’s (2006) research touches on psychological factors such as stress and depression that may affect the families of disabled children and assesses the attitudes of non-disabled people towards disabled people. As an example of the latter, Salih and Al-Kandari (2007) find that prospective teachers who completed a course about social work with disabled people showed negative attitudes towards learning disabled students. Furthermore, Al-Kandari and Salih (2008) believe that disability is culturally/socially stigmatised among non-disabled people, arguing that disabled people, specifically those who are learning disabled, are unable to participate effectively in society. This orthodoxy causes families to exclude their disabled children and hide them from sight.

These studies are valuable on the social and cultural level, as they allow one to identify the perspectives of disabled people’s families and the attitudes of some non-disabled people towards disabled people. However, as Al-Kandari (14 July 2014) confirmed, when I met her, these studies have changed nothing in the state’s policies in relation to disability. I believe that these shortfalls can be attributed to both sides of the debate (i.e. academics and politicians). First, they
can be attributed to a lack of coordination between the academics and politicians in partnership research between the universities and the government. Second, Al-Kandari’s studies have provided general recommendations about what needs to be done, but they lack clarity on how these suggestions can be implemented to improve the lives of disabled people in Kuwait. For example, if there is a stigma, and shameful and negative attitudes are held by non-disabled people towards disabled people, how can they be challenged? In other words, what plans and strategies should the state adopt to raise awareness among non-disabled people?

Third, among all these studies, the presence of disabled people is glaringly absent. All participants in Al-Kandari’s studies are non-disabled people, raising the question, what is the role of disabled people? What are their views about these disability issues? Why are their views absent in Kuwaiti disability studies? As I will show in Chapter 4, alienating and disempowering disabled people in disability research is an issue that has led academic researchers such as Finkelstein (1985), Zarb (1992), and Oliver (1992) to call for the adoption of research strategies that are both emancipatory and empowering. The principles of these strategies emphasise conducting research with disabled people rather than on disabled people (Swain and French, 2004). However, in contrast, through the exploration of the Kuwaiti disability research, it seems that disabled people are not even research subjects, let alone participants or co-researchers.

In addition, other criticisms can be directed at Salih and Al-Kandari’s studies regarding the nature of the language used in their papers. For example, they used the term ‘mental retardation’ to refer to learning disabled individuals (see Salih
and Al-Kandari, 2007; Al-Kandari and Salih, 2008). In relation to this, I want to argue that the use of such terms reinforces negative ways of thinking about learning disabled people and causes them to be less valued (Shakespeare, 2014).

In addition to these shortfalls, academic researchers in Kuwait have been negligent in conducting qualitative research, which can provide deeper analysis and give disabled people a chance to share their experiences at different levels, including medical/psychological, political/economic, cultural/social, and environmental (Hartley and Muhit, 2003).

2.3.4 Summary

In the first section, I have addressed Kuwaiti culture and explored the role that religion plays in the formation of people’s perceptions of disability, and how these perceptions are reflected in people’s language and behaviours. In the second section, I have provided an analysis of the Kuwaiti economy and policies regarding disabled people and disability. I have shown the role that PAPDA plays in relation to ensuring the rights and the services of disabled people. I ended the section with a panoramic exploration of the Kuwaiti situation in relation to the production of disability research. However, in order to be able to develop a model for understanding and analysing disability in Kuwait, it is crucial to explore disability studies in other parts of the world (i.e. the Global North) and take advantage of the long history of the Western society in the field. This exploration will be the core of the next section.
Section B: Disability Studies Perspectives

2.4 Introduction

There are many differing disability perspectives or disability models worldwide (Goodley, 2011; Iriarte, 2016). However, in this section, I intend to explore the most dominant disability studies perspectives in Western societies. There are three main disability perspectives. The first perspective is an individual model of disability or an essentialist approach, associated with the medical factors or the biological characteristics of individuals (Bhaskar and Danermark, 2006). The other two main perspectives explain the emergence of socio-political theories of disability in Britain. The first is engrained in the materialist analysis of history associated with Marxism (Barnes, 1997; Corker, 1999) and is referred to as the social model of disability. The second perspective owes much to the work undertaken by cultural disability studies and critical disability studies through the examination of cultural representations, language, and the attitudes of non-disabled people towards disabled people (Shakespeare, 1994, 2014; Meekosha and Shuttleworth, 2009; Goodley, 2011; Watson, 2012) and is referred to as the cultural perspective on disability. This postmodernist/poststructuralist stance is inspired by the work of feminists through the analysis of media representation, the arts, and cultural and historical texts (Shakespeare, 1994; Snyder and Mitchell, 2001; Gerland-Thomson, 2002, Goodley, 2011).

Although the two perspectives (i.e. the social model and the cultural perspective) offer different explanations for the emergence of disability studies, both place the
notion of ‘normality’ at the centre of the work. For example, in the case of the social model, the inability that disabled people faced in meeting the ‘norms’ during industrialisation excluded them from capitalist society (Oliver, 1990b). This materialist approach focuses on researching the material social forces and physical barriers that disabled people face, rather than ideas, cultures, and discourses (as in the case of the cultural perspective) (Shakespeare, 2014).

Another perspective, critical realism, emerged in the UK disability studies as a result of the work of such theorists such as Tom Shakespeare and Nick Watson (Shakespeare and Watson, 2010; Watson, 2012; Shakespeare, 2014). This perspective is, it is claimed, often adopted by researchers in Nordic countries (Barnes, 2012). The advocates of this perspective claim that critical realism provides room for more complexity in the lives of disabled people than simply reducing the analysis of disability at the biological and psychological levels (individual model) or the socio-material level (social model) or socio-cultural essentials (Bhaskar and Danermark, 2006; Shakespeare, 2014).

In this chapter, I explore each perspective separately, starting with the individual model, followed by the social model, and ending with the cultural perspective (the work of cultural theorists and Michel Foucault’s works). In Chapter 3, I will explore the critical realism perspectives and specifically the work of critical realists in the UK and Nordic countries. After this exploration process, I develop my own conceptualisation (Chapter 3) and propose a model for understanding disability in the Kuwaiti context (Chapter 8).
2.5 The Individual Model of Disability

I have shown in the first section of this chapter how people, as a result of the influence of religions and cultures, perceive disabled people as God’s creation resulting from sins, plague, or punishments. This was an opportunity for religious people, conversely, to show the miracles of the ‘incarnated divine’ for healing disabled people (see my earlier discussion on disability and religion). The belief in Jesus’s miracles of healing disabled people (more specifically blind people) was widespread, especially during the European Middle Ages, allowing the church to hold cultural control over disability and medicine (Wheatley, 2010).

However, the church control over medicine diminished at the end of the 18th century, with the beginning of modern biomedicine (Barnes, 1997). The rise of modern biomedicine paved “the way for the distinction between the normal and the pathological” (Hughes, 2005, p.82). As a result of this modernist distinction, the individual model of disability emerged. Thus, the emergence of the individual model can be understood as a natural consequence of the European modernity project:

The individual and medical models of disability, which perceive and classify disability in terms of a meta-narrative of deviance, lack and tragedy, and assume it to be logically separate from and inferior to ‘normalcy’, are characteristics of the kinds of epistemologies or knowledge systems generated by modernism (Corker and Shakespeare, 2002, p.2).

I have shown in the first section of this chapter (Section A) how the individual model, according to Oliver (1997), in addition to perceiving disability in a ‘triadic
way’ also has psychological and medical elements. “In this way individual models can be either materialist or idealist in emphasis; they may be concerned with either the physical or the psychological concomitants of impairment” (Priestley, 1998, p.75). In other words, the former (individual materialist models) concerns analyse disability at the biological/medical level, while the latter (individual idealist models) are interested in analysing disability at the psychological level.

The biomedical view of disability has remained dominant up to the present day through the widespread use of medical definitions of disability worldwide, as seen in both the UK and American Disability Discrimination Acts (Reeve, 2002; Seale, 2006). The individual model currently dominates globally, as seen in governments concentrating resources on medical care and support services that are often accessed as a result of ‘impairment labels’ (as I explored in my earlier discussion relating to Kuwaiti society), and through the use of the model in determining welfare benefits (Oliver, 2013; Iriarte, 2016).

In conclusion, the individual model identifies disabled people by their impairments and views the difficulties they face in their lives as a result of a dysfunctional body (Hughes and Paterson, 1997). It has been argued that this limited conception of disability makes the negative attitudes around disability remain unchallenged. From this point, the prevalent individual view of disability started to be challenged in the 1960s by the disability movement, followed by the emergence of the social model of disability (Bhaskar and Danermark, 2006; Goodley, 2011).
2.6 The Emergence of the Social Model of Disability

The roots of the social model of disability date back to the discussion at the meeting of ‘Fundamental Principles of Disability’, held by the Union of the Physically Impaired Against Segregation (UPIAS) and the Disability Alliance on 22 November, 1975. The main definition of the British social model was published in a 1976 UPIAS document, *Fundamental Principles of Disability* (Shakespeare and Watson, 2002; Watson, 2004). For the first time, this document made an explicit distinction between disability and impairment (Blyth, 2009), stating:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called ‘disability’, of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression (UPIAS, 1976, pp.3–4).

In this document, UPIAS produced a socio-political definition of disability that made a vital distinction between disability, which is created and constructed by and in society, and impairments that are strictly related to the body (Barnes, 2012). Furthermore, UPIAS (1976) redefined disability as a form of social oppression resulting in disabled people’s lack of participation in society.
This distinction between disability and impairment led to the formulation of the social model of disability (Oliver, 1990a). Oliver coined the term ‘social model of disability’ in his contribution to a collection of five papers entitled The Handicapped Person: A New Perspective for Social Workers in 1981.

Social modellists such as Vic Finkelstein, Mike Oliver, and Colin Barnes discussed the oppression faced by disabled people, and tried to find a way to theorise disability in the UK (Finkelstein, 1980; Oliver, 1990b; Barnes, 1991). They contend that the lack of participation and oppression that disabled people started to face occurred due to the rapid development of industrialisation associated with the capitalist society (Oliver, 1990b). Disabled people have not met the required physical ability to keep pace with the evolution of the manufacturing era that began by the end of the nineteenth century.

This realisation leads social model theorists to take Marxism as a ‘roadmap’ through deconstructing social class associated with capitalism, hoping that disabled people find their way towards social equality and emancipation (Oliver, 1990b; Corker and Shakespeare, 2002). The early disability movement took a similar or parallel road to other social movements such as feminist, queer, and race movements (Shakespeare, 1993; Goodley, 2011). This can be seen through the similar distinction made by disability theorists between disability and impairment and the feminist distinction between gender and sex (Corker and Shakespeare, 2002).

The early works of these disability scholars provide a socio-economic analysis
based on Marxism that illustrates the link between industrialisation capitalism and
the pathologising of disability (Finkelstein, 1980; Oliver, 1990b; Barnes, 1991).
The economic development during industrialisation resulted in the establishment
of institutions of care or treatment that turned the gaze on the body and led the
creation of the individual model of disability (Barnes, 1997). This “locates the
‘problem’ of disability within the individual and … sees the causes of this
problem as stemming from the functional limitations or psychological losses
which are assumed to arise from disability” (Oliver, 1990a, p.3).

Oliver (1990a) harshly criticises the power that the medical profession has over
the lives of disabled people, revealing that doctors are practising their knowledge
as experts by providing disabled people with medical care and rehabilitation based
on the prevalent medical discourse that it is their responsibility to ensure that,
where possible, all disabled people should be restored to ‘normality’. He goes on
to state that such medical interventions and the ‘ideology of normality’, whatever
their costs in terms of the suffering and pain of disabled people, are always
justified by doctors.

He also stresses that society is responsible for accepting disabled people as they
are, not as society thinks they should be, emphasising that, rather than ‘fixing’ the
body, we should be ‘fixing’ the disabling society. In essence, Oliver (1990a) calls
for, what I referred to earlier as, the ‘gaze on the body’ to be shifted to a ‘gaze on
society’. However, at the same time, Oliver is not suggesting that power is taken
away from doctors completely; instead, he is signifying that disabled people and
doctors must share power so that they can gain a better understanding of the issues associated with disability. Social model theorists do not deny the impairments, illnesses, and medical interventions that disabled people may experience, but they place the focus of their analysis on society, not on the body (Barnes, 2012). Thus, those theorists would argue that they are far from negligent the body, but the core of the social model is on society not on the body per se, and thereby it is a very deliberate omission.

Generally, it can be concluded from the above that the social model confirms important principles by challenging prevalent understandings of disability: it distinguishes between people’s impairments and the oppression they experience, and “it defines ‘disability’ as [a form of] … social oppression” (Shakespeare and Watson, 2002, p.10). Furthermore, according to Shakespeare and Watson (2002) and Shakespeare (2014), the social model was vital to the disability movement for two main reasons: first, it identified a political strategy to reinforce inclusion through removing social barriers; and second, it had an impact on disabled people themselves by replacing the medical view (which situated the problem in the body) with a social model view (which situated the problem in society). This significant ontological shift suggests that disabled people should not feel ‘despair’ or ‘loss’ regarding their physical or cognitive limitations, but instead, they should feel anger and a desire to challenge society, as it is society that is at fault, not them (Shakespeare and Watson, 2002; Shakespeare, 2014). Thus, in short, the “social model scholars turned attention away from a preoccupation with people’s impairments to a focus on the causes of exclusion through social, economic,
However, the focus on these causes is not equally distributed. The vast majority of the work of the most ardent social modellists such as Finkelstein, Oliver, and Barnes is focused on the socio-political and socio-economic structure of society rather than cultural, relational, and psychological factors (Finkelstein, 1980; 2007; Oliver, 1990b; 2013; Barnes, 1991; Oliver and Barnes, 2006). Also, the crude distinction between disability and impairment places the work rooted in social model in a dilemma resulting in negligence (although it is deliberate) of the biological in their analysis. Thus, it is argued, “the social model of disability creates a conceptual barrier to the development of a sociology of impairment and creates a disembodied notion of disability” (Hughes and Paterson, 1997, p.330). As a result, a number of disability scholars, such as feminists, postmodernists, and critical realists, have demanded that the body should be brought ‘back in’ to disability analysis (Williams, 1999, p.805). In the next part of this chapter and in Chapter three, I will explain why I believe the body needs to be included in disability analysis. I will start my argument with the early criticisms that came from disabled feminists to the social model.

2.6.1 The Limitations of the Social Model of Disability

The early criticisms of the social model came from disabled feminists who “cogently argued for the need to bring ‘impairment back in’ to the disability debate” (Williams, 1999, p.804). The main criticisms of the social model directed by those feminists is that it fails to accommodate the personal experiences
associated with impairment. Morris (1991), for example, reflects on her own experience of encountering social barriers but goes on to call for the personal experiences to be incorporated:

While environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying (Morris, 1991, p.10).

In addition, French (1993) confirms the role of impairment in restricting social activity, recounting her experience as a visually impaired woman, stating how her impairment always impacts of her daily activities. Reflecting on this, she explains how simply providing accessible information and social adaptation cannot remove all disabling barriers. Furthermore, Crow (1996) criticises the social model for its failure to include disabled people’s experiences associated with their impairments:

As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives. We must find a way to integrate them into our whole experience and identity for the sake of our physical and emotional well-being, and, subsequently, for our capacity to work against Disability (Crow, 1996, p.7).

Thomas goes further, proposing what she terms a ‘social relational understanding of disability’ (Thomas, 2004a, p.22). Thomas (1999) describes disability as a form of social oppression that results in activity restrictions on disabled people and thus affects their psycho-emotional well-being. Thomas (2004a, p.31) posits that the oppression disabled people experience operates on two levels: the micro-level ‘inside’ and the macro-level ‘outside’:
It is about being made to feel of lesser value, worthless, unattractive, or disgusting as well as it is about ‘outside’ matters such as being turned down for a job because one is ‘disabled’, or not being offered the chance of a mainstream education because of ‘special needs’ (Thomas, 2004a, p.31).

Thomas (1999, p.43; 2004a, p.32) confirms the role of impairment in restricting disabled people’s activity in society, using the term ‘impairment effects’. However, it is important to add here that Thomas (2004a) is not suggesting that the social model should be abandoned; rather, she intends to provide an accompanying analytical framework through recognising the power relations between disabled and non-disabled individuals and their effects on the psycho-emotional factors of disabled people. Notably, Thomas’s approach can provide practical insight into the lives of disabled people, and it can be useful in identifying imagery, cultural representations, and the attitudes of non-disabled people. However, I will show later in this section how such an approach, on its own, also has limited usefulness when accounting for the complexities of disabled people’s lives.

However, unlike those who call for reforming the social model (e.g. Morris, 1991; French, 1993; Crow, 1996, Thomas, 2004a), Shakespeare and Watson (2002, p.10) believe that the social model of disability, which they call ‘the strong social model’, is an ‘out-dated ideology’ that should be discarded altogether. Their criticisms of the social model centre on the disability–impairment dichotomy and, as they see it, the failure of the social model to incorporate the experiences of many disabled people.
Shakespeare and Watson (2002) argue that impairment and disability are inseparable because impairment plays a role in causing disability in the lives of disabled people:

Impairment and disability are not dichotomous, but describe different places on a continuum, or different aspects of a single experience. It is difficult to determine where impairment ends and disability starts, but such vagueness need not be debilitating. Disability is a complex dialectic of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision (Shakespeare and Watson, 2002, p.24).

Moreover, Shakespeare (2014) addresses the argument of social modellists related to the accessible design of buildings/environments that can accommodate all disabled people. He points to the impossibility of a ‘Universal Design’, providing a number of examples to show how difficult it is to make all environments accessible for disabled people:

People with impairments will always be disadvantaged by their bodies: they will not be able to climb every mountain or visit every beach … In urban areas, it is possible to make both private homes and public buildings accessible. Yet if a wheelchair user lives on top of a hill, then they will face major barriers to getting around their local environment … Some cities, for example, San Francisco and Bristol, are innately less accessible than others, for example, Berlin or Cambridge. Equally, wheelchair users in Nordic countries are regularly disabled by snowfall, whereas their counterparts in southerly latitudes can negotiate the streets throughout the winter mounts (Shakespeare, 2014, pp.36–37).

However, while he stresses that building-accessible environments can reduce the difficulty associated with impairment, they cannot equalise disabled and non-disabled people (Shakespeare, 2014). Indeed, it is difficult to create one accessible environment to accommodate the needs of all disabled people. This is because

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there is a wide range of impairments, so designing an environment accessible for everyone is a utopian dream. It would be impossible to create a system that is user-friendly for everyone (Savidis and Stephanidis, 2004); rather, it is necessary to consider an individual’s specific needs (Kelly, Phipps and Swift, 2004). Therefore, each accessible environment should be a separate case, taking into consideration the specific needs of disabled people. As Shakespeare (2006, p.46) puts it:

Implicit in the notion of a barrier-free world is the idea that Universal Design can liberate all. Yet, while in each case a solution to an access barrier can often be found, taken as a totality it may be impossible to create one environment which is accessible for all potential users.

Blyth (2009, p.50) explores how attempts to meet the access needs of people with one specific impairment can lead to the exclusion of others:

In an attempt to make a building accessible to a person with a visual impairment, it would be possible to ensure that bright lighting was utilised. However, whilst for many people with visual impairments bright lighting is important, for others it can prove extremely disabling.

The idea of ‘Universal Design’ takes the social model from materialism to idealism. By considering this notion, the social model falls into the same trap as the belief that lies at its foundation, Marxism. When talking about communism, the Marxists describe a utopian society that is free of power and where equality between all people is achieved. However, this utopian society witnesses the presence of opposites (e.g. the dialectic between life and death), and the Marxists interestingly moved away from materialism and entered ‘the door of idealism’. With the presence of the death phenomenon, how one can make sure that his/her
ideas remain after his/her death? Is it not necessary that utopia must be accompanied by the disappearance of all opposites, including the life/death dialectic?

The Limitations of the Social Relational Understanding of Disability

Despite the advantages of Thomas’s (1999, 2004a) social relational approach discussed above in offering an understanding of disabled people’s lives, Shakespeare and Watson criticise it for its failure to address the needs of all disabled people. First, in common with the work rooted in the social model and in line with gender/sexism studies, it assumes that disabled people are necessarily an oppressed group (Shakespeare and Watson, 2010; Watson, 2012). In other words, Thomas clearly defines disability as “a form of social oppression” (Thomas, 1999, p.60). Thus, in this regard, the question becomes “not whether disabled people are oppressed in a particular situation, but only the extent to which they are oppressed” (Shakespeare and Watson, 2010, p.61). This will eventually ‘write out’ both positive experiences faced by disabled people in their daily activity as well as their very personal experiences associated with impairment per se (Shakespeare and Watson, 2010; Shakespeare, 2014). Additionally, although there are commonalities between gender, race, sexuality, and disability studies, the experiences that disabled people face are more complex than sexism and racism, because, unlike gender and sexuality, both disability and impairment lead to effects that remain even when all oppression is removed (Shakespeare, 2014).

Second, the impairment effect and disabling barriers are interwoven, so it is
difficult to recognise what is an impairment effect and what is disablism (Watson, 2012; Shakespeare, 2014). Watson (2012) continues his criticism of Thomas’s approach and states that there is a risk in adopting it because it assumes that the ‘problem’ of disability is a dual-source phenomenon rather than a complex, intertwined system:

There is a danger in Thomas’ work that impairment and disablement may become envisaged as dual systems rather than a complex interwoven matrix. Discussions on disablism may become a debate about boundaries and about whether a particular experience arises as the result of impairment effects or of social processes (Watson, 2012, p.197).

As stated, my aim in this chapter is to explore the various dominant conceptualisations of disability and then, drawing upon these, develop my own conceptualisation that is appropriate when seeking to critically consider and analyse disability issues in a Kuwaiti context. Thus, what I have provided so far is a historical glimpse into the emergence of the individual and social model. I then addressed the limitations of the social model as well as the social relational model. I will now discuss another dominant perspective of disability within the western context, the cultural perspective of disability.

2.7 The Cultural Perspective of Disability: A Foucauldian Perspective

In this section, I will explore the cultural approaches to disability. However, exploring the cultural approaches is not an easy task as these approaches are complex and, in some ways, fluid. For example, these cultural approaches are
divided into two groups: the typical North American label for a university department is Cultural Disability Studies and the British and European school label is Critical Disability Studies. The former involves the work of authors such as Davis (1995), Snyder and Mitchell (2001), Garland-Thomson (2002; 2010), and Tremain (2005), while the latter school involves the work of Meekosha and Shuttleworth (2009), Goodley (2011), and Shildrick (2012).

Exploring the work of both schools demonstrates how far these ‘new waves’ of thinking have come from the original social model, but also just how complex and diverse the field now is. However, one can realise that the common factor between the works from both schools are Foucault’s ideas. Thus, I find it useful to steer this section into the exploration of how such Foucauldian ideas are being adopted in disability studies.

The cultural perspective, it could be suggested, is closely related to the work undertaken by the Critical Disability Studies theorists. Critical Disability Studies (CDS) offers a deeper analysis of culture and language, suggesting “that the struggle for social justice and diversity continues but on another plane of development – one that is not simply social, economic and political, but also psychological, cultural, discursive and carnal” (Meekosha and Shuttleworth, 2009, p.50). This cultural perspective began to be formulated in the 1990s, and the focus centred on how the ideas, discourse, and ideologies around impairment and disability were constructed in different cultures (Bhaskar and Danemark, 2006; Watson, 2012). Cultural theorists are interested “in exposing the myth of the
‘disabled/abnormal body’ – and its needed opposite ‘the able/normal body’” (Goodley, 2011, p.15). Thus, their interests are focused on studying and deconstruct the binary dichotomies such as ‘impairment/disability’ and the ‘body/society’ (Hughes and Paterson, 1997; Goodley, 2011).

The scholars of the cultural perspective are strongly influenced by poststructuralist and postmodernist authors such as Judith Butler and Michel Foucault (Shakespeare, 2014). For example, the influence of Butler on disability theorists came from her notion of deconstructing the binary oppositions of sex and gender. Butler (1990; 1993) argues that sex is always seen through the lens of gender:

> Gender is culturally constructed: hence gender is neither the casual result of sex nor as seemingly fixed as sex … If the immutable character of sex is contested, perhaps this construct called ‘sex’ is as culturally constructed as gender; indeed, perhaps it was always already gender, with the consequence that the distinction between sex and gender turns out to be no distinction at all (Butler, 1990, pp.6–7).

“Sex, in other words, is no longer a ‘biological given’ upon which gender constructs are artificially imposed. Instead it becomes a ‘cultural norm’ or ‘regulatory ideal’ which governs the materialisation of bodies themselves” (Williams, 1999, p.800). In line with Butler, disability theorists such as Dan Goodley, Mark Rapley, and Shelley Tremain sought to apply the same notion to the impairment/disability binary. For example, Goodley and Rapley (2002, p.133) state that “impairment in the modern, materialist world remains characteristically biological and not an aspect of disabled people’s lives that can or should be changed”. Also, Tremain (2002, p.42) argues that:
impairment has been disability all along. Disciplinary practices in which the subject is inducted and divided from others produce the illusion of impairment as their ‘prediscursive’ antecedent in order to multiply, divide and expand their regulatory effects.

From the quotes above, it seems that these theorists suggest “that the alleged impairment and the possible incompetence related to, for example, Down syndrome can and should be abolished merely by re- and deconstructing the impairment” (Vehmas and Mäkelä, 2008, p.93).

Furthermore, the failure of the social model to incorporate the corporeal into understanding disabled people's experiences (Bhaskar and Danermark, 2006), which resulted in producing an incomplete picture of the lives of disabled people, not only inspired feminists (as shown earlier in this chapter) but also encouraged the cultural scholars to find an alternative analytical framework that provides deeper analysis into the lives of disabled people. From this point, Foucault’s work became a crucial tool for inquiries into disability (Hughes, 2005).

Foucault’s work has inspired scholars across different disciplines, such as history, philosophy, medicine, and psychology, “to question what had previously been considered self-evident, timeless, unchanging, and necessary” (Tremain, 2005, p.1). Foucault’s ways of thinking rely on studying the historical events of a particular phenomenon in the present (e.g. madness, criminality, and sexuality). In his book *Madness and Civilization* (1967), Foucault describes how the idea of madness was constructed in European culture. To understand this notion, he tracked the concept of madness in European history from the Classical Age (17th
and 18th centuries) to modern times. During these centuries, ‘mad’ people were isolated from wider society and chained in prison. By the end of the 18th century, the notion of madness started to be recognised as mental illness. For Foucault, both the Classical and the modern understanding of madness are socially constructed and have nothing to do with the ‘truth’ of madness (Gutting, 1994). Generally, Foucault sees the notions of ‘madness’, ‘criminality’, and ‘sexuality’ all hovering around the discourse of ‘normality and abnormality’, which was formulated by a minority group in power at the time. This means that contemporary institutions, such as hospitals, asylums, and prisons, would not have been inevitable if the past had been ordered differently (Gutting, 1994). For Foucault, these practices are forms of disciplinary powers that are closely interconnected with knowledge (Foucault, 2000).

The interconnection between power and knowledge started to manifest clearly after the French revolution by the end of 18th century when medicine, psychiatry, and a penal system have been developed (Fillingham, 1993). For Foucault (1967; 1994), these fields provided examples of disciplinary and regulatory powers that led to the formation of new norms/standards. Professionals at institutions such as prisons, hospitals, and rehabilitation centres practiced these norms through surveillance and gaze (Foucault, 1977).

In the field of medicine, for example, the end of 18th century represents a transitional phase of medicine from the control of the church to the control of doctors and clinics (Foucault, 1994). In this period, doctors started to practice
their knowledge and control over the docile bodies through the medical gaze. For Foucault, this medical gaze was not conducted solely on the visible organs of human body but also reached the human insides. Thus, in this period:

... scientific objectivity met the naked individual. The doctor could look at a person’s outsides and see the insides, and his power came from his way of seeing rather than from his abstract theories (Fillingham, 1993, pp.74–75).

The paradigm shift in thinking that occurred in this era represented what Foucault (2000, p.327) called the ‘objectivizing of the subject’. This was the era in which biomedicine started to take control over individuals followed by the emergence of the individual model (see my earlier discussion on the individual model). Taking control over the body can be referred to as what Foucault (1988, p.18) called ‘technologies of power’. “Technologies of power ... determine the conduct of individuals and submit them to certain ends or domination, an objectivizing of the subject” (Foucault, 1988, p.18). “Through this technology of power, the object of the gaze becomes known to the viewer, and the observer gains expertise and control over those being gazed at” (Reeve, 2002, p.498). However, Foucault (1988) does not solely show a one-sided power through the domination of society over docile bodies but also a resistance to that power from the other side (the body). He is content that the power relation cannot be operatised and maintained without resistance. Thus, in order to show how these two-sided power relations work, Foucault employs the concept of ‘technologies of the self’:

Technologies of the self ... permit individuals to effect by their own means, or with the help of others, a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as
to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection or immortality (Foucault, 1988, p.18).

However, these technologies of the self and resistance are not without social and cultural restrictions (Reeve, 2002). This was one of the main issues that exposed Foucault’s works to criticism, as he did not show clearly how the resistance path could be achieved (Williams and Bendelow, 1998). I will expand on the criticism of Foucault’s works in the next section.

In the field of disability, Foucault’s ideas are relatively underutilised (Hughes and Paterson, 1997). However, Foucault and the Government of Disability provides a deep analysis of Foucault’s work in relation to disability issues, specifically “rehabilitation, community care, impairment, normality and abnormality, inclusion, prevention, genetic counselling, accommodation, and special education” (Tremain, 2005, p.3).

I would argue that adopting the Foucauldian ideas into the field of disability has enabled cultural analysts to “explore how today’s treatment of disabled people reflects the phantoms of the past, including eugenics, institutionalisation and science” (Goodley, 2011, p.15). Therefore, as Foucault would argue, to gain a better understanding of the lives of disabled people today, it is vital to explore their history. This can be achieved through exploring the construction of discourse around disability and the exploration of institutional/disciplinary power throughout history.

When the differentiation between ‘the normal’ and ‘the abnormal’ occurred
through the medical gaze as explained above, this act of disciplinary power created new medical norms. These new norms enabled medical professionals to control disability and link it to impairment (Chadwick, 1996). These medical standards exposed disabled people’s bodies to both the social gaze from non-disabled people and medical gaze from professionals (Reeve, 2002). As an example of the social gaze, Garland-Thomson (2010) mentions the story of disability rights lawyer, activist, and storyteller Harriet McBryde Johnson, who taught people how to look at her disabled body by showing it on the cover of the New York Times Magazine. Garland-Thomson (2010) states that Johnson has a rare beauty that is difficult to recognise without her instructions on how to look at her. Johnson starts by describing her body to the audience, and then talks about what happened to her, showing satisfaction with her condition:

Two or three times in my life … I have been looked at as a rare kind of beauty … some people call me Good Luck Lady (Garland-Thomson, 2010, p.202).

Although Johnson has shown a positive response towards those who stare at her, she reveals that what people usually recognise when they look at her “is unbearable pain, insurmountable adversity, a diminished life, and a fervent desire for a cured body” (Garland-Thomson, 2010, p.202). This provides an example of how people in society perceived, under the influence of the prevalent medical discourse, Johnson’s body in a ‘triadic way’. Another example can be taken from Jenny Morris. In her book Pride against Prejudice: Transforming Attitudes to Disability: A Personal Politics of Disability, Morris (1991) recounts her reflection
as a disabled writer on non-disabled people who interact with her in everyday life:

We often experience the fascination that non-disabled people have with ‘just how do you manage?’ They have a consuming curiosity about how we pee, how we shit, how we have sex (do we have sex?) (Morris, 1991, p.29).

This quote shows how the medical discourse that created differences between people based on ‘normality’ led people’s curiosity to interfere with the personal issues of disabled people. These are two examples of how the medical discourses and the constructed norms that are based on ‘ableist’ ideas can have influence on people’s perceptions and their attitudes towards disabled people.

In relation to the medical gaze, Reeve (2002) sought to employ Foucauldian concepts such as gaze and surveillance to see how these two concepts negatively affect disabled people. The concept of surveillance came from ‘the Panopticon’, a prison in which the prisoners were isolated in a small room and subjected to observation at all times by a person in the centre tower (Fillingham, 1993). This kind of surveillance does not solely occur in prisons, but also in schools, hospitals, and institutions through disciplinary power (Foucault, 1977). This permanent observation by others (surveillance or gaze) leads prisoners, pupils, patients, etc. to conceptualise an idea about their own bodies through self-surveillance, thereby trying to make themselves acceptable according to the ‘prevailing norms’ (Reeve, 2002). Reeve expands on this debate and points out that both the medical power of the gaze and self-surveillance can affect disabled people’s psycho-emotional dimensions, such as feeling worthless and rejected. Reeve (2002) argues that this
medical gaze is a form of institutional abuse that leaves disabled people vulnerable. She also mentions that the self-surveillance of the bodies of disabled people can bring to the fore the issue of ‘normality’ and ‘abnormality’ through the frequent examination of their own bodies. This kind of self-surveillance often happens when disabled people claim benefits such as Disability Living Allowance (DLA). Machin and Mayr (2012) also furnish another example of medical power when doctors provide people with the care that they need.

The exploration of the cultural perspective of disability shows that it has many advantages. These include its usefulness in providing insights into and understanding of the construction of discourse around norms and disability throughout different cultures and religions as shown in Section A, shedding light on the power relations between disabled and non-disabled people, as well as exploring the attitudes of non-disabled people towards disabled people. However, these cultural approaches are not without criticism.

2.7.1 The Limitations of the Cultural Perspectives of Disability

As stated earlier, the cultural approaches to disability are influenced by postmodernism and poststructuralism. As poststructuralism and postmodernism are considered forms of social constructionism (Shakespeare, 2014), they have been exposed to similar criticisms related to discursive reductionism and relativism. Critical realists such as Roy Bhaskar and Berth Danermark differentiate between two forms of social constructionism: strong and weak (Danermark, 2002; Bhaskar and Danermark, 2006). They reject the first form that
sees a “social phenomenon such as some specific form of disability exists only as an idea or belief” (Bhaskar and Danermark, 2006, pp.283–284). However, they accept the weak form of social constructionism, “which involves the idea that there is a necessarily interpreted element in the construction of any theoretical understanding and any social object” (Bhaskar and Danermark, 2006, p.283). Moreover, social constructionists are criticised as they problematise the idea of truth and reliability. They claim, for example, “that there is no reality independent of us and/or that we cannot gain any reliable knowledge about it” (Danermark, 2002, p.58). This issue brings the notion of relativism to the fore, which has led constructionists to fall into the trap of conflating the ontological existence of the object with the idea of the object (Williams, 1999; Sayer, 2000; Bhaskar and Danermark, 2006; Shakespeare, 2014). In other words, in the field of disability, it is argued that social constructionists failed to recognise that diagnosis is not the same as impairment (Shakespeare, 2014). The critics of postmodernism and other forms of constructionism generally emphasise the idea that “names and concepts are important, but not as important as the things (including people and practices) to which they refer” (Sayer, 2000, p.71).

By reducing everything to discourse, the cultural approaches to disability arguably deny the real lives of disabled people, and thus the possibility of resistance is evaporated (Watson, 2012; Shakespeare, 2014). The cultural perspective is preoccupied with how people speak or the way in which they speak rather than what they speak about (Bhaskar and Danermark, 2006).
For example, rather than research poverty, research ways of talking about poverty. Rather than research the lives of disabled people, research how ‘disability’ has been constructed at different times and in different places (Shakespeare, 2014, p.55).

Furthermore, cultural approaches and postmodernists have arguably done little to offer practical and political suggestions for how such discourses could be challenged (Barnes, 2012; Shakespeare, 2014). Therefore, it is difficult to recognise how these approaches can help disabled people around the world face their issues in relation to justice, equality, and inclusion (Watson, 2012).

Other criticism of the cultural approaches to disability is directed to the works of Foucault. Although Foucault employed technologies of the self to reduce the severity of the domination of society over the body, he has been criticised for adopting a passive and negative view of the body dominated by society and a vague view of resistance (Hughes and Paterson, 1997; Williams and Bendelow, 1998; Hughes, 2005; Sayer, 2011). These criticisms have led scholars to stress the adoption of a form of phenomenological or ‘lived’ experience of the body, emanating from the body per se, stressing that the body can both form and be formed by the world around it (Williams and Bendelow, 1998; Hughes, 2005). Also, Foucault’s work has been criticised by Hughes (2005) for its limitation on theorising disability. Hughes believes that Foucault’s work has usefulness in showing that impairment is a social construct, but he believes that this argument can be made without the help of Foucault. He concludes “that disabled people would benefit equally, if not more, from arguments that valorize their voices, their embodied experiences, and their collective efforts to establish rights and
overcome discrimination” (Hughes, 2005, p.79).

2.8 Which Disability Model/Perspective is Appropriate for Kuwait?

In this section, I want to go back to the inquiries I raised in the beginning of the chapter (Section A) regarding the analytical framework that might be useful in shedding light on disability issues in Kuwait: are these predominant models in the Global North relevant to a country such as Kuwait? Is it possible to modify these to suit the situation of Kuwait?

In the following, I will address these questions, discussing whether the social model and the cultural approaches to disability are appropriate for adoption in the Kuwaiti context.

2.8.1 The Appropriateness of the Social Model in the Kuwaiti Context

It is crucial to ask the question here as to whether the social model provides an appropriate analytical framework for understanding disability in Kuwait. In addition to the general criticisms addressed earlier, I believe that there are additional limitations with the model that makes it difficult to adopt in the Kuwaiti context. I want to start my argument by recalling Finkelstein’s (2007) reflection on disability models:

In 1996 I wrote a paper on different disability models … I wanted to show that social models only really make sense when understood in
particular contexts. Change the context and the model may well become inappropriate. I tried to illustrate a whole range of models – all associated with ‘disability’ but all very different.

For example this is what I mean: a model house for a child living in a very hot climate would be very different if it were modelled for a child living in a very cold climate. The former might depict a light post and canvas construction and the latter a more robust solid brick construction. They look very different but both could be labelled as ‘model houses’. The models enable different insights in the different versions (Finkelstein, 2007, p.2).

In this paper, Finkelstein clearly states that the social model failed to respond to the local and global social changes in the 1990s. He emphasises that the changes in the social context should be followed by changes in the model itself, as the social model should involve dynamic processes that allow it to interact with the changes in the social context.

From Finkelstein’s point, since the social model had a lack of response to the global and local social changes within one social context (British society), this makes it difficult to adopt as a whole in a very different context. I want to argue that the social model as a whole is not appropriate to adopt in the Kuwaiti context. The model is UK based, so importing it to the Kuwaiti context without scrutiny is problematic. Kuwait and the UK are very different in terms of culture, political systems, economics, and demographics. Some of the embedded Western values that call for giving people greater freedom may be in opposition to Islamic culture.

For example, I have shown in the first section of this chapter how Kuwait has shown reservations to some of the Articles in the UN Convention on the Rights of Persons with Disabilities (CRPD) related to liberty of movement and individual
rights to live with a partner outside legitimate marriage. While these practices are acceptable in a Western society such as Britain, they contradict with both the political system of the state of Kuwait and its culture that is based on the Islamic religion.

On the other hand, it can be noticed from the exploration of the social model that some of the model’s principles already exist in Kuwait. For example, I have shown in the first section of this chapter how Kuwait is considered, largely, a socialist society, providing free services such as health and education for its citizens and assuming responsibility to improve the income resources for all citizens. This issue served as a foundation that inspired the social model in the first place (Corker and Shakespeare, 2002), enabled by the small size of the country and population in the presence of oil resources.

However, the other principles of the social model that emphasise empowering and emancipating disabled people and the issues that focus on building accessible environments are still not met in Kuwait. Thus, I believe it is useful to take the advantage of the social model and adopt some of the principles that help disabled people in Kuwait to resist and challenge the current situation that alienates and disempower them, in the hope of bringing social change and emancipation for disabled people. However, I am mindful of the criticisms directed at the model such as the negligence to incorporate the experiences associated with impairments as well as the recognition of the impossibility to design an environment that accommodates all disabled people. Similarly, I contend that the ‘social relational
understanding of disability’ is also limited in providing in-depth/complex analysis in the lives of disabled people, for the reasons addressed in the chapter. The most important is that impairment, solely, can cause psychological effects; it is not static, and pain associated with impairment can become worse over time. In Chapter 7, I will provide examples from the data generated. Indeed, such a question as to whether the social model or even ‘social relational understanding of disability’ is an appropriate analytical tool for the Kuwaiti context cannot be answered fully here, and will be revisited later in the thesis.

2.8.2 The Appropriateness of the Cultural Approaches to Disability for Kuwait

In Kuwait, cultural approaches are helpful in deconstructing ‘disablist’ discourses associated with cultural/religious beliefs such as the phrase ‘praise and thanks be to God’. I find deconstructing aspects of politics, religion, culture, social life, and Arabic habits to be extremely important for Kuwait. For example, people in Kuwait might be persuaded to stop using the phrase ‘praise and thanks be to God’ when they see disabled people if they know that this phrase is not related directly to their religion, but is an issue that has been inserted into religion and has become usable in daily language. It is clear from the Quran that people are urged to show thanks and praises to God for graces, but why are these thanks and praises uttered when disabled people exist? In other words, why do people see ‘disabled people’s bodies’ as a reminder of their ‘graces’? This ‘disablist’ phrase and other phrases, indeed, have negative effects on disabled people’s lives. They also reinforce the notion of ‘normality’. Thus, by adopting a social constructionist approach, it is
clear to see how this term/belief has become pervasive in Kuwaiti society and how discursively it operates to have negative influences on disabled people’s lives in Kuwait. Deconstructing this phrase that is embedded with negative connotations would be helpful for disabled people in Kuwait to challenge ‘disablist’ and negative discourses. These issues will be explored in detail in Chapter 7, with examples provided from the data.

Nevertheless, in addition to the criticisms provided by critical realists, the work of the cultural perspectives, in particular Critical Disability Studies (CDS), aims to deconstruct; for example, the impairment/disability binary in order to equalise or breakdown the differences between disabled and non-disabled people (Corker 1999; Meekosha and Shuttleworth, 2009; Goodley, 2011; Shildrick, 2012), is, in my view, unhelpful for Kuwait. As CDS scholars view the construction of binary dichotomies as an apparatus that reinforces the notion of ‘normality’, this may not be the case in Kuwait. As Kuwait experiences those who perpetrate fraud in the welfare benefit system, it is necessary to recognise the differences of disabled people in order to ensure their rights and provide adequate services for their needs.

According to the state and disabled people in Kuwait, as discussed in the first section of the chapter, there are a number of non-disabled people who use the services and disability allowances intended for disabled people. This problem has led to the question, who are ‘the real’ disabled people who deserve support from the state? As a result of this problem, some disabled people have found themselves deprived of their rights and services as they were confused with those ‘non-deserving claimers’. This has led the former Director General of PAPDA to
call for re-diagnosing and re-examining the documents of all disabled people, thereby granting the rights and services to those who are in genuine need. Based on this situation, these procedures seem necessary to protect the rights of disabled people in Kuwait and ensure that they can access services properly. Thus, the process of claiming disability benefits should not be seen as, according to Reeve (2002), a form of a Foucauldian biopower that can affect disabled people’s psycho-emotional well-being. Instead, I believe that, based on the current situation, recognition of impairment, impairment categories, and the differences between disabled and non-disabled people are all important steps that can ensure the rights and services for disabled people in Kuwait, and I contend along with Vehmas and Watson that:

… without these categories we would not know what it is we have to do, what actions we have to take or what services we have to put in place to include disabled people. Indeed, for many disabled people the disadvantages they are subjected to arise not as the result of domination but through neglect and the denial of services and through society failing to take responsibility for those in need … Recognition of impairment is also crucial regarding legislation and policy that aim to protect disabled people against discrimination (Vehmas and Watson, 2014, p.648).

Generally, disabled people in Kuwait are experiencing problems in receiving their civil rights and the services allocated to them by the state and by non-disabled people who tend to, for example, use the parking and priorities allocated for disabled people. Therefore, according to the status quo, medical diagnosis and welfare assessment are crucial so that disabled people in Kuwait can receive disabled parking badges and welfare benefits (Shakespeare, 2014). However, I am
aware that these processes can be a form of oppressive biopower when, for example, misdiagnosis or unnecessary bureaucratic procedures happen. I believe that these procedures are important to detect those who, according to the state and disabled people, claiming fraudulently; but this does not mean that we should not try to avoid them in future when this problem is resolved. I will re-examine these issues in more detail in Chapter 7 and Chapter 9.

2.9 Summary

In the first section (Section A) of this chapter, I gave a general overview of the Kuwaiti context. I then moved on to discuss disability in Kuwait. In Section B, I talked about disability perspectives in Western societies. By drawing upon the most dominant perspective of disability in the Global North, I am now in a better position to develop my own conceptualisation that is appropriate to provide an understanding of disability in Kuwait. The next chapter will discuss the conceptual framework adopted in this project.
Chapter Three

The Conceptual Framework

3.1 Introduction

In the previous chapter, I discussed the most dominant Western conceptualisations of disability and I have argued that each of these perspectives fails to adequately accommodate the complexities of the lives of disabled people. I also showed the limitations of these perspectives and, to differing degrees, the inappropriateness of adopting such perspectives in the context of Kuwait; however, at the same time, I showed how each perspective has, at least in part, advantages in terms of contributing to a possible framework for the analysis of the lives of disabled people in Kuwait.

This realisation leads to a consideration of other perspectives that can provide a more holistic picture, taking the uses of each perspective of disability into account, and explores disability in a complex way that covers different levels of reality. Thus, in this chapter, I will explore a disability perspective that, following my literature-based research, I believe to be the most suitable approach in the context of Kuwait. This perspective is rooted in critical realism that allows an investigator to explore disability in a complex way according to different levels of reality, including biological, psychological, medical, socio-economic, socio-cultural, and political perspectives (Danermark and Gellerstedt, 2004; Bhaskar and Danermark, 2006; Shakespeare and Watson, 2010; Watson, 2012).
In the first part of this chapter, I will explore critical realism in general, before transitioning to a discussion of its advantages in the field of disability. The chapter will conclude with a discussion of the conceptual framework adopted for this study.

### 3.2 Critical Realism

Critical realism is a philosophy of the sciences and social sciences that is often associated with the British philosopher, Roy Bhaskar (Bhaskar, 2008). The primary reason for its emergence was to provide a critique of the positivist approach that had been dominant since the 1930s (Danermark, Ekström, Jakobsen and Karlsson, 2002). It criticises positivism or, more specifically, classical empiricism as represented by Hume for reducing objects of knowledge to observable events as constituted by given facts and their conjunctions (Bhaskar, 2008). Moreover, critical realism provides a critique of Kant’s transcendental idealism that merely views knowledge as consisting of abstract models or ideals constructed in the human mind (Bhaskar, 2008). Critical realism argues that these philosophies of science failed to provide an adequate explanation of nature, claiming that the objects of knowledge:

… are neither phenomena (empiricism) nor human constructs imposed upon the phenomena (idealism), but real structures which endure and operate independently of our knowledge, our experience and the conditions which allow us to access them (Bhaskar, 2008, p.25).

Thus, from this point, critical realism offers a metatheory that combines ontological and epistemological elements (Bhaskar, 1998a). Because of this
division between ontology and epistemology:

... critical realism is believed to set up a powerful challenge to postmodernist and other constructionist and relativist variants of sociology ... and thus avoids the ‘epistemic fallacy’—that is, the idea that nothing ‘real’ can exist because, tautologically, all we can know are our ideas about it (Thomas, 2004b, p.576).

However, although critical realism, as the quote above suggests, provides a challenge to postmodernism and constructionism, I will show in this chapter and the remaining chapters of this thesis how, rather than simply rejecting these philosophies altogether, it is more beneficial to use their best ideas. I will show (in Chapter 7 in particular) how combining ideas that come from different philosophies and approaches can be beneficial for analysing disability in Kuwait.

Ontology is identified as the nature of being or existence, where epistemology is identified as the nature of knowledge about the world (Miller, 2011). Ontology includes being, things, etc., while epistemology involves language, knowledge, thoughts, ideas, and theories. Ontology is not restricted to material things; it includes the three states of matter: solids, liquids, and gases, as well as discourses, social structures, and artefacts (Fleetwood, 2013). The distinction between ontology and epistemology leads to what critical realism calls the transitive and intransitive objects of knowledge. The transitive dimension includes theories, the raw material of science, models, methods, and techniques of inquiry (Bhaskar, 2008), whereas “the intransitive objects of knowledge are in general invariant to our knowledge of them: they are the real things and structures, mechanisms and
processes, events and possibilities of the world; and for the most part they are quite independent of us” (Bhaskar, 2008, p.22).

Bhaskar (2008, p.21) stresses the importance of acknowledging these two dimensions for science as a ‘central paradox of science’, stating:

Any adequate philosophy of science must find a way of grappling with this central paradox of science: that men in their social activity produce knowledge which is a social product much like any other, which is no more independent of its production and the men who produce it than motor cars, armchairs or books, which has its own craftsmen, technicians, publicists, standards and skills and which is no less subject to change than any other commodity. This is one side of 'knowledge'. The other is that knowledge is 'of' things which are not produced by men at all: the specific gravity of mercury, the process of electrolysis, the mechanism of light propagation. None of these 'objects of knowledge' depend on human activity. If men ceased to exist sound would continue to travel and heavy bodies fall to the earth in exactly the same way, though ex hypothesi there would be no-one to know it.

It can be concluded from the above that critical realists make a clear distinction between ontology, or the intransitive dimension of reality, and epistemology, the transitive dimension. The intransitive dimension has powers and mechanisms that cannot be observed directly, but that individuals can experience indirectly, through their causal power (Danermark, et al., 2002). Thus, critical realists, particularly Bhaskar (1998a; 2008), differentiate between three ontological domains: the empirical, the actual, and the real.

The empirical domain contains the individual experiences of the world. In scientific work, one cannot experience events directly, but through an interaction between theories and the data generated (Danermark, et al., 2002). However,
critical realists view people’s general and scientific experiences through their senses as misleading and untrusted (Burnett, 2007), and they are exposed to what Bhaskar (1998a, p.23) calls, ‘the epistemic fallacy’.

Bhaskar (1998a) views the actual domain of reality as the events that happen in the world. People can either experience these events or not and their observations of these events are not the same as what is really happening (Danermark et al., 2002). The real domain concerns the underlying mechanisms and structures that produce events in the world (Bhaskar, 1998a). By keeping these triplex domains in mind, the aim of “scientific work … [is] to investigate and identify relationships and non-relationships, respectively, between what we experience, what actually happens, and the underlying mechanisms that produce the events in the world” (Danermark et al., 2002, p.21). Plant (2001, p.4) offers a useful example of how these three domains work and interact with each other:

Gravity is the mechanism that governs the Moon’s orbit round the Earth since gravity is a fundamental property of all matter. The Moon’s gravitational pull is a causal power that cannot be observed directly but becomes manifest in the domain of the actual as a ‘bulge’ in the Earth’s oceans. For example, this event may be experienced in the domain of the empirical reality of everyday life as the ebb and flow of the tide on a beach, ships leaving and entering a port, or turtles laying eggs on a beach.

I will later discuss how these three domains operate in relation to the lives of disabled people. However, before such a discussion takes place, it is important to begin with a discussion of the differences between the natural and the social world.
3.2.1 Natural and Social Structures

The underlying mechanisms and structures in the natural world are different from those in the social world. This involves the notion of scientific inquiry regarding the difference between the natural and social sciences. Critical realists argue the possibility that social structures can be known through continuous interaction between humans and society (Burnett, 2007). As a result of this interaction, individuals can reproduce and transform these social structures, or as Bhaskar (1998b) states:

The model of the society/person connection I am proposing could be summarised as follows: people do not create society. For it always pre-exists them and is a necessary condition for their activity. Rather, society must be regarded as an ensemble of structures, practises and conventions which individuals reproduce or transform, but which would not exist unless they did so (Bhaskar, 1998b, p.36).

The critical realist perspective of social reality shows individuals as both reproducing and transforming social structures, as well as being shaped by them, whereas the social structures can both shape and impose constraints on individuals and can be the result of the incessant/interactive activity of individuals (Burnett, 2007). The social and cultural structures are produced by human activity but, at any given time, these social and cultural structures are pre-existent, and remain as potential objects of inquiry (Wikgren, 2005). Thus, social structures are social products, unlike natural structures that exist independently of human activity. For example, any object in nature has intrinsic features such as mass, chemical composition, particles, etc., and these features work independently of human observation (Vehmas and Mäkelä, 2008). As an example of social structure,
Burnet (2007) provides an example from the field of education. He suggests that there are underlying structures/mechanisms of power/knowledge relations that may or may not be exercised, between professionals as experts, and a parent as a layperson. Indeed, this power/knowledge relationship cannot stand alone away from human activity. Bhaskar (1998b, p.38) makes clear distinctions between natural and social structures:

1) Social structures, unlike natural structures, do not exist independently of the activities they govern.

2) Social structures, unlike natural structures, do not exist independently of the agents’ conceptions of what they are doing in their activity.

3) Social structures, unlike natural structures, may be only relatively enduring (so that the tendencies they ground may not be universal in the sense of space-time invariant).

Identifying and understanding structures that produce events and discourses can be a crucial step towards social change and emancipation. As Bhaskar (2011, p.4) states, “the world cannot be rationally changed unless it is adequately interpreted”. For Bhaskar, then, emancipation means the transition of individuals from undesirable to desirable sources of determination (Corson, 1991). The researcher, through their own beliefs and attitudes, can achieve the process of emancipatory transformation and bring about social change through investigating, and trying to understand, the intransitive dimension of knowledge (the underlying structures
and mechanisms) in the transitive dimension (people’s knowledge of the world) (Burnett, 2007). By doing so, one can, as Bhaskar (2011) said, ‘reclaim reality’. Bhaskar (2011) reveals that, through this reclaiming of reality, one can eradicate “the prejudice, errors, unsupported claims, and philosophical false trails which have covered or disguised reality for us; and … [use] this reclaimed reality as the only basis for emancipatory social practice” (Corson, 1991, p.232).

Due to the fact that this social research may contribute to emancipation and social change, and improve the lives of disabled people, understanding structures and mechanisms that constitute the ‘problem’ of disability seems crucial. As stated above, by identifying the underlying social structures, one can reproduce them and, thus, bring about social change. In the second section, I will discuss how these social and cultural structures and mechanisms can be explored at different levels of reality; however, before such exploration takes place, it is also crucial to explore how critical realism can be a useful approach in contributing to language theory. This will clarify how I will approach the data generated for this study. For example, because this project aims to explore the experiences of disabled people in Kuwait, I am interested in what the co-researchers and the participants in this project say (as in empiricism) and how they make sense of what they say (as in constructionism).
3.2.2 The Emergence of Human Language: Combining the Theories

As shown earlier, critical realism rejects positivist and idealist positions in the philosophy of science, attempting to develop a model that reconciles the two positions as well as realising the recognition of the underlying structures and mechanisms that produce phenomena in the world. Hume’s empiricism identifies event regularities as constant conjunctions, while Kant’s transcendental idealism identifies these events as models or ideals constructed in the human mind (Bhaskar, 2008). Critical realism views these observable events as a result of scientific work, not as facts in and of themselves, and attempts to transition the scientific work from studying events/phenomena to studying the structures that produce them (Wikgren, 2005).

I believe that it is difficult to discuss critical realism without comparing it with the other philosophies of science. However, it is not my aim here to explore each of these philosophies in detail, but rather to provide a brief description of each in an attempt to show how these different philosophies combine to constitute the conceptual framework adopted in this study.

To show how these different perspectives came to be recognised as philosophies to interpret the world, I would like to refer to a few verses in the Quran related to the process of creating Adam. I want to refer to these verses because I believe that (through the narrative of Adam’s creation) they simplify well, and explain the emergence of realism/empiricism and constructionism in relation to the nature of
language rationally. The emergence of empiricism can be drawn from the following verses:

And [mention, O Muhammad], when your Lord said to the angels, ‘Indeed, I will make upon the earth a successive authority.’ They said, ‘Will You place upon it one who causes corruption therein and sheds blood, while we declare Your praise and sanctify You?’ Allah said, ‘Indeed, I know that which you do not know.’

And He taught Adam the names – all of them. Then He showed them to the angels and said, ‘Inform Me of the names of these, if you are truthful.’

(Surah Al-Baqarah, 2:30–31).

These verses explain the process of the creation of Adam. Before I embark on an explanation of the verses, I want to clarify some terminology. The term ‘Adam’ for many Muslims (and even Christians and Jews) refers to a person. Following Hassan (2007), I believe ‘Adam’ is the group of Homo sapiens that evolved into mankind and who have the ability to learn about and conceive the world. Also, both Muslims and Christians refer to Adam’s wife as ‘Eve’, while I believe the word ‘wife’ (as it has been translated from Arabic) refers to the other primitive group of human beings that did not evolve. In these verses, I have used the English standard translation from the Arabic language. It is clear from this translation that the interpreters translated the verses as they understood them from the Arabic text. Thus, they used, for example, the singular formula ‘his’ when referring to ‘Adam’.

According to the verses, after the creation processes took place, God taught Adam the names of all the objects in the world. This can be referred to as a ‘vertical’
relation between signifiers (language, words, images, sounds) and referents, the objects in the world (Sayer, 2000, p.35). Thus, God taught Adam language (signifiers) and then showed the named (referents) to the angels to inform him of the names of these objects. This dualistic relationship between signifiers and referents can be viewed as naïve realism/empiricism (Bhaskar and Danermark, 2006).

The story continues as follows:

And We said, ‘O Adam, dwell, you and your wife, in Paradise and eat therefrom in [ease and] abundance from wherever you will. But do not approach this tree, lest you be among the wrongdoers.’

But Satan caused them to slip out of it and removed them from that [condition] in which they had been. And We said, ‘Go down, [all of you], as enemies to one another, and you will have upon the earth a place of settlement and provision for a time.’

Then Adam received from his Lord [some] words, and He accepted his repentance. Indeed, it is He who is the Accepting of repentance, the Merciful.

(Surah Al-Baqarah, 2:35–37).

After the process of acknowledging the physical world and its signifiers, Adam and his wife (the other group of mankind) made a mistake when approaching the ‘accursed tree’. However, the group received words from God and he accepted their repentance. The question that comes to mind, then, is how can repentance be displayed? Indeed, repentance exists only as an abstract idea or belief. This brings the notion of the ‘horizontal’ relations between signifiers (the words that Adam received) and the signified (the concept of repentance) (Sayer, 2000, p.36) into
consideration. This twofold relationship between signifiers and the signified can be viewed as constructionism (Bhaskar and Danermark, 2006).

Both empiricism or naïve realism and constructionism have failed to provide an adequate explanation of the social world. The former fails to “address how we identify and make sense of the referent” (Sayer, 2000, p.35), while the latter witnesses “the elimination of the referent—the death of the object—is, of course, consistent with the turn to discourse and away from materialism in social theory” (Sayer, 2000, p.36).

Due to the fact that my conceptualisation is rooted in critical realism, I am interested in combining both perspectives through the triplex relationship between the signifier, signified, and referent (Bhaskar and Danermark, 2006). Figure 1 shows this triplex relationship. Based on this relationship, I will expand on how I will specifically approach and analyse the associated data in Chapter Four.

### 3.3 Critical Realism on Disability Studies

In Chapter 2, I showed the criticisms directed towards the individual and social models as well as the cultural approaches. As a result of these criticisms, a number of disability scholars in the UK, such as Tom Shakespeare and Nick Watson, became critical realists, which is very much consistent with many Nordic researchers’ understanding of disability (Barnes, 2012). Shakespeare and Watson are highly influenced by critical realism theorists such as Roy Bhaskar and Berth Danermark, as well as other critical realists (Watson, 2012).
Although the body has been written out of disability studies analysis (Hughes and Paterson, 1997; Williams, 1999), both postmodernism and critical realism have demanded the re-entry of the body into disability analysis, despite their adoption of different forms of embodiment. The former demands a return of a discursively created/maintained body, while the latter embraces a form of biological body.

Figure 1: Triplex Relationship Between the Signifier, Signified, and Referent
Simon Williams suggests critical realism as an alternative analytical tool for analysing/exploring disability issues (Bhaskar and Danermark, 2006). Williams (1999, p.797) states that critical realism is an approach that:

… enables us to: (i) bring the biological body, impaired or otherwise, ‘back in’; (ii) relate the individual to society in a challenging, non-conflationary or non ‘uni-directional’ way; and (iii) rethink questions of identity, difference and ethics of care through a commitment to real bodies and real selves, real lives and real worlds.

The critical realist perspective has attracted disability scholars because it allows space for complexity (Shakespeare, 2014). Critical realism enables the physical, biological, psychological, medical, psycho-social, socio-economic, cultural, and normative factors to be taken into consideration, because, from my perspective, they are all crucial for understanding disability (Bhaskar and Danermark, 2006, p.288).

To convey how these areas can operate in reality, critical realists emphasise recognising the biological body in disability analysis, providing the right medical diagnosis and rehabilitation, providing social/cultural support, campaigns for civil rights, and the removal of physical barriers (see Danermark, 2002; Danermark and Gellerstedt, 2004; Bhaskar and Danermark, 2006; Shakespeare and Watson, 2010; Watson, 2012). Furthermore, by reflecting on their previous projects, Shakespeare and Watson (2010) found critical realism to be a useful approach for providing a complex and nuanced understanding of the lives of disabled people. The authors show how the participants in their studies responded to disability-related issues in a very complex way, and they reveal a number of issues at different levels, from
the psychological/medical to the social/cultural, environmental, economic, and political levels.

From the above, it is clear that critical realists attempt to benefit from the features of critical realism and apply them in the field of disability. It is clear that these theorists seek to emphasise disability research according to different levels of reality, and attempt to identify the mechanisms working at each level. Indeed, studying a complex phenomenon such as disability at various levels requires one to conduct interdisciplinary research and deploy theories and methods for each level. As Danermark (2002, p.61) states:

… interdisciplinary research is the study of a common complex phenomenon and how that phenomenon is manifested at different levels of reality. This is done by using specific theories and methods developed for each level. The results are then integrated in an attempt to reach a more holistic perspective on the phenomenon.

Another feature of critical realism that has attracted a significant amounts of attention from critical realists is the crude distinction between ontology and epistemology. For example, they differentiate between impairment that has “intrinsic features [that] don’t give a damn about observers and exist independently of observers” (Searle, 1995, p.11) and the knowledge of impairment; however, at the same time, they recognise that impairment can have different social and political meanings based on the context. These meanings are often influenced by culture, class, and gender (Danermark, 2002). For example, Shakespeare (2014) endorses the work of social constructionism and, more specifically, the work of Goodley (2011) in recognising how Down’s syndrome
has had different names and social meanings at different times. However, at the same time, he emphasises that:

… this does not mean that Down syndrome, as an organic impairment, is different now from what it was when Goya painted people with Down syndrome in Madrid in the early nineteenth century: it is an intellectual impairment caused by having three copies of chromosome 21, and always was (Shakespeare, 2014, p.59).

By taking the complexity associated with disability into consideration, critical realists, as shown above, aim to develop a non-reductionist model for understanding disability through tackling different levels of reality (Danermark, 2002; Danermark and Gellerstedt, 2004; Bhaskar and Danermark, 2006; Shakespeare and Watson, 2010; Watson, 2012). In line with these theorists, I intend to develop a similar model, but one that is consistent in the context of Kuwait. This model will be discussed in Chapter 8.

Furthermore, in addition to the previous advantages of critical realism, I believe that it is vital to provide an example from the field of disability that shows how critical realism can be a practical tool for inquiry in analysing the lives of disabled people. This process can be achieved by drawing upon the three domains of reality suggested by Bhaskar (1998a). With regard to the empirical domain, this relates to disabled people’s daily lives, the knowledge that they gain, and their interactions, whether with their families, friends, or society in general. These experiences stem from a deeper level (i.e. the actual domain) that produces a number of events in the world of which disabled people may or not be aware; however, it is important to acknowledge these social events in order to identify how they shape the
experiences of disabled people. As an example, disabled people may experience a number of social events such as prejudice, discrimination, inequality, etc. These social events that disabled people experience are driven by real, underlying structures and mechanisms that might be related to their culture/religion (for example the notion of ‘normality’) or political stance. These social phenomena are likely to be driven by underlying structures/ideologies related to power/knowledge relationships between disabled people and non-disabled people, such as professionals, doctors and religious leaders.

3.4 The Conceptual Framework

After exploring different dominant perspectives of disability (the individual model, the social model, the cultural model, and critical realism), one may notice that critical realism offers an open/interactional approach that allows for complexity within different domains, ranging from biological/psychological to social/cultural, and to political/economic. The individual model focuses solely on medical or so called ‘deficits’ aspects, which clearly leaves social and cultural factors without challenge. The social model of disability focuses mostly on one level of reality (i.e. the socio-economic) and neglects the experiences of many disabled people associated with their impairments, and deals with them as a homogeneous group. Also, embracing the ‘social relational understanding of disability’ would only allow one to view disability as a dual system rather than a complex phenomenon. However, I am not suggesting here that the social model and the social relational model do not recognise impairment as real. Both of these
models equally accept, as does critical realism, that impairment is real, but they focus on how society responds to disabled people with these ‘real’ impairments. Critical realism goes beyond this and enables one to explore the impact of actual impairment, as this is something that the social model explicitly rejects.

Moreover, the work undertaken by cultural theorists that highlights the socio-cultural level is limited at the political and practical levels (Shakespeare, 2014). Thus, the question that can be asked in this regard, pragmatically, is how cultural and historical investigations and discursive practices related to disability can improve the lives of disabled people.

Nevertheless, one should not deny that each perspective of disability promises certain benefits. For example, the individual model stresses the importance of recognising impairment and its associated pain and functional limitation (Shakespeare, 2014). The emergence of the social model helps disability scholars to recognise social, economic, political, and cultural factors that lead to the exclusion and oppression of disabled people (Goodley, 2011). The cultural perspective also does important work by examining cultural representations and discourse, as well as the attitudes of non-disabled individuals (Shakespeare, 2014).

Therefore, the conceptual framework that I want to propose for this study is rooted in critical realism, which differentiates between the ontological existence of impairment and the knowledge about impairment (Williams, 1999; Bhaskar and Danermark, 2006; Shakespeare, 2014). It also combines medical, social, and
cultural aspects:

The critical realist perspective appears to offer a good basis on which to elaborate a workable understanding of disability, which combines the best aspects of traditional approaches, strong social model approaches, and social constructionist approaches (Shakespeare, 2014, p.74).

My interactional/non-reductionist approach is similar to Thomas’s (1999; 2004a) approach, which shows disability as an interaction between intrinsic physical and psycho-emotional factors and extrinsic social and cultural factors. However, in Chapter 2, I showed the limitations of Thomas’s approach because it mainly conceptualises disability as a dualistic interactional experience between extrinsic and intrinsic factors, and neglects to describe how, even if the cultural stereotypes are taken out, impairment solely can cause psycho-emotional effects (Shakespeare, 2014). As discussed above, I want to emphasise here that the social model and the social relational model do not deny impairment effects (e.g. pain, depression, etc.), but they most certainly neglect them.

Also, the assumption that Carol Thomas makes in defining disability as a form of social oppression excludes the experiences of some disabled people occurring at the individual level such as pain and fatigue (Shakespeare and Watson, 2010), as well as excluding the positive experiences of disabled people (Shakespeare, 2014). Thus, disability should not be seen as a form of social oppression, but rather “as the outcome of the interaction between individual and contextual factors, which includes impairment, personality, individual attitudes, environment, policy, and culture” (Shakespeare, 2014, p.77).
My approach is much closer to the World Health Organization’s (WHO) International Classification of Functioning, Disability and Health (ICF) (2001) understanding of disability. In this framework, disability is viewed as a complex phenomenon ranging from interaction between impairment and activity limitations, to participation restrictions and environmental obstacles. Furthermore, my own understanding of disability is similar to the Nordic relational approach. The Scandinavian ‘relative interactionist’ perspective on disability is:

… emphasising a multi-level approach, that is, a theoretical perspective that rejects assumptions about any primordial analytical level and rather takes a programmatic position in favour of studying disability on several different analytical levels (Gustavsson, 2004, p.62).

Additionally, I have found that the method of dealing with disability issues in Scandinavian countries is relatively similar to Kuwait, especially in terms of the welfare system and impairment categorisation. For example, in a similar fashion to the Kuwaiti context, the welfare policies of Nordic countries are based on medical and psychological interpretations as well as measuring impairments and labelling (Barnes, 2012). Moreover, both Kuwait and “Nordic countries have expanded disability services in ways that have been championed as some of the world’s best” (Goodley, 2011, p.16). In Sweden, for example, Swedish parents can receive 18 months of paid parental leave, highly supported child care including a monthly child allowance, and free aid and support from different disability organisations (Broberg, 2011). The tone of challenge in providing the world’s best privileges and services for disabled people was clear through the discourse of the Deputy Director General of the PAPDA in Kuwait:
Extract 3.1

The Rights of Persons with Disabilities Act No. 8/2010 granted the best Act award in the region. If you go and search on the Internet for international conventions for disabled people’s rights, you will find that this [Kuwaiti] law is better. We took the fruit of disabled people’s rights conventions and legislated it and made it in a law that aims for inclusion. This law took the most important articles of disabled people’s rights convention … We took all the privileges of this convention. You will not find any country in the world that has these privileges. I challenge them at conferences, every time I say to them what we are doing for disabled people, and they say ‘you are spoiling them’!

(Essam, male, aged 53.
Interview date: 6th August 2013).

Thus, after this exploration, I have found it vital at this stage to consider the critical realism perspective, especially when approaching my data, as this will help me to look openly at different areas, rather than focusing on one particular aspect of disability. Opening up the issues of disability allows the disability theory to be generated empirically by letting context sensitivity and empirical discoveries lead the way and decide where the most analytical weight of a particular study can be found (Gustavsson, 2004; Bhaskar and Danermark, 2006). Therefore, I find critical realism important to consider as an approach in the Kuwaiti context because it proposes practical solutions to move disabled people towards social inclusion (see Bhaskar and Danermark, 2006; Watson, 2012; Shakespeare, 2014). However, taking a pragmatic disposition does not negate the need for “research
and theory to push the boundaries” (Goodley, 2014a, p.660); otherwise, rather than writing a thesis, I would be ‘out there’ pragmatically fighting to improve disabled people’s lives.

Finally, critical realism, and its call for social change and emancipation as an alternative philosophy of positivism and postmodernism, might be welcome among disabled people and other oppressed groups in Kuwait. With critical realism and the concept of emancipation in mind, emancipatory projects, participatory strategies, and the lives of disabled people will form the core of the next chapter.

3.5 Summary

This chapter discussed the conceptual framework adopted for this project. The conceptual framework is rooted in critical realism, which analyses disability from multiple levels. I began this chapter by talking about critical realism in general. Then, I moved on to discuss the use of critical realism in the field of disability. The chapter ended with a discussion of the proposed conceptual framework adopted in this study. The conceptual framework I suggest for this project requires the biological body to be present in disability analysis, accompanied by the exploration of other effective disability factors rooted in culture, society, and economy. Having developed the conceptual framework that will be adopted for this project, the next chapter will discuss the research methodology, practicality, and methods constructed for undertaking the project.
Chapter Four

Methodology

4.1 Introduction

This chapter is divided into two sections. The first discusses the philosophical background of participatory research strategies, such as emancipatory research and participatory research, in the field of disability studies. The second comprises two parts. The first addresses the methodology underpinning this research and practicality, while the second discusses the rationale and justification of methods used for data collection, validity and reliability, and ethical considerations. The chapter ends with a discussion of the approaches embraced in order to analyse the data generated for the purpose of the project.

As the nature of this project is based on collaborative work between the co-researchers and myself, I find it vital to start this chapter with a philosophical and historical glimpse into inclusive research with disabled people. I will focus particularly on two kinds of research strategy: emancipatory and participatory research.

4.2 Emancipatory and Participatory Research

Alienating and disempowering disabled people in the production of disability research is an issue that has caused academic researchers, such as Finkelstein
(1985) and Oliver (1992), to call for the adoption of research strategies that are both emancipatory and empowering (Kitchin, 2000). Oliver (1992) has criticised both positivist and interpretive paradigms for maintaining the social and material relations of research production unchallenged. He states that the positivist paradigm shows the experiences of disabled people as extremely distorted because it shows disability as an individual problem. He also notes that the work undertaken within the interpretive paradigm has failed to have any effect on disabled people’s services and their quality of life. Briefly, Oliver (1992, p.106) sees that:

… interpretive research is just as alienating as positivist research because what might be called ‘the social relations of research production’ have not changed one iota. Not only that but the defects of both positivist and interpretive approaches merely reinforce one another.

Due to this situation, Oliver (1992) and other disability researchers such as Zarb (1992) and Stone and Priestley (1996) have called for an adoption of research strategies that are emancipatory, empowering, and relevant to the lives of disabled people. Emancipatory research challenges social oppression and the power structures that fund and form the social relations of research production; moreover, it is based fundamentally on reciprocity and achieving social change/transformation through the empowerment of research participants (Oliver, 1992). However, the issue of emancipatory research is not about empowering participants, but about enabling disabled people to play an active role in the
research and thus making them more than participants. As Oliver (1992, p.111) puts it:

The issue then for the emancipatory research paradigm is not how to empower people but, once people have decided to empower themselves, precisely what research can then do to facilitate this process. This does then mean that the social relations of research production do have to be fundamentally changed; researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose. The task for emancipatory research is not, as is sometimes implied, to help the researched to understand themselves better, but to develop its own understanding of the lived experiences of these very subjects.

Oliver (1997; 2002) emphasises the same issues that he raised in 1992: criticising the social relation of research production and the research methodologies that cause the alienation and disempowerment of disabled people. In 1997, he confirmed the principle of reflexivity in emancipatory research, no matter how painful, and stated that one cannot claim that his/her research is emancipatory until after it has taken place and its impact has been witnessed. Thus, the role of the researcher is to engage in the research process and facilitate the way for those who are pursing emancipation. The researcher should facilitate the self-empowerment of disabled people and engage in the process of research, and the nature of engagement should be decided by disabled people themselves (Stone and Priestley, 1996). Therefore, the main task of the emancipatory paradigm is to change the material and social relations of research production, and place control in the hands of the researched, not the researcher (Zarb, 1992; Oliver, 1997).
Shakespeare (1996), on the other hand, holds a pessimistic view of emancipatory research, as he reveals that:

I have major reservations with the concept of emancipatory research, even while admiring the motivation and commitment of those engaged in it. I am cynical about the possibility of research achieving major change, whether it be radical and emancipatory, or traditional social policy research. Ideas clearly have a role, but actions decide the day, and while it is possible to make the research process more balanced, grandiose claims for its revolutionary potential seem to me to be over-optimistic (Shakespeare, 1996, p.118).

It can be seen from this extract that Shakespeare addresses both emancipatory and traditional research in his criticisms, confirming the notion that ideas rarely influence and change society, if they are not accompanied by practical actions. Therefore, he stresses the reconciliation of theory and practice. This idea led Shakespeare to differentiate between his position as an academic and his position as a disability activist and concludes that:

… it is necessary for there to be a division of labour between academics and activists: notions of accountability and representation are relevant in the political context, while notions of engagement and commitment are more relevant in the sociological context. Ultimately, political action achieves change. Intellectual activity contributes to a climate in which change becomes possible and offers theoretical support to practical debates (Shakespeare, 1996, pp.118–119).

Zarb (1992) expresses an opinion similar to Oliver, as he points out that research regarding disability, until that point in time, was not managing obviously to empower disabled people, and all that one could achieve at that time was participatory research. However, according to Zarb (1992), participatory research that helps to identify the needs and experiences of disabled people can be a
precondition of emancipatory research, through recognising the challenge to the ideology of objectivity and putting it into practice.

The rise of participatory research strategies constitutes an essential shift “from doing research on people to doing research with people” (Swain and French, 2004, p.1). Involving disabled people in participatory research might thus give them a chance to share their voices and experiences of disability issues, thereby opening the door to further research. This approach accords with Maguire’s (1987) suggestion that “participatory research offers a critique of, and challenge to, dominant positivist social science research as the only legitimate and valid source of knowledge. It provides a radical alternative to knowledge production” (p.11). In general, disabled people have little opportunity to share their experiences through research. As Morris (1991, p.8) states, “Disabled people […] have little opportunity to portray our own experiences … This lack of a voice, of the representation of our subjective reality, means that it is difficult for non-disabled feminists to incorporate our reality into their research”. Thus, participatory research provides opportunities for non-academic disabled people to participate in the entire research process, including in the generation of ideas, hypotheses, data analysis and interpretation, and writing the final report (Kitchin, 2000). Academics in the field of disability studies, such as Wamsley and Johnson (2003), also emphasise that disabled people should be able to exercise some control over research processes and outcomes.

As outlined in Chapter 2, these two kinds of research (i.e. emancipatory and
participatory) that aim to engage disabled people in the research are not currently found in the research literature in Kuwait. Thus, this project is likely to be the only study in Kuwait that provides disabled people with an active role to in the research processes as co-researchers. Although, it is vital, as Wamsley and Johnson (2003) point out, to give participants some control over the research process, an equalising partnership seems an unrealistic goal, to me, echoing Shakespeare (1996, p.118):

I aim to equalise the research relationship, and give participants some control over the process, over their words and over their participation. I try to be accountable to research participants, and I am committed to representing interviewees and giving them a voice within my publications. At the end of the day, I am not naive enough to imagine I have completely equalised the relationship, because I believe this is ultimately impossible. I write the articles; I have the academic voice and authority; I have the education and the language which contributes to the acceptability of what I write (Shakespeare, 1996, p.118).

I will expand on discussing partnership in Chapter 6. In the next section, I will discuss an important exercise that is often related to the qualitative paradigm in general and inclusive research in particular; that is, reflexivity.

4.2.1 Reflexivity in Research

In this section I will discuss how the researchers practiced the process of reflexivity in their research and the outcome of this process. It is crucial that this process of reflexivity is discussed and clarified, as this process goes to the heart of this project.

Reflexivity is a practice that “is commonly used in qualitative research and has
been posited and accepted as a method qualitative researchers can and should use to legitimize, validate, and question research practices and representations” (Pillow, 2003, p.175). By reflecting on their own collaborative projects, Zarb (1992), Stone and Priestley (1996), and Oliver (1997) conclude that disabled people and their representative organisations have little influence on the research agenda and control over the research process. They contend that this problem is owing to the material and social relations between disabled people, researchers, and funding bodies. Their criticism relates to disillusion with research that is based on the positivist and interpretive paradigms, which have left disabled people alienated and disempowered. As an example of research that alienated disabled people can be found in the national disability survey undertaken by the Office of Population Censuses and Surveys (OPCS) on behalf of the British Government between 1985 and 1989 (Oliver 1990b; Oliver, 1992). (For details about the survey see https://discover.ukdataservice.ac.uk/catalogue/?sn=2577&type=Data%20catalogue).

This survey views disability through an individual lens and assumes that disability is caused directly by individual impairments (Oliver, 1990b; Barnes, 1991). Oliver (1990b; 1992) believes that this survey is methodologically problematic. First, because it alienates disabled people from the research process, as “they were not consulted about the research in advance; what issues should be investigated, how the research should be carried out and so on” (Oliver, 1992, p.104). Second, the questions in the interviews were designed in a very structured way that led the disabled participants to believe that the problems they face in their lives arise from
functional limitations:

It is in the nature of the interview process that the interviewer presents as expert and the disabled person as an isolated individual inexperienced in research, and thus unable to reformulate the questions in a more appropriate way. It is hardly surprising that, given the nature of the questions and their direction that, by the end of the interview, the disabled person has come to believe that his or her problems are caused by their own health/disability problems rather than by the organisation of society. It is in this sense that the process of the interview is oppressive, reinforcing on to isolated, individual disabled people the idea that the problems they experience in everyday living are a direct result of their own personal inadequacies or functional limitations (Oliver, 1990b, p.8).

Kitchin (2002), on the other hand, asked disabled people themselves about how disability research should be conducted, before reflecting on his three pieces of participatory action research in Ireland, which sought to assess the development of emancipatory research. In relation to the opinions of disabled participants regarding how to conduct disability research, the views were varied. Generally, the views centred on the issue that disability research is non-representative of disabled people, as it is dominated by non-disabled researchers. Also, the participants revealed that the disability research failed to change social relations or have an impact on the lives of disabled people. These issues made the disabled participants call for the adoption of participatory strategies and inclusive research.

In his three projects, Kitchin (2002) addresses failures and successes, and whether these three projects were really participatory action research (PAR). Participatory action research (PAR) is a term that describes collaborative work carried out between researchers and participants to gather information on social issues, in
which cooperation takes place at every stage of the research and involves discussion and sharing skills (Pain, Whitman, Milledge and Trust, 2010).

Kitchin (2002) found that one of the problems with his PAR projects is the time commitment required. He also reveals that, although the disabled participants were involved in setting up the agenda of the projects and data collection, the analysis and the writing-up process were left to him. He was keen to equalise tasks with his co-researchers, but, because of his research experience and familiarity with the literature, he controlled and shaped the projects. As a result, all three projects went from being fully participatory to semi-participatory. Despite these limitations, however, the projects drew upon reciprocity, as the disabled participants were able to learn new skills and contribute to wider debates and publications in academic journals.

Along the lines of Oliver (1997), Zarb (1992), Stone and Priestley (1996), and Kitchin (2002), this participatory study offers self-reflexivity throughout the research process:

Self-reflexivity acknowledges the researcher’s role(s) in the construction of the research problem, the research setting, and research findings, and highlights the importance of the researcher becoming consciously aware of these factors and thinking through the implications of these factors for her/his research (Pillow, 2003, p.179).

This type of research emphasises continual reflection, criticism, and awareness of where the power lies and who affects it (Chapman, 2005). In relation to my research, the self-reflexive exercise helped the co-researchers and myself to shed
light on the issue of power relations between the co-researchers and myself, as a non-disabled researcher, as well as how these issues affect decision making. In addition, it allowed us to discuss the challenges we faced, and whether certain aspects could have been carried out better. The possibility of this research paving the way towards empowerment and emancipation was also addressed. This exercise was practised effectively through the regular meetings conducted with the co-researchers during the fieldwork. In these meetings, the co-researchers and myself were able to effectively provide on-going reflections on the research processes. As a large part of this research is about the process of participatory research with disabled participants, this exercise is at the forefront of the thesis and extends throughout the chapters. In this chapter, I will show the exercise of self-reflexivity through describing the research process, while Chapter 6 intends to provide analysis of these processes through the analysis of the focus groups and interviews conducted with the co-researchers in relation to the research processes.

The next section of this chapter describes the research process and practicalities, with the participants who have worked with me as co-researchers on this project. Recounting the process of this project in detail is crucial in order for the reader to recognise and judge for themselves the quality and quantity of participation between the co-researchers and myself, and between the co-researchers themselves, as both the co-researchers and myself had different levels and degrees of participation. It is essential that the roles of myself as the main researcher and those of the co-researchers, as well as the level of participation between the co-researchers themselves, are clarified. This distinction can be useful in formulating
a clearer picture of the power/social relations of research production. In addition to describing the role/task distributions between the co-researchers and myself, the next section also demonstrates the shift in the research process and decision making (e.g. the shift from the decision to create an open online course, to making a short disability awareness film).

Although, as stated above, there are a number of research strategies, such as participatory and emancipatory, that can provide principles for conducting research, they do not necessarily address the issues of power relations and support, or the skills required to be an active researcher (O’Brien, McConkey and Garcia-Iriarte, 2014). A relatively small amount of literature has addressed practicality in participatory and inclusive approaches (see, for example, Radermacher, 2006; Abell et al., 2007; Mcclimens, 2008; Cook and Inglis, 2012; O’Brien et al., 2014). However, I agree with Mcclimens (2008) when he says of literature:

I felt that some of the grittier and messier aspects of collaboration were being glossed over or perhaps ignored … [so that] the collaborative research process was no more taxing than a walk in the park (p.273).

Additionally, it is important to note here that I am aware that “the illicit politics of the pronoun is neglected. An ‘I’ that stands for a ‘we’ amounts to theft, while a ‘we’ that expresses an ‘I’ is a fraud” (Blyth et al., 2016, p.292). Therefore, in the next section, I will be careful and clear in stating what tasks/roles I have undertaken individually, and what tasks/roles the co-researchers and I have undertaken collectively. I will use the pronoun ‘I’ to refer to the roles that I have undertaken individually and ‘we’ to refer to the roles that the co-researchers and I
have jointly undertaken.

4.3 Research Processes and Practicalities

As stated in Chapter 1, having been through a series of events that led me to eventually decide on the current topic, I concluded that the best course of action for my research would be to design an open online course that would raise awareness among non-disabled people of disability issues. I also showed in the first chapter that I decided to collaborate with disabled people because these issues can have such a profound influence on their lives. This collaboration was intended to cover the creation of the course (which shifted to the disability film later), data collection and analysis, and the holistic evaluation of the experiment.

Based on this conclusion, I decided to return to the participants I met during the exploratory phase to explain my topic in detail and to discuss their willingness to participate in this project as co-researchers. Depending on their decision, I would then be able to prepare my proposal with them, collaboratively. However, this activity was not possible, because I was in Manchester at the time and was unable to contact the participants. Nonetheless, I had anticipated a positive response from them, as they had shown tentative enthusiasm for my project topic during our previous encounters. Thus, the only choice for me was to prepare my research proposal individually, but in a flexible way that made it easier to be modified and revised, collectively. For example, I made a clear statement in my proposal:

In line with this spirit of participation, the plans, roles, and responsibilities involved in the research process should be discussed
and shared with the participants. The next part of this proposal will, therefore, only demonstrate my expectations of the agenda for this research and may be modified upon further consultation (author’s proposal, 2014, p.5).

At the end of my proposal, I made another statement with an alternative research strategy, in case the participants declined to participate in my research as co-researchers:

I recognise that the process that I have outlined relies on the continued participation of the co-researchers and that this is a risk, here. I believe that my pilot study, which was conducted with the same group, showed that they are likely to be willing to participate, but if their enthusiasm is not maintained, then I will still be able to construct and trial the course and use my own field notes, and the focus groups and interviews with non-disabled participants, to complete my research satisfactorily (author’s proposal, 2014, p.11).

In fact, designing my research proposal individually was the first issue to affect my desired approach and prevent it from being fully participatory (I will expand on this in Chapter 6). Another issue to affect the research methodology is the ethical procedure that is built on the positivist paradigm, which assumes that the researcher should know the participants before meeting them (Radermacher, 2006). This ethical procedure allows issues with power relations between my supervisors and myself, on the one hand, and with the Research Ethics Committee, on the other hand, to rise to the fore. The ethical considerations and power/social relations within this project will be discussed in detail in the next part of this chapter.
4.3.1 Bringing the Participants as Co-researchers into the Project

After I prepared my research proposal and after it was approved by the panel, I returned to Kuwait in order to bring the participants I met during the exploratory phase into the project as co-researchers. As stated previously, during the exploratory phase of this research, I met with two groups comprising ten disabled people: students in their final year at a secondary school and students currently studying in higher education. Both groups included members who are physically impaired and regularly attend a sports club for disabled people.

I went to the sports club for disabled people in order to engage the ten participants as co-researchers. I asked the managing coordinator at the club to allow me to meet with the participants, but, unfortunately, they were not available. I went back to the club after a week and was able to meet with only four of the ten participants, two males and two females, but they allowed me to meet up with another three of their friends. Eventually, seven participants agreed to participate in the project as co-researchers (four males and three females). However, one female showed up to only one of our meetings; thus, officially, there were six people who remained committed to attending the meetings (although their commitment varied). The co-researchers who agreed to participate in the project were five physically impaired people and one partially sighted person. Table 2 shows the characteristics of the co-researchers.
Table 2: Characteristics of the Co-researchers

<table>
<thead>
<tr>
<th>Co-researchers</th>
<th>Gender</th>
<th>Age</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kholood</td>
<td>Female</td>
<td>24</td>
<td>Ministry of Social Affairs and Labour</td>
</tr>
<tr>
<td>Saja</td>
<td>Female</td>
<td>22</td>
<td>A student at the Basic Education College</td>
</tr>
<tr>
<td>Yagoub</td>
<td>Male</td>
<td>21</td>
<td>A student at the Social Sciences College</td>
</tr>
<tr>
<td>Abdurrahman</td>
<td>Male</td>
<td>20</td>
<td>A student at Al Shari'a College</td>
</tr>
<tr>
<td>Omar</td>
<td>Male</td>
<td>18</td>
<td>A student in high school (special education)</td>
</tr>
<tr>
<td>Abdullah</td>
<td>Male</td>
<td>21</td>
<td>A student at the Basic Education College</td>
</tr>
</tbody>
</table>

In this table, and as can be seen in Tables 3 and 4, I have used the real names of the co-researchers and participants. However, I will later (in the ethical consideration section) discuss in detail why I decided to use real names.

4.3.2 Setting up the Agendas/Processes and the Arrangements Required for Undertaking This Project

After the participants agreed to participate as co-researchers in the project, I gave them the participant information sheet and consent form to be signed (see Appendix 1). After the forms had been signed, we set up 14 meetings. These meetings had three functions: 1) to discuss and revise the research plan to make sure that progress was being made towards achieving our research aims; 2) to continue to discuss research methods and to construct instruments; and 3) to
explore disability in Kuwait and support the creation of the disability awareness film. These meetings were regular, once or twice a month, and were conducted over the course of seven months (from April to November 2014). However, not all co-researchers were available at every meeting. The time commitment was one of the difficulties we faced throughout the research process. I will talk about this issue in Chapter 6.

As one of the aims of this participatory project is to give disabled people a chance to play an effective role, it is crucial to make sure they are well supported in relation to the skills required for conducting research (Abell et al., 2007; O’Brien et al., 2014). Thus, throughout these meetings, we explored qualitative research strategies such as data collection and analysis methods, ethical procedures, and validity and reliability.

We also explored participatory research principles. In order to gauge the understanding of the co-researchers on what they had learned from exploring research methodologies, we undertook an activity. In this activity, we explored together a research topic we were interested in and formulated research questions and suggested appropriate data-generation methods to answer the questions. Their positive responses to this activity indicated a good understanding of qualitative research. For example, Kholood, who was interested in counselling and educational psychology, suggested a research question related to exploring how schools deal with the psychological issues of pupils. In order to explore these
issues, she suggested interviews as a method of data collection with some of the schoolteachers.

Also, other positive indications were displayed in the discussion of the differences, advantages, and disadvantages of qualitative and quantitative research. Kholood, for example, addressed the fact that questionnaires are more appropriate and more measurable than qualitative research methods such as interviews and focus groups. Abdullah, on the other hand, was a fan of qualitative research methods, arguing that questionnaires are not an accurate scale for expressing his thoughts. In line with Abdullah, my supervisors and myself are more interested in qualitative research because it allows for more ‘in-depth’ knowledge into the social phenomena rather than ‘breadth’ (Blaxter, Hughes and Tight, 2006, p.64). However, if I had agreed with Kholood and wanted to pursue quantitative work we would have found other staff to join the supervisory team. This is the PhD process itself; it has a certain format and expects certain things to be in place and to happen in a certain way. It is a rite of passage for myself, not for the co-researchers. I get a PhD; what do they get?

These issues are important and go to the heart of this research, and raise questions about who can/cannot participate? What if the co-researchers had not understood qualitative research strategies? Would I have excluded them? Or could I have supported them in a more effective way? I will discuss and deal with these questions in more detail in the analysis chapter (Chapter 6).
Furthermore, in the meetings, in order to answer the research questions, three research methods were used: focus groups, interviews, and a research diary (I will talk about each in detail later in this chapter). I ran two focus groups and interviews with the co-researchers. All the co-researchers were involved in these focus groups. Each focus group took approximately one-and-a-half hours. Also, in these meetings we decided collectively upon interviewing a number of non-disabled people in Kuwait who work in different places in the state. Each interview took approximately half an hour. I conducted these interviews individually. The aim of these interviews was to identify the missing points that non-disabled people do not recognise about disabled people as well as their attitudes towards disabled people. Identifying these issues was crucial in order to have a better understanding about the disability issues in Kuwait, and thus create an appropriate film to raise awareness of disability and disabled people. Table 3 illustrates the characteristics of the non-disabled participants.

Table 3: Characteristics of the Non-disabled Participants

<table>
<thead>
<tr>
<th>Co-researchers</th>
<th>Gender</th>
<th>Age</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdurrahman</td>
<td>Male</td>
<td>74</td>
<td>Imam</td>
</tr>
<tr>
<td>Khalid</td>
<td>Male</td>
<td>36</td>
<td>Head of tests and measurements at the Public Authority for People with Disabilities</td>
</tr>
<tr>
<td>Rashid</td>
<td>Male</td>
<td>53</td>
<td>Assistant Undersecretary of the Public Authority for People with Disabilities (education and</td>
</tr>
</tbody>
</table>
Also, in these meetings, I worked collaboratively with the co-researchers to provide initial analysis of the data set such as generating initial ideas and a coding process (see Chapter 5). The coding process involved commenting on the text and thinking about it critically while reading it, as well as generating ideas in relation to the research. For example, we discussed the role of the media and how Kuwaiti actors and celebrities sometimes offend disabled people in Kuwaiti TV programmes. These ideas made us think about interviewing actors and actresses and encouraging them to use the online awareness course that we intended to create when we were still considering the idea of creating an online course. At a later stage, some of the co-researchers tried to access some actors and actresses who played disabled characters, but they were not able to reach them. This made us change the plan and we decided to use the participants with whom I was able to conduct interviews, as shown in Table 3.

The co-researchers were engaged effectively in the process of generating initial ideas and codes across the data set. However, I was responsible for deeper analysis, to create a final thematic map of the data set, though I was keen to talk openly with the co-researchers about the initial analysis. The initial analysis helped us to highlight the issues/themes emerging from the data of, for example, the first focus group, and to follow up on them in further interviews/focus groups.
However, although the co-researchers were involved actively in the analysis process, deeper analysis at later stages (often in relation to relevant literature and theory) was mainly my job since the nature of the study makes this imperative (see Appendix 2 for a summary of the co-researcher meetings [CRMs]).

**A shift in the research plan**

Although I started the project working with seven co-researchers, I ended the research with only one co-researcher (Kholood) who remained committed to the project to the end, since five co-researchers withdrew from the group during the research process. Some provided reasons, while the rest left without stating any reason. However, it is crucial to state here that the commitment of the co-researchers varied. Although it was rare that we all met on the same day, the co-researchers remained committed to the project until they decided to withdraw. Appendix 3 shows how long the co-researchers remained committed to the project, when they left and the reasons.

The lack of participation by the co-researchers caused a delay in the research process. As a result of this problem, I agreed with Kholood, the only person who continued to work with me to the end of the project, that a short film would take less time than the creation of an online course. Moreover, we both believed that a short film would be more effective than an open online course.

It had always been my intention to use the making of the film as a part of the data collection process and transcripts of the interviews made as a part of the film were
included in the data set. The four participants in the film were provided with information about the research project and gave their consent to the use of their interviews as a part of the data analysis (see Appendix 4).

I acquired a high-quality camera and enlisted the support of someone with the technical ability to add subtitles. The film shows four people (a non-disabled mother talking about her disabled daughter and three disabled people) talking about their issues, in relation to the behaviour and attitudes of non-disabled people towards disabled people, their views about social inclusion, their views about the political decisions with regard to disabled people and disability, and the role of the media (how disabled people are depicted in the media). I edited and directed the film using the iMovie software, and then uploaded it to YouTube (https://www.youtube.com/watch?v=BbuQMmYAHWM). Table 4 shows the characteristics of the people who participated in the disability film.

Table 4: Characteristics of the People Participating in the Film

<table>
<thead>
<tr>
<th>Participants</th>
<th>Gender</th>
<th>Age</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Metab</td>
<td>Male</td>
<td>26</td>
<td>Working at the Ministry of Information</td>
</tr>
<tr>
<td>Sara</td>
<td>Female</td>
<td>22</td>
<td>Student at art college</td>
</tr>
<tr>
<td>Fahad</td>
<td>Male</td>
<td>28</td>
<td>Employee at a special education school</td>
</tr>
<tr>
<td>Manal</td>
<td>Female</td>
<td>48</td>
<td>Secretary at a primary school</td>
</tr>
</tbody>
</table>
4.3.3 Overall Evaluation of the Participatory Research Process

After we had completed the process and created the disability awareness film, I wanted to meet the co-researchers who had worked with me, in order to explore their experiences of the project, by answering the last research question: what were our (i.e. the researcher and the co-researchers) experiences with the process of participatory research? I contacted all of the co-researchers but, unfortunately, I was only able to meet up with Khoolod and Saja. I interviewed them as a pair, within two days, and I was unable to meet with them for more than half an hour. In these interviews, we shared our experiences from the project in terms of developing skills, decision-making processes, power relations, and the difficulties we faced. Table 5 in Chapter 5 summarises all the data used for the data analysis.

Generally, this project experienced a number of difficulties. These difficulties included the co-researchers’ commitment and time constraints as well as other difficulties related to the managing coordinator at the sports club. As stated earlier in the chapter, the co-researchers and myself organised regular meetings (14 meetings) at the sports club over the course of seven months (see Appendix 2). Each of the meetings had to be organised by the managing coordinator. The task of the managing coordinator was to organise the time and place for each meeting. These processes went smoothly at the beginning, yet became more difficult over time. The managing coordinator dealt with me politely at the beginning, as he showed interest in the project and was very supportive. His treatment of me changed, however, once he realised that the project was taking longer than he had expected, even though I had permission from the manager of the club to conduct
the project with the club members. He tried to distract us many times during our meetings by stating that we did not have enough time or sometimes stating that there was no place for us to meet. He even said once that the manager of the club was concerned about my frequent presence at the club as the research was taking a long time. Whatever the reasons were for these issues with the managing coordinator, they became one of the difficulties we faced during the project.

4.4 Research Methods

The first part of this section examines the rationale and justification for choosing the methods for data collection, while the second part discusses the techniques I followed in the deploying the methodology. There were two main methods for data collections: focus groups (two with the co-researchers) and interviews (two with the co-researchers, four with non-disabled people, and four during the disability awareness film). I also kept a research diary throughout the research process in order to record the events and my personal accounts (see Appendix 5 for a diary format).

4.4.1 Constructing Research Methods

Constructing the data collection methods was my job primarily, but it was subject to modifications jointly with the co-researchers throughout the research process. In relation to the focus groups, I designed these separately for a number of reasons. Focus groups as a method stemmed from the participatory spirit cultivated within this project because they can reinforce collaborative work,
participation in decision-making, and the exchange of skills (Biello, 2009). Thus, focus groups were an appropriate choice to gather the information needed for this study, since, as a method, they offer the means by which to acquire insight into a wide range of views about a specific issue as well as to observe how a group interacts and discusses the issue (Liampittong, 2011).

Additionally, the conceptual framework (rooted in a critical realist paradigm) and the methodology (the participatory qualitative paradigm) of this study underpinned the design and formation of both the focus groups and other methods of data collection. For example, the conceptual framework calls for emancipation, social change, and a complex understanding of disability, including its psychological, physiological, social, cultural, economic, and political dimensions. Thus, in order to give the participants the opportunity to explore a wide range of disability issues in Kuwait on these different levels, qualitative methods were chosen, since “if you are concerned with exploring people’s life-histories or everyday behaviour, then qualitative methods may be favoured” (Silverman, 2014, p.9). Thus, it is vital to confirm that the aim of this methodology was to explore how the co-researchers and the participants derive meaning from their experiences, and how wider society, in contrast, affects those meanings, while taking into consideration material and non-material realities (Braun and Clarke, 2006).

Similarly, interviews as another method of data collection were vital to explore both the experiences within the research process as well as the experiences with
disability in Kuwait. In conducting these interviews, three principles were kept in mind: 1) the acknowledgment of a person’s own knowledge is as important as the knowledge that he/she strives to know; 2) what he/she wants to know determines which questions should be asked; and 3) what he/she already knows determines the way the questions are asked. As Leech (2002, p.665) puts it:

In an interview, what you already know is as important as what you want to know. What you want to know determines which questions you will ask. What you already know will determine how you ask them.

Moreover, in this project a research diary was used, solely by myself. The co-researchers were encouraged to keep diaries as well, but none were obliged to do so. I urged the co-researchers to keep diaries because I believe that such a method can involve both researchers and participants in giving personal accounts of daily events, discussions, and interactions (Borg, 2001). Additionally, diaries can be used repeatedly to examine continuing experiences and give individuals the opportunity to explore social and psychological processes within daily situations (Bolger, Davis and Rafaeli, 2003). A diary was a useful approach that helped me to be reflective and reflexive throughout the research process. I also used my diary to document what was said/discussed in the meetings.

4.4.2 Techniques in Deploying Research Methods

In relation to the techniques I followed in the data collection, the focus groups and the one-to-one interviews were semi-structured. This means they used open-ended questions that provided opportunities for both interviewers and interviewees to
discuss different topics in detail (Hancock, 1998; Leech, 2002). Similarly, my role as a facilitator in the focus groups was flexible in order to reinforce group dynamics (Noaks and Wincup, 2004). I designed the questions for the focus groups myself (the first one, in particular, see Appendix 6), but the questions and the topics of the one-to-one interviews with the non-disabled participants and the participants in the disability film were designed collaboratively with the co-researchers. Designing the questions for the first focus group individually stemmed from the fact that this focus group was held at the very beginning of the research processes when the co-researchers were not fully involved in the project. They also were not adequately supported in terms of research methodology. In the second focus group, I started by showing the co-researchers my initial analysis of the first focus group, then moved on to explore some of the issues raised in the first one in detail. The second focus group took the nature of a conversational meeting more so than the first. In relation to the interview questions conducted with the participants in this project, we designed the interview schedules collaboratively during the regular meetings (see Appendix 7 for a sample of an interview schedule). This interview schedule was designed when we were still considering the idea of creating an open online course.

Furthermore, during the focus groups, the co-researchers were encouraged to share their personal experiences, because these play a substantial role in this kind of project, which aims to study social change. Also, I found it useful for the research to share my personal experiences. For example, I shared my experiences with my disabled niece and addressed the issues that my sister faces when she
goes out with her daughter.

Additionally, during the focus group, I most of the time played a listening role (Robson, 2011), giving participants more room to express their feelings, talk about the problems they face in society, and suggest solutions. This approach can also reinforce the core idea of the focus group, whereby the participants interact with each other rather than only with the researcher's agenda (Cohen, Manion and Morrison, 2011).

Krueger (2002) expatiates other issues with focus group techniques when he addresses concerns surrounding the number of the participants, environment, moderator skills and analysis, and results reporting. In relation to the number of participants in a focus group, the views of qualitative theorists vary. For example, Liamputtong (2011) suggests that each group should involve six to eight individuals from similar social and cultural backgrounds or with similar experiences or concerns. On the other hand, Morgan (1998) proposes that each group could involve between four and twelve people. Moreover, Fraenkel and Wallen (2006) suggest that a group should have four to eight participants. Based on these different views, I was careful not to run a group with fewer than four participants, but with no more than six, as I believe that a large number of participants may lessen effective participation from some of the members. This problem can arise, as some participants may have difficulties speaking in front of many people. This problem is a subject of debate among scholars. For example, Smithson (2000) believes that there is a problem if only one voice is heard, which
can happen if there is a dominant member of the group trying to suppress dissenting views on controversial topics. This problem occurred for me when I ran the second focus group with six participants, although I believe that this number is reasonable for a focus group. To overcome this problem, as a moderator, I gave greater opportunities to members in conflict with the dominant participants' opinions. Also, conducting one-to-one interviews with the co-researchers could have solved this problem, but, unfortunately, this never happened. I was able, as I stated earlier, to conduct one-to-one interviews with only two co-researchers. I would consider my inability to conduct in-depth one-to-one interviews with the other co-researchers as a limitation of this project.

Additionally, my role as moderator was to keep the discussions on topic as much as possible and to show an interest in a discussion topic without reinforcing extant expectations or confirming a prior hypothesis (Liamputtong, 2011; Sim, 1998). However, at the same time, I found it useful to share my disability perspective with the co-researchers and get feedback from them. For example, at the time of data generation, as my reading related to disability perspectives was still somewhat inadequate, I was influenced by the social model of disability. Thus, it was meaningful at the time to share a UK-based perspective and discuss with the co-researchers its suitability to be applied in the Kuwaiti context.

4.5 Reliability and Validity

This section demonstrates the strategies I followed to ensure the reliability and validity of this project by drawing upon the works of qualitative theorists such as
Guba and Lincoln (1981), Silverman (2014), and Morse et al. (2002).

Hammersley (1992, p.67) defines reliability as “the degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions”. He describes validity as “the extent to which an account accurately represents the social phenomena to which it refers” (1990, p.57). Generally, a considerable number of qualitative researchers think that “in social sciences, the principle of replicability is seldom achievable in the same way” (Lepper, 2000, p.178). People are different and they present themselves in various ways in differing contexts. Therefore, obtaining the same results on different occasions is difficult and not desirable. However, this issue has not prevented qualitative researchers from making many attempts to deal with issues related to reliability, and they have developed methods for testing the quality of their results (Lepper, 2000).

In their 1980s accounts on qualitative research, Guba and Lincoln replaced the terms ‘reliability’ and ‘validity’ with the corresponding concept of ‘trustworthiness’, which was comprised of four aspects: credibility, transferability, dependability, and confirmability (see Guba, 1981; Guba and Lincoln, 1981; Lincoln and Guba, 1985). Although the procedures and techniques of these four aspects are achievable in qualitative research, Morse et al. (2002) suggest that these standards are not applicable to all such methods. For example, they reveal that ‘confirmability’, which is undertaken to ensure that findings are the results of participants’ experiences and are not influenced by the characteristics of the
researcher (Shenton, 2004), is not relevant to postmodern perspectives such as feminism and critical theory, which view the researcher’s experience as a part of the data, and which understand reality as dynamic and changing.

The notion of ‘transferability’, in which the researcher is responsible for providing numerous details about the context of his/her research in order to verify whether the findings can be applied to other situations (Shenton, 2004), is also in conflict with social philosophies such as postmodernism and constructionism, which view reality as changeable, transmittable, and multiple. This issue may also lead to a problem with the ‘generalisability’ essentially built into quantitative research, since such work often strives to understand the sample being researched as representative of the whole population (Stenbacka, 2001). ‘Generalisability’ is also in opposition to these social philosophies because human experience is different according to the situation and person, and thus cannot be generalised. However, Yin (2009), on the other hand, believes that the term ‘generalisability’ can be relevant to qualitative research if its aim is to give an analytical understanding of a particular phenomenon rather than a statistical generalisation. For Yin (2009), generalisation in qualitative research is not about an inference about a population as in quantitative research; rather, it is about using a previously developed theory as a vehicle and comparing it with the empirical results of the case study. Yin (2009, pp.38–39) concludes that, “if two or more cases are shown to support the same theory, replication may be claimed”. In this case, from a critical realist perspective, replication is possible and can lead the qualitative researcher to develop reliable knowledge that leads to scientific progress (Sayer,
As this project is founded on the critical realist paradigm, the problematic procedures suggested by Guba and Lincoln in the 1980s made me think about other strategies more suitable to ensuring reliability and validity in the current project. However, from the discussion above, it seems that not all of these procedures are problematic to my critical-realist-informed perspective. For example, as my experiences as a researcher and my conceptualisation cannot be taken away in any way from the study findings, ‘confirmability’ obviously is in conflict with my critical-realist-informed perspective. However, to find out whether the criterion of ‘reliability’ replaced by ‘authenticity’ for constructionists (Guba and Lincoln, 1989; 1994) is consistent with my critical-realist-informed perspective is a matter of controversy. This issue goes back to the debate concerning strong and weak social constructionism. If the main driver that causes strong social constructionists to reject, for example, the criterion of ‘reliability’ stems from their rejection of replicability and their claim that “there exists no external reality independent of us and/or that we cannot gain any reliable knowledge about it” (Danermark, 2002, p.58), then I disagree. I believe that there is a reality that is independent of us and “we can … develop reliable knowledge of the world and have scientific progress” (Sayer, 2000, p.71). However, at the same time, I accept weak social constructionism, which claims that “there is no neutral access to the world, knowledge is linguistic (by and large) and social, and language is not a transparent, stable medium, but opaque and slippery” (Sayer 2000, p.71).
In short, I believe that reliability is achievable in qualitative research and scientific progress is attainable. The next part of this section will provide the reliability and validity strategies I have taken into consideration throughout the research process and that I believe are consistent with my critical-realist-informed perspective.

Silverman (2014) suggests that audiotapes and transcripts (which can record soft utterances such as ‘yeah’ or ‘mmm …’) are important for enhancing reliability in qualitative research. This is because they can offer a number of advantages: tapes are a public record for the scientific community and can be replayed, while the resultant transcripts can be improved because the tapes preserve sequences of speech (Silverman, 2006). However, some would argue that the idea of letting others listen to the tapes is in conflict with the current ethics regulations of the University of Manchester. Thus, in the case of this study, the scientific community allowed to listen to the tapes is restricted to my supervisors and myself.

Producing the audio recordings and transcriptions of the data was my job as the principal researcher. It is fundamental to mention that all focus groups and interviews in this study were voice recorded and field notes were written in Arabic. Throughout the research process, I transcribed the data directly after each focus group or interview. I transcribed each firstly into Arabic and then translated it into English; the data obtained in both languages were read repeatedly to search for meaning. After this process, I forwarded the transcripts to a proofreader in order to make sure that the English version was fluent and could be clearly understood. When I received the corrected document, I made further changes
based on the proofreader’s comments, if any were necessary. This process was another challenge in this research, as I found that the transcription and translation of the data were very time consuming: for just two interviews, the process could take as long as two weeks. However, it was crucial to ensure that the data translated from Arabic accurately reflected the accounts of the participants. This can improve the reliability of the data. The analysis process including coding the extracts of the data set and searching for themes has been conducted initially in Arabic. After all the extracts have been coded in Arabic and the themes emerged from the data, I translated them into English.

Another issue with regard to enhancing reliability is ‘collective analysis’, or what Silverman (2014) calls ‘inter-rater reliability’, defined as “comparing the analysis of the same data by several researchers” (2014, p.90). I have taken these two approaches into consideration in order to enhance the reliability of the data. In relation to this process, this research was designed to reinforce the spirit of collaboration throughout the process. It was based fundamentally on analysing the data collectively with the co-researchers and on continuous interactions with the data set.

Moreover, other strategies I have taken into consideration are those suggested by Morse et al. (2002). They suggest verification strategies for ensuring rigour in qualitative research that is cultivated in the research process per se, rather than strategies that can be checked by external reviewers at the end of the project. These strategies include investigator responsiveness and verification strategies
such as methodological coherence, sampling sufficiency, developing a dynamic relationship between sampling, data collection and analysis, thinking theoretically, and theory development. I have followed all of these strategies in this project.

In relation to investigator responsiveness, Morse et al. (2002) refer to this as the skills, creativity, sensitivity, and flexibility of the researcher that enable him/her to verify reliability and validity throughout the research process. This can be achieved through a continuing analysis of the preliminary data that helps the researcher to determine future participants. This process is congruent with what Silverman (2014) calls ‘analytic induction’, a process based on an on-going analysis and revision of the hypothesis or redefinition of phenomenon until a relationship between the hypothesis and the phenomenon is achieved.

This process served as a ‘launch base’ in this project (see Chapter 1). As I stated in the introductory chapter, I went through a series of exploratory events that led me eventually to decide on the current topic. I explained in the first chapter how I started with a topic and ended up with a different one: my decision to change was built on the data I generated from both disabled and non-disabled people throughout the exploratory phase (for more detail about this process, see Chapter 1).

The other issue taken into consideration in this project was the verification strategies suggested by Morse et al. (2002). The first verification strategy is ‘methodological coherence’, which aims to ensure consistency between the research questions, the methods of data collection, and the analytic procedures.
Clearly, this is a qualitative project, so the methods of data collection that helped me to answer my research questions were qualitative, such as focus groups and interviews. I found these methods potentially useful in answering my research questions. However, Morse et al. (2002) add that this strategy is not merely about designing appropriate methods: it is also about treating the data differently by changing or modifying methods if required. For example, it was determined in my research proposal that the data-generation method for the last research question (i.e. about the co-researchers’ experiences of the project) would be a focus group with the participants who collaborated with me on the project. However, this goal was not achievable. I contacted all co-researchers who collaborated with me, but I was able to meet up with only two of them. Since it was not possible to run a focus group with only two participants, I changed, after a consultation with the two co-researchers, my methods of data generation from a focus group to interviewing the participants as a pair.

The second verification strategy is the ‘appropriateness of the sample’. Morse et al. (2002) confirm that the participants should be representative and have knowledge about the topic. As the participants who worked with me on the project were co-researchers, they were familiar with the topic and became more involved in the research process over time. The non-disabled participants and the additional ones who participated in the disability awareness film were also able to gain information about the project and its purpose before taking part.

The third strategy is ‘collecting and analysing data concurrently’. For Morse et al.
(2002), this process is essential for reaching reliability and validity. The co-researchers and I looked at the data generated directly after each focus group or interview. This interaction with the data was helpful in making decisions about the needs of the process and project.

The fourth strategy is ‘thinking theoretically’. This is a concern that the ideas emerging from the data are reconfirmed in the new data (new ideas), which must be verified in the data already generated: “thinking theoretically requires macro-micro perspectives, inching forward without making cognitive leaps, constantly checking and rechecking, and building a solid foundation” (Morse et al., 2002, p.13). One way to achieve this, and thus increase validity in this type of research, is by the use of critical reflection throughout the research process (Melrose, 2001), or what Shenton (2004) calls ‘reflective commentary’. Shenton (2004) suggests that reflective commentary includes recording initial impressions of data-generation sessions to help clarify themes generated from the data and theories. As the nature, procedures, and practices of this project suggest, this exercise was crucial in this type of research.

The final strategy is ‘theory development’. Morse et al. (2002) confirm that this is about determining whether the data generated in the study can potentially constitute a conceptual or theoretical understanding. Thus, for them, theory can be developed as an outcome of the research process and as a pattern for comparison and further development of the theory. Therefore, determining the continuous interplay between data collection and analysis throughout the research process can
lead to the development of a grounded theory (Strauss and Corbin, 1998). This is important, and could lead eventually to a theorising of disability in Kuwait (see Chapter 8).

Moreover, it is vital to add here that triangulation between methods of data collection (such as focus groups, interviews) was another way of enhancing the credibility of the findings (Stringer and Genat, 2004). However, triangulation does not aim to seek the ‘truth’ of the participants’ accounts, nor does it provide a complete picture of a particular phenomenon (Silverman, 2014). Rather, it is “a strategy that adds rigor, breadth, complexity, richness and depth to any inquiry” (Denzin and Lincoln, 2011, p.5). Take as an example the exploration of the issue of non-disabled people who claim fraudulently. Participants raised this issue during both the exploratory phase and in the main study. For further exploration of the theme, the co-researchers and I thought about interviewing decision makers to verify the existence of this phenomenon. The triangulation between the accounts of the focus group members and the interviews with the decision makers helped us to acknowledge the existence of this issue, despite the divergence of views on how it has arisen (see Chapter 2).

Another strategy that I have taken into consideration to verify validation was ‘member checking’ (Frankel and Wallen, 2006) or ‘respondent validation’ (Silverman, 2014). Frankel and Wallen (2006) define ‘member checking’ as the process of participants reviewing the accuracy of the research report. However, Silverman (2014), by drawing upon the works of theorists such as Bloor (1978;
191983), Abrams (1984), and Fielding and Fielding (1986), reveals that respondent validation of the final report is problematic, as the language used in the final report may be not accessible for research participants or they may not be interested in the topics. Nevertheless, he confirms that this does not imply that the researcher should not seek feedback from the participants. Instead, rather than validating the final report, researchers can deal with feedback on the accuracy of the dialogue throughout the research process as another source of data and suggestions for further analysis.

As this research is based on ongoing interaction with the data throughout the research process, this exercise (i.e. respondent validation) has been taken into consideration. I was able to check the accuracy of the transcripts from the focus groups with the co-researchers. This exercise was useful for us as it helped us to decide on whether we needed to collect more data and the characteristics of the participants who we intended to invite into the project. However, on the other hand, we were not able to check the accuracy of the interviews conducted with the non-disabled participants. I sent the transcripts for each individual in order to check what was said and asked them to provide feedback, but I received no response. This may be due to their busy with work schedules, lives, etc., or different priorities. However, I aim to summarise the key findings of the project, then send them to the co-researchers and all members who participated in the project. This process will help to make the thesis or the final report accessible to the general public and thus enable me to seek feedback.
4.6 Ethical Considerations

The most important ethical issue related to this research is that of protecting participants from physical or psychological harm, discomfort, or danger that may occur due to research procedures (Fraenkel and Wallen, 2006). Therefore, participants’ consent to be part of the research was obtained, which included, for example, information on the purpose, content, procedures, reporting, and dissemination of the research (Cohen et al., 2011). Consent forms (see Appendix 1 and Appendix 4) for both focus groups and interviews were given to the co-researchers and participants to offer them the chance to decide whether they wanted to be part of the study. In addition, all information, including audio recordings and personal documents required from the participants, were used only for the purposes of this study, as well as presenting at conferences and future publications.

Generally speaking, when designing and considering the ethical aspect of a research project, gaining “formal informed consent is necessary for all qualitative research methods” (Mack et al., 2005, p.7). However, when involving the participants as co-researchers and not as research subjects, I believe the situation is different. Indeed, all of them had the right to agree or disagree with participating; however, strictly following ethical procedures may allow the issues of power dynamics in participatory research to be highlighted, which makes me wonder why I needed a consent form for the co-researchers when I was not required to sign one myself. Nonetheless, because of the positivist procedures of the university that both my supervisors and I must follow to complete the PhD
satisfactorily, I had no choice but to give the participants the consent form to be signed. However, I think that anonymising the co-researchers’ names is not appropriate in this kind of project, as this may disregard their scientific right to be noted as co-researchers rather than as research subjects (Bruckman, Luther and Fiesler, 2015). Thus, as stated earlier in this chapter, I have mentioned the real names of the co-researchers with their consent. I have not only, however, stated the real names of the co-researchers but also the names of the other participants with their consent. This raised the issue of what, or who, should be anonymised in research (Clark, 2006). In this project there were disabled people who participated as co-researchers, non-disabled people in different political positions in the state, and people who participated in the disability film. Anonymising research data may include participants’ names, age, ethnicity, location, and political and religious beliefs, but it is a decision to be made based on the study purpose (Clark, 2006). Moreover, according to the research ethics at the University of Manchester, data management and the protection of the participants’ personal information comply with the UK Data Protection Act (1998) and guidance (e.g. Research Governance Framework, NHS Code of Practice on Confidentiality or the NHS Care Records Guarantee) (University of Manchester website).

What is applicable to the participants in the UK does not necessarily apply to the participants in Kuwait. First, there is no law in Kuwait that forbids stating the real names and detecting the identities of participants in research unless this leads to psychological harm or in the case the participants requesting not to be named. Second, I find some characteristics of the participants such as gender, religious
belief, and political position to be crucial for data analysis; thus, anonymising these would mean providing an incomplete picture about the experiences of the participants. Third, if the participants agreed that their real names and identities could be disclosed then this should not be seen as a problem. For these reasons, I feel it is appropriate to refer to the co-researchers’ and the participants’ real names (see also Bruckman, Luther and Fiesler, 2015).

4.7 Data Analysis

In Chapter 3, I showed how the conceptual framework adopted for this study allows an exploration of disability at different levels, including intrinsic factors (biological/medical and psychological) and extrinsic factors (socio-cultural and socio-economic). However, I want to be clear that I am not suggesting that every level is isolated from the other levels. Rather, the analysis will show how intrinsic factors (impairment/body) and extrinsic factors (disability/society) intersect. For example, when considering the notion of ‘normality’, I will illustrate how it is vital that different dimensions be discussed by showing the interactions between biological and socio-cultural factors, and will show that this notion is not merely related to medical issues, but is also a social and cultural construction. Thus, in order to explore the data from these different perspectives, I found that incorporating multiple approaches is useful for analysing disability in Kuwait. For example, to explore the socio-economic level, I found materialist approaches, such as the social model of disability, to be extremely important to acquire a better understanding of the material lives of the co-researchers. Moreover, integrating
the work of the cultural and critical disability scholars inspired by Foucauldian analysis is also vital for exploring the socio-cultural level and the role of discourse. Therefore, my approach to analysing disability is similar to the approaches of those critical realism theorists who analyse disability from a critical realist perspective (see, for example, Williams, 1999; Danermark and Gellerstedt, 2004; Bhaskar and Danermark, 2006; Shakespeare and Watson, 2010; Watson, 2012; Shakespeare, 2014). The works of these theorists focus on non-reductionist approaches to disability by combining the best aspects of the:

... individual essentialist, associated with the medical (clinical or biological) model; contextual essentialist, associated with the social (or socio-economic or economic) model; social constructionist (post-modernist or post-structuralist), associated with the linguistic or cultural model (Bhaskar and Danermark, 2006, p.278).

In the first edition of his book, Disability Rights and Wrongs, Shakespeare (2006) gives a useful example of how manifold approaches are beneficial for analysing disability from different perspectives:

I have found a plurality of approaches beneficial in the analysis of disability. For example, feminism offers the concept of the personal being the political; Foucault highlights the medical gaze, and the genealogical method; post-structuralism deconstructs notions of identity; post-modernism challenges binary dichotomies and opens-up space for complexity (Shakespeare, 2006, p.55).

Considering this plurality of approaches will help me to develop a better understanding of the complex lives of the co-researchers. However, although I consider these different approaches, the analysis will show how I sometimes need to broaden my approach, especially when these approaches limit the recognition
of the biological level. I would also benefit from the features of critical realism and go beyond the discursive practises of the co-researchers. I will consider other discursive and non-discursive practices, such as embodiment and materiality, and deal with them as an extra-discursive ontology that might play a role in the lives of disabled people in Kuwait (see Sims-Schouten, Riley and Willig, 2007; Fairclough, Jessop and Sayer, 2010). Discursive practises are associated with the exploration of what the co-researchers discursively reported in this project. The extra-discursive practices go beyond the points that the co-researchers stated through the exploration of both discursive and non-discursive practises that exist in their lives. By exploring these extra-discursive practices, one can acquire a better understanding of the lives of the co-researchers. For example, the exploration of the role of the body/impairment that might play a role in the lives of the co-researchers, as well as their social and physical environment, can help me to interpret their choices in discourse (Sims-Schouten, Riley and Willig, 2007). Furthermore, an exploration of current governmental policy towards disabled people in this project can also help me to interpret why the co-researchers used certain traits of language and not others. For example, the existence of high levels of financial resources allocated for disabled people in Kuwait, and a high standard of living, produce extra-discursive practices that might affect their choices of discourse. Also, the analysis of the data generated from non-disabled people will serve as extra-discursive practises that help me to acquire a better understanding of the co-researchers’ social and physical lives.

I am interested in, as shown in Chapter 3, the triplex relationship between the
signifier, signified, and referent. Thus, I am interested in what the co-researchers and the participants say and how they say it because I believe that “we cannot completely explain how we are speaking without taking into account what we are speaking about (and not just what we think we are speaking about)” (Bhaskar and Danermark, 2006, p.284). In short, I am interested in “the ways individuals make meaning of their experience and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of ‘reality’” (Braun and Clarke, 2006, p.81). In order to explore this relationship, I find thematic analysis a useful approach for data analysis because it has the advantage of going beyond the semantic content of the data to the latent level through examining the underlying concepts and ideologies that shaped the semantic level of the data (Braun and Clarke, 2006). Following the process of thematic analysis suggested by Braun and Clarke (2006), the next chapter will show the main themes and sub-themes that emerged from the data set.

4.8 Summary

In this chapter, I discussed the philosophical background of participatory research strategies, such as emancipatory research and participatory research, in the field of disability studies. In the second section, I addressed the methodology underpinning the research and practicality, and discussed the rationale and justification of methods used for data collection, validity and reliability, and ethical considerations. The chapter ended with a discussion of the approaches embraced in order to analyse the data generated for the purpose of this project.
The next chapter will show the process of analysis, including the coding process, and the main themes and sub-themes that emerged from the data set.
Chapter Five

The Analysis Process

5.1 Introduction

This chapter shows the steps I have followed to analyse the data generated. It shows the main themes and sub-themes that emerged across the data set. In order to analyse the data, thematic analysis is an appropriate approach that enables me to answer the research questions. I have followed particularly the steps suggested by Braun and Clark (2006).

In order to gain a better understanding of the data generated, the data was subjected to different stages of analysis, from description to deep analysis and interpretation. Description is allowing the data to “speak for themselves” (Wolcott, 1994, p.10), while analysis is “the interplay between researchers and data” (Strauss and Corbin, 1998, p.13). Analysis concerns organising, reporting, and identifying the key features in the data in a systematic way (Wolcott, 1994). In relation to interpretation:

… the goal is to make sense of what goes on, to reach out for understanding or explanation beyond the limits of what can be explained with the degree of certainty usually associated with analysis (Wolcott, 1994, pp.10–11).

All of these phases have been considered in this project. In relation to the first two phases (description and analysis), I found them to be necessary processes that
helped me to decide on the current research topic during the exploratory phase. I also conducted the process of data description and part of the analysis process collectively with the co-researchers, when we were, at this stage, more driven by the data than a theoretical interest (Braun and Clarke, 2006). However, deeper analysis and interpretation in relation to the conceptual framework developed for this project were conducted individually at a later stage.

There are different methods involved in thematic analysis; however, in this project, I follow the steps suggested by Braun and Clarke (2006). I will begin this chapter with the exploration of the data set used for analysis. Then, I will go through the steps of thematic analysis followed in this project.

5.2 The Data Set

The data set consists of two focus groups with the co-researchers, two pair interviews with co-researchers, and four interviews with non-disabled people from different positions in the state. Additionally, the data set contains the accounts of those who participated in the disability awareness film (one non-disabled and three disabled participants). Table 5 summarises all the data used for analysis in this project.
Table 5: The Data Set

<table>
<thead>
<tr>
<th>Data collection method</th>
<th>Number of interviews</th>
<th>Number of members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus group</td>
<td>2</td>
<td>Six co-researchers</td>
</tr>
<tr>
<td>One-to-one interviews</td>
<td>4</td>
<td>Two decision makers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>One lecturer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Imam</td>
</tr>
<tr>
<td>Pair interviews</td>
<td>2</td>
<td>Two co-researchers</td>
</tr>
<tr>
<td>Interviews in the</td>
<td>4</td>
<td>One non-disabled participant</td>
</tr>
<tr>
<td>disability film</td>
<td></td>
<td>Three disabled participants</td>
</tr>
</tbody>
</table>

5.3 Analysis Process

Thematic analysis is a method used for identifying, analysing, and reporting themes within data as well as organising and describing a data set in rich detail (Braun and Clarke, 2006). The method involves the identification of themes through “careful reading and re-reading of the data” (Rice and Ezzy, 1999, p.258). In addition, “it is a form of pattern recognition within the data, where emerging
themes become the categories for analysis” (Fereday and Muir-Cochrane, 2006, p.4).

A number of researchers have addressed different techniques in thematic analysis. For example, Ryan and Bernard (2003) suggest several tasks for analysing text: discovering themes and subthemes, deciding which themes are important in any project, building hierarchies of themes or code books, and linking themes into theoretical models. In addition, Attride-Stirling (2001) describes a process of thematic analysis aided by thematic networks.

Braun and Clarke (2006) specify six phases in thematic analysis: becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. In this project, I have followed these phases to identify the themes emerging across the data set.

5.3.1 Phase One: Becoming Familiar with the Data

I collected the data for this project myself. All focus groups and interviews were voice recorded and field notes were written in Arabic. In order to conduct a thematic analysis, the data was required to be transcribed into written form (Braun and Clarke, 2006). Thus, I transcribed the data into Arabic and then translated this into English; the data obtained in both languages was read repeatedly to search for meanings.

Transcribing data in detail from audio recordings is a crucial step. As stated in the previous chapter, both audio tapes and transcripts can offer a number of
advantages. Sacks (1984), for example, stresses that one should work with ‘actual occurrences’ of the talk. This is important in order to be able to record such incidents as pauses, overlaps, in breaths, and so on (Silverman, 2006).

However, thematic analysis does not require very small distinctions to be examined, but, at a minimum, it requires a precise and comprehensive account of all verbal and sometimes non-verbal utterances such as coughs (Braun and Clarke, 2006). It depends actually on what one is interested in, and looking for tiny details such as pauses and overlaps may not always be useful in analysis. However, by studying voice tapes, the researcher is able to focus on the ‘actual details’ of the aspects in which he/she is interested (Silverman, 2006).

In this project, I am more interested in the ideas raised by the co-researchers and the participants in the discussion. In this phase of analysis, it is a good idea to start taking notes or marking ideas for coding (Braun and Clarke, 2006). As stated in Chapter 4, I worked initially on analysing the data collaboratively with the co-researchers. As a result of this collaborative work, the co-researchers and I were able to generate “an initial list of ideas about what is in the data and what is interesting about them” (Braun and Clarke, 2006, p.88). By going through the data, the following list of ideas was generated in relation to the research process and disability in Kuwait:

- This research is beneficial in changing people’s negative views about disability and developing research skills
- There are negative attitudes by non-disabled people towards disabled people in Kuwait
- The representation of disabled people in the media is distorted
- Society has failed to include disabled people in Kuwait
- The buildings in Kuwait are not accessible for disabled people
- There is a lack of policies and legislations that ensure the rights and the services of disabled people in Kuwait

In the next part, I will show how we generated initial codes from the data set.

5.3.2 Phase Two: Generating Initial Codes

“Codes are tags or labels [used] for assigning units of meaning to the descriptive or inferential information complied during a study” (Miles and Huberman, 1994, p. 56). “A ‘good code’ is one that captures the qualitative richness of the phenomenon” (Boyatzis, 1998, p. 1). Charmaz (1983) describes coding as “simply the process of categorizing and sorting data” (p. 111). There are different ways of extracting codes. In the manual method of coding, one can code the data by writing notes on the text that is analysed, by using highlights or coloured pens to indicate potential patterns (Braun and Clarke, 2006). This can be done by line-by-line, phrase-by-phrase, or word-by-word analysis (Strauss and Corbin, 1998).

Similar to the previous phase, I generated the initial codes collaboratively with the co-researchers. At this stage, as stated earlier in the chapter, the co-researchers and I were driven by the data and not by a theory. In the former, the themes
depend on the data, while the latter depends on a specific question the researcher is keen to code around (Braun and Clarke, 2006). We looked together at all the data generated for the purpose of this study and searched for potential codes across the data set. Figure 2 illustrates the initial coding process of an extract from the data of the first focus group with the co-researchers. The extract consists of the discussion on benefits the co-researchers’ gained from the research processes. After examining all of the data, we were able to develop potential codes. Figure 3 shows some of these potential initial codes across the entire data set.

Figure 2: Generating Initial Codes from an Extract of the Data
5.3.3 Phase Three: Searching for Themes

Boyatzis (1998) defines a theme as “a pattern in the information that at minimum describes and organises the possible observations and at maximum interprets aspects of the phenomenon” (p.161). This phase begins when all data has been initially coded and collated across the entire data set (Braun and Clarke, 2006). “Themes that are presented are often simply labels for metacategories (a more inclusive category), or perhaps as a classification of codes into types of categories” (Bazeley, 2009, p.7).

![Figure 3: Some of the Initial Codes Across the Data Set](image)

By examining the data set and the codes generated, we were able to produce an initial thematic map. Figure 4 shows the themes and sub-themes that emerged
initially from the data set. The figure shows two main themes. It also shows how two sub-themes emerged from the other main theme of disability in Kuwait.

Figure 4: Themes That Emerged Initially from The Data Set
5.3.4 Phase Four: Reviewing Themes

This phase consists of two levels of reviewing and refining: level one involves reviewing at the level of the coded extracts and level two involves a similar process but in relation to the entire data set (Braun and Clarke, 2006). Unlike the previous phases, which were based on a collaborative work with the co-researchers, from this phase, I started to work individually. Also, from this phase, as my reading of the literature expanded, I became more theory-driven, interested in specific features in the data set (Braun and Clarke, 2006). For example, I started to notice the link between what the co-researchers and the participants said and the social model and individual model of disability. Specifically, I became more interested in how the co-researchers make meaning of their experiences and how society imposes on those meanings. In other words, I became keen to examine how both the social attitudes of non-disabled people and social structure have had an impact on the identities of the co-researchers, enabling them to adopt different disability conceptualisations (e.g. individual model and social model) throughout their discourse. Also, in this phase, I was looking for singularity in the data. In a sense, I became more interested in searching for disability issues that give specificity to the Kuwaiti context, such as the medical test before marriage and those who are, according to the co-researchers, claiming fraudulently. As a result of this, I reviewed the codes and themes and refined and deleted some that were unnecessary. Throughout the process of refinement, I found an overlap between the two themes of ‘societal structure’ and ‘social attitudes’. Thus, I decided to
group them into one theme ‘societal structure and social attitudes towards disabled people’. Figure 5 shows the outcome of this refinement process.

5.3.5 Phase Five: Defining and Naming Themes

This phase involves the defining, refining, and naming of the themes in the final analysis (Braun and Clarke, 2006). I went back to the data extracts for each theme to organise the themes and sub-themes in a coherent manner. Because coding is an ongoing organic process (Braun and Clarke, 2006), I found it useful for clarity and structure to break down the theme of ‘the construction of normality’ into three sub-headings: ‘accepting the norms’, ‘politicising and medicalising’ and ‘language suitability’. Also, the discourse about disability conceptualisations (i.e. adopting the individual or social model spontaneously) was occurring throughout the discourse of the co-researchers and the participants. This means that the discourse of the co-researchers and the participants about the individual and social model overlapped with other topics, thus making it difficult to specify one sub-theme concerning ‘individual model vs. social model’ (see Figure 5). As result of this interweaving, I decided to delete this sub-theme, but taking into consideration the inclusion of the codes that represented this topic within different themes and sub-themes of the data.

Moreover, as it would be known to the reader at this stage of the thesis that the project was conducted in Kuwait, I found it unnecessary to keep the theme ‘disability in Kuwait’ in the final thematic map. Thus, the final thematic map consists of two themes. The first theme is the ‘research process’, which is related
to the process of participatory research, while the second theme is ‘societal structures and social attitudes towards disabled people’, which is related to disability in Kuwait. Additionally, in this phase I was able to tell the story that each theme captures and its relationship with the overall story throughout the data, and in relation to the research questions (Braun and Clarke, 2006). Figure 6 shows the final thematic map of the data set.
Figure 5: The Outcome of the Refinement Process
5.3.6 Phase Six: Producing the Report

The write-up of a thematic analysis is intended to tell the complicated story of the data in a way that convinces the reader of the value and validity of the analysis (Braun and Clarke, 2006). The next two chapters (Chapters 6 and 7) discuss the overall story of the data set. Chapter 6 discusses the themes that emerged in relation to the research process, while Chapter 7 tells the story of the data related to disability issues in Kuwait. The final reports of both chapters include data extracts for each theme.
Figure 6: Final Thematic Map, Showing the Two Main Themes
5.4 Summary

I have discussed in this chapter the analysis process that I followed in this project as suggested by Braun and Clarke (2006). I have shown how, at the beginning of the process, I collaborated with the co-researchers and then worked individually at later stages. The chapter addressed the main themes and sub-themes that emerged across the data set. The main themes that emerged were related to the research processes and to disability-related issues in the Kuwaiti context. The next two chapters will discuss the final phase of the analytic processes suggested by Braun and Clarke (2006). Chapter 6 will discuss the themes that emerged in relation to the research process, while Chapter 7 discusses the themes related to disability in Kuwait through the presentation of the experiences of disabled people in Kuwait.
Chapter 6

Findings and Discussion

The Experiences in Participatory Research Processes

6.1 Introduction

This chapter presents and discusses the findings and the main themes and sub-themes related to participatory research processes and the experiences of the co-researchers in this project. In this chapter, I will present and discuss the findings of the data generated from the focus groups and interviews with the co-researchers.

The themes and sub-themes that emerged from the data set appeared to be influenced significantly by the research questions and the co-researchers’ interests as well as my conceptual framework. As my conceptual framework is rooted in critical realism that seeks to explore the underlying structures/mechanisms that produce phenomena, exploring the complexity of the power relations between the co-researchers and me, as the main researcher, is essential. The awareness of power relations and reflexivity is vital in participatory strategies (see Chapter 4), as this enables the recognition (and exploration) of the social relation in research processes and production (Oliver, 1997). My main interest in the issues of power relations seen as underlying mechanisms that determine the relationship between the main researcher and the co-researchers formed the important topics in this
Therefore, based on the process of analysis described in Chapter five, the themes and sub-themes that emerged from the data on the research process were related to the following:

- **Research process**
  - Developing research skills
  - Whose research?
  - Changing social attitudes and societal structure
  - Hearing from the others
  - Research difficulties

One main theme (research process) and five sub-themes emerged from the data. The next section will discuss each sub-theme separately by providing extracts from the data set.

### 6.2 Research Process

The co-researchers expressed several reasons why they agreed to work with me as co-researchers and participate in this project. The most important point was changing people’s views on disabled people and disability. Kholood, Saja, and Yagoub agreed with this perspective:
Kholood: Well, this research can help us change people’s points of view around disability and disabled people… and also, we want to help you with your research. We want people to know more about disabled people… we also can benefit from the process, as we can know how to conduct research in a better way.

Hussain: Can this research help you develop research skills?

Kholood: Yeah, and change people’s views.

Hussain: “And change people’s views”, is this an important issue for you?

Saja: Yes.

Kholood: And benefits you in your research.

Hussain: And benefits me.

Kholood: Inshallah.

Hussain: What else?

Yagoub: As my sister said, to change people’s views – this is essential.

(Focus group date: 10th April 2014)
It is clear from this extract that the co-researchers had several reasons for agreeing to participate in this project. In the following sections, I will discuss each of these reasons separately.

6.2.1 Developing Research Skills

The co-researchers stated that one of the motivations behind engaging in this research was to benefit from the research process by developing research skills, such as preparing interview schedules, data analysis, and critical thinking skills:

Extract 6.2

I benefited from the way we do research. I mean the steps… in my work at university, I carry out research, but there are steps you made me aware of… I have never analysed before; I cannot say I will apply this now, but I will follow [these steps] in the future… I used to give presentations and get my marks… You taught me how to deal with research in the right way and I thank you for this.

(Saja, female, aged 22. Interview date: 2 November 2014.)

Kholood confirmed this notion:
Extract 6.3

This is my first time doing research in this way… ah, em, I mean I used questionnaires; I mean we have learned these things at university… but this is my first time doing research like this, complete research, video, case study… and discuss everything… everything we say, we discuss it in other meetings… this is the first time we learnt this.

Kholood, female, aged 24.
Interview date: 2 November 2014.

These two extracts highlight that Saja and Kholood felt they had benefited from the research process by developing new skills, such as qualitative research skills and analysis. In fact, developing new skills is important in participatory, emancipatory, and inclusive research; researchers conducting inclusive research who seek to support disabled participants need to use the necessary research skills throughout the research process (see, for example, Abell et al., 2007; O’Brien et al., 2014; Stevenson, 2014; Strnadová, Cumming, Knox and Parmenter, 2014). As shown in Chapter four, however, relatively few studies have highlighted power relations or supported the developing of research skills (O’Brien et al., 2014). Highlighting power relations and the awareness of where the power lies and who affects it is crucial in this kind of research (Chapman, 2005). In this project, I tried to address power relations by providing the co-researchers the opportunity to acquire some of the skills I have, thus creating a situation where power is more equally balanced forming a power balance (as much as I possibly could in these
situations). However, my attempts to provide the co-researchers an opportunity to acquire some of the skills I have could not equalise the balance of power, as in this type of research, one can never equalise the balance of power. In these situations, the participatory research is often led by the academic researcher (Kitchin, 2002).

This study, however, draws upon some of the principles of participatory research by sharing expertise with the co-researchers and supporting them in an effective way (Walmsley, 2001). Furthermore, by highlighting the issues of power relations and skills development, one can explore the complexity that is often ignored (such as failures, frustrations, and difficult times faced by researchers) in collaborative research (McClimens, 2008). The issues of power relations underline the complexities of the researcher’s role and raise the question regarding whether the role of the researcher is only to support co-researchers or seek empowerment and make a contribution to developing skills (Chapman, 2005).

In this project, I tried to provide the co-researchers the opportunity to learn the skills required to conduct qualitative research. In Extract 6.3, Kholood referred to quantitative research by saying that she used questionnaires and that this was the first time she conducted qualitative research. In order to analyse this situation, I would like to return to the discussion I raised regarding the meeting I set up with the co-researchers to explore qualitative research.

In Chapter four, I showed how the co-researchers and I jointly explored qualitative research strategies such as data collection and analysis methods, ethical
procedures, and validity and reliability. After this exploration, we undertook an activity that helped gauge their understanding of what they had learned. The co-researchers showed a good understanding of qualitative research. This, as stated in Chapter four, raised a number of power relations questions regarding who can/cannot participate. What if the co-researchers had not understood the qualitative research strategies? Would I have excluded them or would I have supported them in a more effective way?

The answer to these questions is that if the co-researchers had not understood the qualitative research strategies, I would have supported them in a more effective way. In fact, we allocated only one meeting to explore qualitative research strategies (see Appendix 2). Therefore, if the co-researchers needed more time to explore and learn more about research methodologies, I would have supported them with extra sessions. Abell et al. (2007), for example, talked about spending 11 weeks supporting learning disabled people on how to conduct research. It is worth noting that the difference may be related to the focal point of the research. In their paper, Abell et al. (2007), discussed how a group of learning disabled people and a group of non-disabled people worked together when conducting inclusive research as a group. The main reason behind group formation was to learn how to conduct research. Thus, the participants were adequately supported with the required research skills. In this project, the situation is different. This project focused on exploring disability issues in Kuwait and the process as whole rather than focusing solely on supporting the co-researchers in developing research skills. However, generally, the co-researchers were able to develop the
required skills practically throughout the process. It is true that we only allocated one meeting to explore qualitative research strategies, but we had other meetings where we could analyse the data and prepare the interview schedules.

Also, in the meeting allocated for exploring qualitative research strategies, the co-researchers seemed to have different views on quantitative and qualitative research. For example, Kholood was a supporter of quantitative research, while Abdullah was a fan of qualitative research. The most important power relations question that should be raised here is what if both of them were a fan of quantitative research and refused to work within a qualitative paradigm? Would I have excluded them?

My honest answer is yes. I would have thought about their potential to work with me within the qualitative paradigm. This is an example of the power relations between the co-researchers on the one hand and my supervisors and me on the other hand. In other words, this issue highlights the dilemma regarding to what extent academics are willing “to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose” (Oliver, 1992, p.111). Furthermore, according to Stone and Priestley (1996, pp.711-712), “at the same time, we find it necessary to satisfy our academic peers and examiners for, in the final analysis, it is the academy rather than disabled people that passes judgment on submitted theses”.

As I stated in Chapter one, I took up this project initially with an experimental research design that combined quantitative and qualitative research. As both of my
supervisors are more interested in qualitative research, this issue made me alter my research design. If, for example, I had insisted on using the research design I suggested initially, I would have had to change my supervisors or would have maybe needed to add a third person to the team with the appropriate knowledge. The same situation applies between the co-researchers and me, i.e. if they had declined to participate within the qualitative paradigm, I would have excluded them and looked for other participants. This issue of power relations led disability scholars such as Oliver (1992) and Zarb (1992) to highlight the difficulty associated with the application of emancipatory research. This is because the social relation in research is still, largely, controlled by academics and funding organisations and not by disabled people. This power relations issue makes it difficult or may be impossible to see this research as emancipatory research, mainly owing to the fact that it is my PhD research, and it is ‘natural’ that the main organisation and ideas of participatory research are under the control of the academic researcher (Chapman, 2005).

Nevertheless, although Kholood was initially a fan of quantitative research, the next extract (Extract 6.4) will show how she changed her view over time. In the pair interviews at a later stage, Kholood shared similar views to Saja’s:
Extract 6.4

Saja: I don’t consider questionnaires as research; I mean you give [it to] the student… he ticks the questions without reading them. He doesn’t read the questions, I myself do not read questions… and one time, I know one person ticked on male and she was in fact female.

Kholood: [laughter].

Hussain: Do you think interviews are better?

Kholood: Yeah and more credible… Tell them that Kuwaitis do not care about questionnaires and they tick without reading, as she said they just want to finish it and give it back to you.

Saja: Also, a questionnaire is biased… the questions have been chosen by the person who has prepared it…

Kholood: The researcher limits them with particular answers… maybe someone has a different answer, which is not available in the choices.

(Interview: Saja/Kholood, 2\textsuperscript{nd} November 2014)

This extract shows how Kholood changed her view of qualitative research over time by sharing criticism of quantitative research with Saja. They also stated that they had never conducted qualitative research before, talked about the new qualitative skills they learnt (as in Extracts 6.2 and 6.3), and specified that Kuwaitis do not care about questionnaires. This may give an indication of the domination of the positivist paradigm and the lack of popularity of the
qualitative/interpretative paradigm in Kuwait (see my discussion on disability research in Kuwait in Chapter two).

Nevertheless, there is another important reason why Kholood may have changed her mind. Since she knew I was a qualitative researcher, she may have wanted to be included in the project to please me. This was clear in Extract 6.1 when Kholood stated that one of the reasons why she agreed to participate in this project was to help me with my research. This situation is an example of how the political identity of the academic researcher can have an influence of the co-researchers’ preferences (Liddiard, 2013).

### 6.2.2 Whose Research?

The questions regarding who was in control and whether the members were only research participants or co-researchers occupied my mind a great deal during and after the research process. Therefore, it formed an important theme for discussion in the last two interviews with Kholood and Saja. They both revealed that they believed their roles were important in changing the research path:

**Extract 6.5**

| Hussain: Ok, throughout the research process, who was more in control? You or me? |
| Kholood: Yeah… our ideas were listened to… you take our ideas, if it is good we do it, if not, we cancel it and think about another idea together. I mean it was your and our opinions together. |
It is clear from this extract that the co-researchers believed that they had some control over the research agenda. However, at the same time, in this extract Kholood interestingly put the onus on me regarding judging whether something is ‘good or not’. This gives impression that she perceived my position as an expert or ‘knower’ in the field who was more able than them to judge whether certain ideas/suggestions were good or bad. This brings to the fore the dilemma that is often associated with both positivist and interpretative paradigms when the academic researcher is perceived as an expert and ‘knower’ (Stone and Priestley, 1996). In other words, she perceived me as a “professional as the holder of ‘privileged’ knowledge and experience against the ‘amateur’ knowledge of the...[co-researcher]” (Burnett, 2007, p. 6). This extract also raises the question related to whether the ideas raised by the co-researchers truly changed my mind.

My honest answer is no. They did not really change my ideas; however, I would say that the events that happened during the research process (for example, the co-researchers’ withdrawal) are one reason why I changed my ideas. It is true that although I had been listening to their ideas and views, I was in control of these ideas. If, for example, their views conflicted with my interest in obtaining my PhD or if they had views that differed from my initial research, this would have raised
questions about their potential suitability. This is because of the nature of my research. As I am conducting this research with the University of Manchester, I am restricted by the university regulations and I have to follow my supervisors’ guidelines.

Although both Kholood and Saja believed that their opinions had an impact on the research decisions, they were aware of the fact that their role in the research process was related to the disability issues rather than the research methodology:

**Extract 6.6**

Saja: We have more roles in the topics, but you have [more roles] in the form and methodology, but it was a complete role.

Kholood: You are more… but we had a role too… we have chosen together how many interviews we need and who do we need to interview and we have shared the work in preparing interviews schedules… but in the methodology, you know better than us about these issues.

(Interview: Kholood/Saja, 4th November 2014)

This extract demonstrates that both Kholood and Saja believed in the importance of their roles throughout the research process, namely, constructing the research methods and disability topics, yet they thought that I had more control than they did on the research methodology as they believed that I knew more than they did. This may give the impression, again, that the co-researchers see me as an expert in the field, which raises issues of power relations again. This brings to the fore the
epistemological assumptions made by academics and the academy in relation to what constitutes knowledge and the way in which ‘proper’ knowledge is constructed/discovered:

Academics working within the dominant paradigms for disability research (positivist and interpretative) have followed suit, casting themselves in the role of expert and ‘knower’ – a role which implicitly (and, on occasion, explicitly) maintains that the knowledge and experience of disabled people does not count (Stone and Priestley, 1996, p.701).

I do not think, however, that the issue was solely about knowledge and who knows more about conducting research; it was again an obligation per the university guidelines (that are often based on the positivist paradigm) that I had to follow before meeting them and inviting them to join the project as co-researchers. As mentioned in Chapter four, I was not able to meet them and bring them in as co-researchers before I had prepared my research proposal and passed the panel; this highlights what I would consider a weakness in my attempt to make the project fully ‘participatory’. Therefore, I was obliged to prepare my proposal and I decided to go ahead with a qualitative participatory research; I prepared my research questions individually. At the time, I was not able to do it differently (i.e. preparing my proposal collaboratively with the co-researchers) because of time constrains and different locations. This is another form of power relations that is clearly at odds with participatory research principles, and again, it was between the university, my supervisors and me.

A fully participatory research gives “disabled people [opportunity to] take an
active role in the whole research process from ideas to hypotheses to data generation to analysis and interpretation to writing the final report” (Kitchin, 2002, p. 3). Including the co-researchers in the whole process was not possible in this research. The idea of making this project participatory was mainly mine. In other words, I decided to make this research participatory and give disabled people the opportunity to be included as co-researchers. This raises a power relation question. When non-disabled academics seek to empower disabled people by giving them an opportunity to participate as co-researchers, are they truly granting disabled people some power and some control or they are actually (because they decided to give disabled people this opportunity) reinforcing their own powers?

I believe, however, that the situation is different and may lessen the control of the main researcher when someone conducts participatory research within a disability organisation where the workers of an organisation work together towards a common goal. This issue and other issues related to the research limitations will form the core of the last theme.

6.2.3 Changing Social Attitudes and Societal Structures

The co-researchers discussed the possibility of this research opening the door for further research and changing people’s views on disability and disabled people:


**Extract 6.7**

Hussain: Do you think that this research can open the door for further research in Kuwait?

Kholood: Yeah, *inshallah*, will open and non-disabled people will also become more aware... so they know about our views... maybe this study emm... maybe there are people who have never known that their views or their movements or their words bother us... this study makes them know.

(Kholood, female, aged 24.
Interview date: 2 November 2014.)

In this extract, Kholood seems optimistic about the possibility of this study opening the door for further research and making non-disabled people more aware about disabled people and changing their negative attitudes. Saja confirms the same notion as Kholood, i.e. the importance of raising awareness in society:

**Extract 6.8**

It is not about programmes, it is about awareness... you raise the awareness of society... you are an intellectual in society, you have petrol, you have workers, you have money – why don’t you raise awareness? Why don’t you make awareness campaigns? Why can’t we be like America, see how people look at disabled people in America?

(Saja, female, aged 22.
Interview date: 2 November 2014.)
Although, Saja expressed the same view as Kholood, her opinions were expressed more strongly. She criticised the country for the negligence of disabled people and the lack of awareness campaigns despite the availability of human and financial resources. Therefore, for Saja, the ‘problem’ of disability is centred on changing not only social attitudes but also societal structures. She also compared Kuwait with the US, hoping that Kuwait will treat disabled people in the same way as they are treated in the US.

Changing societal structures and policies was one of the reasons why the co-researchers wanted to be involved in this project. They believed that this project might pave the way for social and political change:

**Extract 6.9**

<table>
<thead>
<tr>
<th>Hussain: Ok… now you want to do this research to raise people's awareness and change their views… Ok, how can this research benefit you in the future?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kholood: Maybe not just people’s views but also things in the government can change.</td>
</tr>
<tr>
<td>Hussain: You mean policies?</td>
</tr>
<tr>
<td>Kholood: Yeah… or better preparation and accessibility in public places. Out of Kuwait, I can push my wheelchair by myself and I can go everywhere from the hotel to the shopping mall; here, I can’t cross the street; I can’t get down from the sidewalk of our house.</td>
</tr>
</tbody>
</table>

(Focus group date: 10 April 2014)
This extract shows how Kholoood expresses her frustration about policies and creating accessibility. As a result, she sees this research as a potential vehicle to express and share their voices and reach decision-makers and politicians in Kuwait in order to achieve social change in terms of laws and create accessible environments for disabled people.

In relation to the methodology (as discussed in Chapter four), although a number of inclusive research studies have been conducted around the world (for example, Atkinson, 2005; Chapman, 2005; Abell et al., 2007), this study appears to be the first in the Middle East to provide an opportunity for disabled people to participate throughout the process of conducting the research. In these three extracts, the co-researchers seem to suggest that by giving disabled people a voice to share their experiences, this study can help pave the way for social changes and the emancipation of disabled people in Kuwait. One might argue, however, that seeking the emancipation of disabled people is a rather ambitious goal for this research, yet this project can contribute to this overall goal by providing an inspiration and a basis for further research towards this aim. Thus, this research may not achieve “major change” (Shakespeare, 1996, p.118), but, at least, can start a conversation or ‘plant a seed’ towards possible social change.

6.2.4 Hearing from the Others

Other benefits of the research centred on identifying the views of both disabled and non-disabled people who participated in this project:
Extract 6.10

I myself benefited and enjoyed the study a lot… and I listened to other views from other people with different impairments. I knew how blind people behave who have impairments that are more severe than mine… the ones who have problems in communication; I was able to know their views; I didn’t know before what problems they suffered from.

Also, there are people in society you have met; we came to know about their views, and with you, we have acknowledged decisions we have never heard about before… this was through your interviews with officials, lecturers, and the Imam… I mean we have seen what they think about disabled people.

(Kholood, female, aged 24.
Interview date: 4 November 2014.)

Kholood clearly showed the benefits of the study for her by identifying the views of non-disabled people who participated in this research as well as the group of disabled people who have different impairments from hers. Although it was not my intention to explore the issues regarding the nature of the language used by the co-researchers in this chapter, it is worth pointing out some aspects of the language that Kholood used when referring to the other disabled people. When referring to those people, she “had created a biography that incorporated … [her] impairment into … [her] sense of identity in such a way as to normalise the impairment” (Watson, 2002, p.517). Although she recognised her impairment, she believed that blind people or those who have difficulties in communication have a more difficult time than she does. By doing this, she created a hierarchy
categorisation by placing her impairment in a mild position and placing blindness
and communication difficulties in a severe or difficult position.

Although Saja talked about the same idea, namely identifying the views of other
people, she focused more on obtaining information about learning disabled people:

Extract 6.11

| Saja: Now I know more about the people with intellectual disability, I see them here at the club... he looks normal you can see he lives a normal life and his impairment is mild and he can live normally... he goes to the coffee shops and drives a car, but he is intellectually disabled. |
| Hussain: What was your view before? |
| Saja: It was different. I thought intellectual [disability] means crazy [laughter]. |

(Saja, female, aged 22.
Interview date: 4 November 2014.)

From this extract, it can be seen that Saja had a particular perception about
learning disabled people before the study. In this last interview, she said that her
view was now different as she used to see them as ‘crazy’. In fact, during our
meetings and focus groups, Saja would use words such as ‘crazy’ and ‘demented’
when referring to learning disabled people, so I am glad that at the end of the
study she started to reflect upon her own attitude. However, I do not think that the
matter is that simple. It is unrealistic and difficult to claim that one study can change what culture and media have fixed in people’s minds over the years. I have shown in Chapter two, for example, how the media in Kuwait shows learning disabled people in a negative way by describing them using inappropriate words and non-representative characters. Moreover, although Saja believed that her views on learning disabled people have changed, the fact that she used the term ‘normal’ says a great deal about her own ‘disablist’ assumptions. Before I proceed, I would like to remind the readers that in this chapter, I am analysing the issues related to the process of participatory research. At the same time, however, I find it difficult to ignore the issues related to language and disability in Kuwait. In this chapter, I hope to provide a glimpse of the issues that I intend to address in the next chapter; however, Chapter seven will explore the disability issues and the experiences of the co-researchers with disability in greater detail.

6.2.5 Research Difficulties

Research difficulties constitute an important issue throughout the research process, as observed at the first meeting. The issue of the co-researchers’ ability to commit remained the main concern throughout the research process. As mentioned in Chapter four, although I started this project with seven participants who agreed to participate as co-researchers, only one co-researcher continued with the project until its completion. Five co-researchers left the project for a variety of reasons, such as personal circumstances related to their studies and families and medical issues requiring treatment abroad (Saja and Abdullah withdrew because
they had to travel abroad for treatment). This gives an indication of the role the impairment might play and how it affected the co-researchers’ participation in the project. This is an example of how impairment does lead to disablement. Clearly, Saja and Abdullah were unable to participate as co-researchers because of their impairments. One would argue, however, from a social model perspective, that the lack of suitable treatment in Kuwait was the cause (thus a societal cause) that prevented them from participating. I am mindful of both causes (i.e. physical and social) and suggest a multi-directional approach – impairment can have an impact on disablement and “disablement can also have an impact on impairment” (Shakespeare and Watson, 2010, p. 68).

Furthermore, in addition to Saja and Abdullah who left the project because of the need for treatment, Abdurrahman also decided to leave, but because of personal circumstances. Omar, Yagoub, and Ahad left the group without stating the reason. In fact, I do not consider the latter as a co-researcher because she only turned up once for our meetings. At the same time, however, the issue of withdrawal may be seen as a natural consequence of the practical realities of life (see the discussion below).

As Kholoood was the only co-researcher who kept her commitment to the end, I discussed the issue of research difficulties with her:
Extract 6.12

Hussain: What were the difficulties in this project?

Kholood: There were a lot of difficulties; the first one is the lack of commitment by those who worked with us... few of them were committed to our meetings... they didn’t attend a lot of meetings... then, they started to withdraw.

Hussain: Why do think they were withdrawing?

Kholood: Because they think this research is not their research, so they may think that they would never benefit from it; they felt irresponsible maybe... they may say “what do I benefit... I may waste my time and he [main researcher] finishes his study”. Perhaps, if we had a chance to bring other people who have better awareness, we could have had a better study than this.

Hussain: Where can we find those people?

Kholood: Maybe in university.

Hussain: Do you think that I came here to the wrong place?

Kholood: Probably... because, here, we are more interested in sports. I mean we train and we feel tired after training sessions and we want to go home directly... or even before training, our coach would keep pressing on us “come on, don’t be late”... so time was limited and this was unhelpful too.

(Kholood, female, aged 24.
Interview date: 2 November 2014.)

This extract shows the reasons why Kholood thought that the co-researchers did not turn up to many of our meetings and withdrew eventually. Kholood stated that
the co-researchers missed many meetings and withdrew as it was not mainly their study and they might have thought they would not benefit from it and waste their time doing it. This issue may be the reason why the co-researchers ultimately withdrew from the study. Therefore, maybe they were committed but just could not make it and then were too embarrassed to tell me. The co-researchers’ withdrawal was another expected issue in this type of research, as this study is mainly my own and they were participating as volunteers and were perhaps not interested or might have lost interest during the research process. They were not getting paid and I was getting a PhD (while they got nothing), so why would they be strongly committed? Unlike the projects undertaken within disability organizations, allocating payments for the co-researchers was not possible. However, not all organizations (owing to funding limitation) are committed to allocating payments to co-researchers. For example, in their inclusive project, O’Brien et al. (2014) state that the expenses of the co-researchers were covered but unlike the university researchers, they did not receive wages. However, this was a deliberate act as the researchers stated that payments would have limited the number of co-researchers engaged in the project, even though their future preferences are directed towards allocating payments for co-researchers.

The issue of what I get out of the research and what the co-researchers get out of it is related to the idea of reciprocity. As stated earlier, the co-researchers believed that they gained research knowledge and skills, yet this cannot be compared to what I am going to get out of this research. I will gain more benefits than they will, as this study will help me develop my skills as well as get a doctorate and
have a better career.

However, I believe that stating the names of the co-researchers (as discussed in Chapter four) would give them credit and recognition in the academic community and this would be beneficial if they wanted to carry on with disability research. Very few inclusive studies have stated the names of the non-academic disabled researchers (see, for example, Abell et al., 2007; Greenstein et al., 2015; Blyth and Docherty, 2015), whereas a large number of inclusive studies have not stated the names of the disabled co-researchers (see, for example, O’Brien, et al., 2014; Strnadová et al. 2014; Stevenson, 2014). For example, in their study which includes four learning disabled researchers and four non-disabled academic researchers, Strnadová et al. (2014) state the names of the non-disabled researchers but fail to mention the names of the disabled researchers. Some would justify this act of negligence considering the ethical procedure that emphasises the confidentiality of information of disabled people. However, if the disabled members were co-researchers (also explicitly referred to as co-researchers in the studies above), then I believe that using pseudonyms is unjustifiable. If the exclusion of the disabled co-researchers names stemmed from a particular educational system and the ethical procedures, then these procedures need to be reconsidered to refrain from blatant exclusion of the co-researchers’ identification.

Furthermore, Kholood addressed a vital issue about the type of people who should be involved in this kind of project. She confirmed that I might have come to the wrong place (i.e. the sports club for disabled people) because engaging in sports
was the main priority of the members. Throughout the research process, I always tried to ensure that our meeting dates and times were suitable for the co-researchers. In this extract, however, Kholood was trying to say that even the time before/after training was not really suitable, as before training, they needed to be prepared for their training well ahead of time per the instructions of their coach, and after the training sessions, they were tired. Perhaps, this was one of the reasons why they missed the meetings. Kholood was probably right: if I had approached participants who were more interested in the field of disability, the study would have had fewer drawbacks. This issue was discussed further with Kholood:

**Extract 6.13**

| Hussain: Do you think it would be better to conduct the research within an organisation? |
| Kholood: Yeah, and this is their work [researching] and they take salary for it, so they would be obligated to do it and present it in a better form… if it is voluntary [work], most of them will be careless. |

(Kholood, female, aged 24. 
Interview date: 2 November 2014.)

In this extract, Kholood identifies another reason why the co-researchers were less interested: they were working with me as volunteers. She believed that a research study within a particular organisation where an employee’s job involves research
would be more appropriate and successful.

Kholood stated that it would be preferable to talk to disabled people as they understand their issues better than anyone else. She also stressed, however, that collaborative work between disabled people and non-disabled academics when researching disability is required:

**Extract 6.14**

Hussain: Do you prefer disabled people talking about their issues themselves?

Kholood: Of course, because they know more about their issues than anyone else; they know more about their needs.

Hussain: Do you prefer collaboration between non-disabled academics and disabled people, or do you prefer disabled people doing the job on their own?

Kholood: I prefer collaboration, but primarily, disabled people should talk about themselves.

(Kholood, female, aged 24. Interview date: 4 November 2014.)

This view is consistent with Barnes’ (2007, p.138) suggestion that because “the [disability] movement can provide direct experiences, academics working from a disability studies perspective can provide a logical and consistent political analysis”. This is at the heart of participatory and emancipatory research.

Generally, most of the participatory and inclusive projects I came across in the
literature were conducted in partnership with disability organisations and even those conducted to obtain doctorates were conducted in universities, but the fieldwork was carried out in disability organisation (see, for example, Chapman, 2005; Radermacher, 2006). Therefore, confirming Kholood’s point, the problems with time restraints, commitment, and interests may be overcome or at least reduced, as within these organisations, it is the job of both the disabled people and non-disabled academics to conduct research to enhance the services for disabled people. Moreover, when the people working together are already well known to each other, the likelihood of achieving positive results is very high. Participatory action research “projects, it seems, are only really suitable in cases where all members are already well known to each other and who know they can work together” (Kitchin, 2002, p.12). In contrast, however, one could argue that there are also definite advantages of not recruiting members from within organisations. On the whole, disabled people in disability organisations are far more aware of disability rights issues, the social model, and activism and therefore will often give far more political views/responses. For example, researchers are required to show their commitment to the core principles of emancipatory research, such as the adoption of the social model of disability (Stone and Priestley, 1996; Walmsley, 2001). Therefore, any deviation by the organisation from the adoption of the social model would be considered inappropriate and erroneous (Shakespeare, 2014). This is often written up as some form of representation of disabled people’s views when, in fact, it is a very small minority of very politically aware disabled people. This is one reason why some researchers recruit
some participants from outside these organisations. Thus, employing disabled people outside disability organisations allows diverse voices and experiences to be heard from people living with their families in homes or in institutions (Strnadová et al., 2014).

Generally, I found commonalities between my project and Kitchin’s (2002) three projects addressed in Chapter four. The first commonality centres on the relationship with the research participants, as we were either unknown or unfamiliar to them. This problem may have led to similarities with our findings, specifically the issues with the time commitment. In Kitchin’s projects, the participants declined to participate because of the time commitment and confidence issues. The researcher also reports that even those who decided to take part, and he himself, had problems with time commitments and other work, eventually leading them to miss some of their meetings and extending their projects. Similar to Kitchin’s participants, the co-researchers in this study may have been surprised to know about the time needed, the time they could not give because of their studies and the sports club. This caused withdrawals and delayed the project:

**Extract 6.15**

| Hussain: You said one of the difficulties is the co-researchers’ lack of obligation; how has this impacted the research? |
| Kholood: First, the study was delayed… we had to change the idea of the research… and of course, there was a limitation as a result… I mean, if we |
Although the limitations in both Kitchin’s project and this project were related to reciprocity, the co-researchers were able to develop new research skills. Therefore, as Kitchin (2002, p.10) summarises, “most of the problems lie not with the principles of inclusive research [i.e. enabling disabled people to play an active role in the research], but with practicalities such as time, skills, resources, and reward”.

Furthermore, in line with Kitchin (2002), who considered his projects semi-participatory as he was largely responsible for the data collection, analysis, and preparation of the write up, as stated, I do not consider my research entirely participatory. Some of the principles of participatory research are more relevant to this study. I am conducting this research with the University of Manchester in order to obtain my PhD, and the ‘nature’ of the study means that I must be in control of the research agenda. For example, despite deciding to make this research participatory, I am nevertheless responsible for writing my thesis by myself. Although this research is not fully participatory or emancipatory, however, it drew upon the spirit of participatory research, and the process stressed on the importance of active and effective participation rather than the extent of participation.

(Kholood, female, aged 24.
Interview date: 4 November 2014.)
Furthermore, returning to the question of whether the participants who worked with me were co-researchers or research participants, I would consider them co-researchers as according to their accounts, they believed that they played an active role that affected the research track, even though they were not all practically involved in all of the research processes, such as the data collection and analysis. In this project, I was keen to give the co-researchers an opportunity to decide on the nature and the extent of their engagement (Stone and Priestley, 1996).

Therefore, the co-researchers and I did not have an equal partnership. This is contrary to Walmsley and Johnson’s (2003, p.148) suggestion that “co-researching implies an equal partnership”. I believe that it is difficult to equalise the research tasks between the main/academic researcher and the disabled participants, as whatever the main researcher does to equalise the partnership is inevitably led by the main researcher (Shakespeare, 1996). For example, as Chapman (2005) and Radermacher (2006) conducted inclusive studies to obtain their doctorates, it was inevitable that they led them. Moreover, it is difficult to equalise a partnership, as co-researchers may find some parts of the research process boring or uninteresting. For example, in a study by Bigby, Frawley and Ramcharan (2014), when the academics in the project attempted to engage disabled participants in a deeper analysis of the data, they replied, “‘we have done this already’ and ‘it’s boring’” (p.57). Some would interpret the situation as them being inadequately supported/trained, rather than being simply not interested.

One final issue that I want to highlight here is the difference between the
characteristics of the co-researchers in this study and the participants in inclusive research in the Global North. The co-researchers in this project were predominantly physically impaired, while most of the participatory or inclusive studies in the Global North, which I have referred to in this chapter and in my discussion in Chapter four, involved engaging learning disabled people in researching disability. This is because of the fact that many of the UK/USA disability studies completely ignore learning disabled people and ‘write them out’ of disability, so some disability scholars desire to give a voice to learning disabled people to research their issues and the quality of their services. In contrast, the disability studies in the Global South research the services of disabled people through the lens of their parents or teachers in special education and clearly exclude the voices of the disabled people themselves (see, for example, Salih and Al-Kandari, 2007; Al-Kandari and Salih, 2008; my discussion of disability research in Kuwait). Therefore, this project may be seen as the first in the region that enables disabled people to share their voices and experiences of disability.

6.3 Summary

This chapter presented and discussed the findings and the main theme and sub-themes related to participatory research processes and the experiences of the co-researchers in this project. In this chapter, I presented and discussed the findings of the data generated from the focus groups and the interviews with the co-researchers. The data showed the emergence of one main theme (i.e. the research process) and several sub-themes. In the next chapter, I will discuss the main theme
and the sub-themes that emerged from the data regarding disability issues in Kuwait.
Chapter 7

Findings and Discussion

Disability in the Kuwaiti Context

7.1 Introduction

This chapter discusses the disability issues raised both by the six co-researchers and the eight participants of this project (see Chapter 4 for the characteristics of these groups). The vast majority of the accounts/discussion, however, will be concerned with the analysis of what the co-researchers talked about, as their issues related to disability represent the primary focus of this project.

As shown in Chapter five, the main themes that emerged from the data set in relation to disability in Kuwait were related to social attitudes towards disabled people and the societal structures in Kuwait. A number of sub-themes emerged in relation to these two main themes. I have shown, however, how the overlap between these two themes resulted in their grouping into one theme: ‘societal structures and social attitudes towards disabled people’. In this chapter, I will discuss the sub-themes that emerged from this overarching theme. The sub-themes that emerged from this data set are as follows:

- Non-disabled people’s attitudes towards disabled people

- The construction of ‘normality’
- The psychological effects and the role of the body

- Cultural representations and the role of the media

- Disability and the role of culture and religion

- Accessibility to buildings and communication

I will explore each of these sub-themes separately. I will examine how both the social attitudes of non-disabled people and the social structures within Kuwait have had an impact on the identities of the co-researchers, driving them to adopt different disability conceptualisations (e.g. the individual model and social model) throughout their discourse. For example, the data will show how the co-researchers sometimes locate the issues or the ‘problem’ of disability in society and culture and, sometimes, locate it spontaneously in the body. Moreover, I will explore how the co-researchers, who are predominately physically impaired, view themselves as compared to other groups of disabled people, such as learning disabled people, and how this relationship is reflected in creating the co-researchers’ different identities. Furthermore, the chapter will show how the non-disabled participants view themselves as compared to disabled people. Understanding these complex interactional relationships is necessary in order to have a richer picture of the lives of disabled people and of disability in Kuwait. One should be aware, however, that a full understanding of these relationships cannot be achieved, as the voices of other groups of disabled people, such as learning disabled people, are totally absent from this study.
7.2 Non-disabled People’s Attitudes towards Disabled People

As discussed in Chapter 6, according to the accounts of the co-researchers, the primary reason that motivated them to work with me on this project was working towards changing the views and attitudes of non-disabled people and raising their awareness about disability. According to the co-researchers, although the attitudes of non-disabled people vary, they can be classified into three groups:

- The first group consists of those who tend to sympathise, pray for, and help disabled people.
- The second group is those who ask disabled people curious questions when they meet them in public places.
- The third group is those who stare at disabled people and utter inappropriate words.

According to the accounts of the co-researchers, one group of non-disabled people includes those who frequently ‘help’ disabled people when they meet them in public places. As an example, Abdullah stated that:

Extract 7.1

| People think that a disabled person always needs their help all the time. |
| (Abdullah, male, aged 21. Focus group date: 10 April 2014.) |
Generally, all of the co-researchers see this as unacceptable and an underestimation of their capabilities:

**Extract 7.2**

One comes and asks me if she can push my wheelchair… [It’s] ok; I am able to push it myself.

(Saja, female, aged 22. Focus group date: 10 April 2014.)

Saja and the other co-researchers confirmed their rejection of such perceptions and attitudes held by non-disabled people. For example, Abdullah’s colleagues in his college often ask him how he can drive a car. Furthermore, Kholood revealed that non-disabled people often question her when she goes out by asking, for example:

**Extract 7.3**

“Did you come here by yourself?”

(Kholood, female, aged 24 Focus group date: 10 April 2014.)

This question would be ‘axiomatic’ or ‘natural’ if it were posed to a non-disabled person by anyone in the general public. A number of co-researchers clearly understand curious questions and offers of help as examples of ‘assumed
hopelessness’ or ‘assumed helplessness’ of disabled people by non-disabled people. By assuming hopelessness or helplessness, non-disabled people are conceptualising disabled people through the lens of the individual model. Disabled people’s biological characteristics became a ‘master status’ (Forge, 2012, p.1) that make non-disabled people make curious inquiries. Moreover, these ‘marveled inquiries’ by non-disabled people allude to the concept of ‘supercrip’ (Deal, 2003; Silva and Howe, 2012), making them wonder how disabled people manage their lives by themselves in spite of the presence of their impairments.

Non-disabled people’s curiosity and their frequent questions when they meet disabled people in public would appear to reflect what Morris (1991) found about how non-disabled people interact with her in everyday life and the curiosity they have in terms of how disabled people manage their own lives (see Chapter two for details). This also echoes what many participants revealed in Watson’s (2002) study. For example, Watson gave an account of a participant narrating how people often undermine her ability to manage her life. This led him to conclude that many disabled people consider impairments a part of their life associated with everyday activities, so they do not impact their sense of self (Watson, 2002).

Moreover, in line with Watson (2002), when talking about their abilities, all of the co-researchers talked about how the only difference between them and non-disabled people was the use of a wheelchair. Saja made this clear by illustrating how society uses her wheelchair as a signifier of ‘difference’. The following extract illustrates the arbitrary nature of the signifier:
Saja raises an interesting issue associated with the relationship between signifier, signified, and referent. Amaglobeli (2012) explains that signifiers comprise things such as words, sounds or signs and signified is related to concepts or meanings of these words or signs, while a referent is the object the words/signs refer to in reality. For example, the wheelchair sign, which appears in many public places such as toilets or disabled parking spaces, alludes to the ‘concept’ of disability or brings the thought of a disabled person to mind. The frequent exposition of these signs makes people in society link them directly to the presence of disabled people in real life. This act of exposition reinforces the notion of ‘difference’ between disabled and non-disabled people, as “the sign ‘disabled’ gathers meaning through its contrast with the sign ‘abled’” (Goodley, 2011, p.104).

Saja continued her discussion and stated that the wheelchair signs are used in school curricula to teach children about disabled people:
Extract 7.5

There is a subject at primary school level where they show a sign of a disabled person; then, they ask “what is this?” [They answer]: this is a disabled person. That is it. You know the sign which you put in the car: I teach my sisters the subject called “national education” for the primary school curriculum. They give them a picture of a disabled person and they ask “what is this?” [They answer]: ok, this is a disabled person. They have to give them something they can understand.

(Saja, female, aged 22. Focus group date: 6 May 2014.)

In this extract, Saja is showing her rejection of the school curriculum that simplifies the lives of disabled people, reducing them to a sign or a picture of a disabled person. Along with the other co-researchers, she does not reject teaching children about disability in schools, but rather, she expects schools to provide more in-depth information about the complexity of disabled people’s ‘real’ lives.

The process of signification occurs at the socio-cultural level. These “socio-cultural processes … generate negative attitudes about impairment and disability, and sustain prejudicial meanings, ideas, discourses, images and stereotypes” (Thomas, 1999, p.56). It is clear that people in Kuwait have developed cultural meanings through the correlation between a disabled person and a wheelchair. This correlation constitutes a difference between disabled and non-disabled people and does not establish a difference, as Saja revealed in Extract 7.4, between spectacles users and non-spectacles users. This process of signification shows the
relationship between bodies, imagery, discourse, and space (Shakespeare, 1994). The presence of disabled people in their wheelchairs in spaces and the existence of wheelchair signs match with the mental image that people create for disabled people. This correspondence constitutes a ‘difference’ between disabled and non-disabled people. It can also lead people to the belief that all disabled people are wheelchair users. This may expose non-wheelchair users or those with hidden impairments to be vulnerable to negative attitudes (Brookes, Broady and Calvert 2008).

I will now move on to discuss how the attitudes and views of non-disabled people discussed above have had an impact on the co-researchers’ perceptions of themselves. I will discuss, in particular, Saja’s experience of how such attitudes of non-disabled people made her adopt different identities spontaneously. The analysis of Saja’s experience will also demonstrate how she views herself as being in a position that is opposite to that of learning disabled people.

7.2.1 Being Differently Different

Saja continued her discussion, talking about how the students in her college are prejudiced regarding her ability to conduct her studies as a disabled student:
In this extract, Saja sees her physical impairment neither as a barrier nor as a hindrance to her academic achievements. Instead, she continues with her studies successfully to an equivalent or even greater standard than many non-disabled students. From this perspective, her presence at a university can be understood as what Beckett and Campbell (2015, p.270) call an ‘oppositional device’. From this perspective, her mere presence in an academic institution is a form of resistance to cultural stereotypes that underestimate the ability of disabled people. This form of resistance, what Foucault (1988, p.18) calls ‘technologies of the self’ can liberate, emancipate and help disabled people transform themselves in order to reach a certain state of happiness. This discussion could be understood as bodies as discourse (Hughes and Paterson, 1997). Therefore, I want to argue that, in direct opposition to the social model, bodies are clearly important. The discourse of ‘the disabled body’ being in a non-disabled space is, it could be argued, one of resisting regulatory power (in a Foucauldian sense). The social model perspective

Extract 7.6

Here, they only ask, “Can you do this, can you do that?” I am a student, same as you, and I can get grades even higher than you.

For example, one time, a student in college asked me, how did I get a grade A while she got a C?… I said to her my impairment is not here [pointing to her head] but here [pointing to her legs].

(Saja, female, aged 22. Focus group date: 10 April 2014.)
would understand resistance as a constituted challenge to the social attitudes and social structures as well as the internalised individual view of disability (Reeve, 2002). However, in the presence of the cultural constraints and the effects of the objective laws such as ageing, illness, impairments, and death, the resistance path (from both perspectives) to be followed does not appear straightforward (Williams and Bendelow, 1998).

I would suggest that when Saja confines her impairment to her legs and not to her head, she is adopting another view, namely, an individual model. At the same time, she is undermining implicitly the ability of those who have other types of impairments, such as learning disabled people. It is clear from her words that she sees herself differently/distinctly from learning disabled people. Thus, she appears to have created an identity for herself that is inseparable from her impairment by situating her physical impairment as a ‘master signifier’ (Schwartz, 2013, p.279) that would not prevent her from attaining academic achievement. Interestingly, she goes on to define her identity in opposition to learning disabled people, whom she clearly views as ‘other’. This reflects what Deal (2003) found in his study, where some disabled people, such as those who are physically impaired, prefer to distance themselves from other groups such as learning disabled people. He identified a number of factors that contributed to this desire. Some relate to the allocation of funding or resources (e.g. competition for the same resources) and others relate to cultural aspects, such as stigma. In the case of Saja, it is clear that cultural factors influenced her desire to distance herself from learning disabled people.
In a further attempt to define her identity as different from that of learning disabled people, Saja disclosed explicitly her view of learning disabled people. She further suggested that the term ‘cerebral palsy’, which is her impairment, should be changed to something else, as people think that a person with cerebral palsy is learning disabled. Saja believes that when people find out that she is learning disabled, they do not give her any attention:

**Extract 7.7**

<table>
<thead>
<tr>
<th>What can an intellectually disabled person do?</th>
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<tbody>
<tr>
<td>(Saja, female, aged 22.</td>
</tr>
<tr>
<td>Focus group date: 6 May 2014.)</td>
</tr>
</tbody>
</table>

Saja thinks that learning disabled people do not represent disabled people (in general) and should be seen distinctly from the physically impaired:

**Extract 7.8**

No, they are not representative. When you say “disabled people”, do not put intellectual disability together with mobility problems.

(Saja, female, aged 22.                      |
Focus group date: 6 May 2014.)
The attitudes of Saja to learning disabled people may be interpreted from her choice of words when she refers to them by using words such as ‘crazy’ or ‘demented’. By seeing her status differently, she raises the notion of social class. When someone talks about the British class system, the famous class sketch from the 1960s that presented the two Ronnies comes to mind. (A short segment of the sketch is available on YouTube: https://www.youtube.com/watch?v=K2k1iRD2f-c&feature=youtu.be). In this sketch, the tall John Cleese represents the upper class, Ronnie Barker is shown as representing the middle class, and Ronnie Corbett, the working class. Each, in turn, talks about his position in society.

In a similar way, when someone lives in Kuwait or in the Arabian Peninsula, he/she will see clearly the classism, tribalism, and sectarianism that is rampant in such areas. Arabian societies have grown up boasting of financial status, political power, race and genealogy, and religious preferences (Franklin, 2013). For example, in relation to race and genealogy, some bloodlines that came from certain places in the Peninsula are more preferable within many societies than those from other places. Most tribal families would not accept, for example, a proposal for their daughters from someone who is not of the same social level, the same race/tribe, or the same lineage. Moreover, in relation to sectarianism, no one could fail to notice the continuing war between Sunnis and Shiites in some of the Arabian countries, such as Iraq and Syria. This conflict persists because every sect believes that its people are the only ‘surviving group’ who gained ‘God’s satisfaction’. One should be aware, however, that the idea of ‘God’s chosen
people’ is not limited to Islamic culture; it is well established in other religions such as Judaism and Christianity (Akin, 1996).

Living in a society characterised by numerous social classifications and preferences, Saja sees herself in a ‘higher class’ than learning disabled people, yet not always as high as non-disabled people, especially when she refers explicitly to non-disabled people as ‘normal’ or ‘healthy’ and perceives herself as a disabled person because of her impairment.

**Extract 7.9**

<table>
<thead>
<tr>
<th>This is reality; they are normal and healthy and we are disabled.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Saja, female, aged 22.</td>
</tr>
<tr>
<td>Focus group date: 6 May 2014.)</td>
</tr>
</tbody>
</table>

Figure 7 illustrates the mutual triplex stratified relationship between Saja, non-disabled people, and learning disabled people.
This figure shows how Saja, depending on the situation, recognises her difference by considering non-disabled people as the upper class. For example, she considers non-disabled people as upper class as she thinks that they are physically more ‘normal’ or ‘healthier’ than her. At the same time, however, she sees herself ‘intellectually’ equivalent or even at a higher standard than non-disabled people. She made this very clear by stating the following:
Extract 7.10

<table>
<thead>
<tr>
<th>Why you [non-disabled person] sympathise with me, I am better than you. I am a university student and you are unsuccessful. You only sit in a coffee shop with your friends and smoke.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Saja, female, aged 22. Focus group date: 10 April 2014.)</td>
</tr>
</tbody>
</table>

These hierarchies of impairments could be understood as a poststructural discussion about discourse as power. Goodley (2011, p.104) sums up this relationship:

In order for a discourse to work it must make its case. It must counter the opposite and distinguish itself from its antithesis. In order to speak of I (able), I must distinguish it from an other (disabled). This simple relationship is the basis of poststructuralism.

To summarise, Saja sees herself as superior to many non-disabled people ‘intellectually’, yet lower than them ‘physically’. Although she identifies her difference by pointing to her impaired legs, she sees herself as different from learning disabled people, especially when she rejects identifying them as disabled people.

The same classification was also found in the discourse of the Amir of Kuwait as the representative of the highest authority in the state. In an annual social tradition, the Amir of Kuwait visits disabled people every year during Ramadan, as a ‘solidarity initiative’ offered on his behalf to disabled people in Kuwait. On one occasion, the Amir met with a Qatari person using a wheelchair. When the
Amir saw the person, he said, “You are not the only one who is serpentine… I am serpentine like you; they take me to the car and bring me back. As long as you have your mind (pointed to his head), say thank God” (an excerpt of this meeting is available at: https://www.youtube.com/watch?v=eZpKqyYeDjk). Interestingly, the Amir used the same classifications and gestures as Saja by attempting to reduce the status of learning disabled people when he was trying to ‘reassure’ the person that he was similar to him (because of aging) and advised him to be thankful to God as long as he had a ‘healthy’ mind. Thus, the Amir defined the person’s body from ‘its antithesis’ (Goodley, 2011, p.104) (in this case, the learning disabled person’s mind). By comparing his impairment as a result of aging to the person’s impairment and telling the person to be thankful, the Amir assumed that the person had a problem with his impairment/body. By doing so, he reinforced an individual view by locating the ‘problem’ of disability in the body and, at the same time, brought the notion of ‘assumed hopelessness’ to the fore. On the other hand, the use of the word ‘serpentine’ to refer to himself and to the man drew my attention. Whilst an English reader would find the usage of this word an odd choice in the field of disability, it is not odd in the Kuwaiti context, especially among old people. Throughout my journey exploring disability in Kuwait, none the interviewees was found to use this word. It is an obsolete word that was used to label disabled people in the past.

From the above, it seems that differences and classifications among people always exist, between disabled and non-disabled people and even among disabled people themselves. Therefore, the differences and classifications are real. They can also
exist between learning disabled people. For example, the other day, my sister, who has a learning disabled daughter, was objecting to her daughter’s school for putting her daughter with other disabled people who could not move. Thus, my sister sees her daughter (because she can walk) as being in a higher position/class than those who cannot walk.

In the above accounts, I have shown how impairments, taxonomies, and differences between people can be a form of discourse as power. Nevertheless, from my critical realist-informed perspective, I believe that people’s classifications and differences are not only constructed socially/culturally as a result of discursive power but also exist as real entities. In his criticism of social constructionism and relativism, Shakespeare (2014) points out that there is always an underlying difference between people. He believes that people with below average intelligence have always existed even prior to the development of IQ tests. Therefore, he concludes that learning disability (especially moderate and profound) is not only socially/culturally constructed but also ontologically real (Vehmas and Mäkelä, 2008; Shakespeare, 2014).

To sum up, from the discussion above, one can notice that if a society readily accepts different forms of stratification, this will clearly facilitate a hierarchy of impairment. However, at the same time, one cannot eliminate the hierarchy of impairment solely as a production of society, as it stems from real entities.
7.3 The Construction of ‘Normality’

7.3.1 Accepting the ‘Norms’

As discussed earlier, when talking about her body, Saja ranked non-disabled people in a higher position as she thinks that they are ‘normal’ and ‘healthy’ and that she cannot be categorised as either because of the existence of her impairment (see Extract 7.9). On another occasion, she confirmed the notion and thanked God for having a ‘healthy’ sister.

Extract 7.11

<table>
<thead>
<tr>
<th>My sister is healthy, thank God.</th>
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<tr>
<td>(Saja, female, aged 22.</td>
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<tr>
<td>Focus group date: 10 April 2014.)</td>
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</table>

It is clear from this statement that Saja believes ‘the non-disabled body’ to be healthier than ‘the disabled body’, so those who have a ‘healthy body’ should be thankful. As shown in Extract 7.9, Saja sees her impaired body as ‘abnormal’ and ‘unhealthy’, and the reality for her is that non-disabled people are ‘normal’ and ‘healthy’. By perceiving her reality as interdependent with her physical impairment, Saja is reinforcing the notion of ‘normality’. Saja was not the only participant in the research who referred to non-disabled people as ‘healthy’ or ‘normal’; this issue has been well established through the discourses of the other co-researchers and the participants in this project since the exploratory phase (see Chapter one). For example, during the data collection in the exploratory phase
Salma recalled an incident where a non-disabled colleague used a common Arabic proverb, “a healthy mind in a healthy body”. She went on to link this to disabled people’s bodies, implying that a ‘healthy mind’ can only be placed in a ‘healthy’ or ‘non-disabled’ body. Salma was disturbed when her colleague used this proverb in this way, yet, oddly, she doubted that she was being referred to by this proverb. This incident provides a useful insight into how some people make a connection between physical impairment and cognitive ability.

**Extract 7.12**

| Salma: One time, I had a discussion with a person. She said to me, “a healthy mind in a healthy body”. I doubted myself; I went to ask a teacher... she said to me, “She is sick; this phrase means a different thing certainly”.
| Saja: It meant to be healthy and fit; it has nothing to do with impairment. |

(Higher education students’ focus group)
Focus group date: 14th August 2013

By accepting this epistemological assumption as ‘reality’, Salma is confusing epistemology with ontology (Williams, 1999; Sayer, 2000; Bhaskar and Danermark, 2006; Vehmas and Mäkelä, 2008; Shakespeare, 2014). In other words, she conflated her colleague’s idea of her impairment (being unhealthy because of her impairment) with the ontological/independent existence of her impairment (her own physical body). It appears that Salma failed to recognise that
this phrase only represents a negative attitude towards her body and has nothing to do with the existence of her impairment.

Furthermore, as shown in this extract, Saja was one of the members who participated in this early focus group, which took place during the exploratory phase. Interestingly, she clarified to Salma that the word ‘healthy’ mentioned in the phrase had nothing to do with impairment, although, as shown above, she accepted the general word ‘healthy’ as an absolute ‘fact’ coupled with ‘non-disabled people’s bodies’. This raises the possibility that disabled people’s reactions to non-disabled discourses are not static and can differ based on the context, situation, and types of words.

Moreover, it was evident from the data that for many co-researchers and participants, the notion of ‘normality’ and the use of terms such as ‘normal’ or ‘healthy’ reinforced a form of essentialist ‘normality’ and indicated, as Goodley (2011, p.104) highlights, that discourse “must counter the opposite and distinguish itself from its antithesis”. In short, it is evident from the data that in Kuwaiti society, as Foucault puts it, ‘the normal’ is defined through ‘the abnormal’ (Fillingham, 1993). Furthermore, these issues suggest that one cannot and should not study disability without scrutinising what it is to be ‘normal’.

From a Western perspective (Global North), it would be reasonable to believe that many (if not all) disabled people would find labels such as ‘unhealthy’ and ‘abnormal’ insulting. When looking at the data from this project, however, it is clear that many of the co-researchers believe that the use of these terms is
unproblematic as for them, the ‘truth’ is that they are disabled people (because of their impaired bodies), and what is important for them is not changing the words but changing the perceptions regarding disabled people. In relation to this issue, I have shown two examples from Salma and Saja’s discussion. Another example is from Kholood’s words. Kholood emphasised seeing her ‘reality’ as a disabled person because of her impairment.

**Extract 7.13**

<table>
<thead>
<tr>
<th>Hussain: OK, the word ‘healthy’, which refers to non-disabled... is it right to use this word?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kholood: Using the word is not a problem; even if you say, “I am disabled”, it is not a bother because I know that I am a disabled person.</td>
</tr>
<tr>
<td>Hussain: But healthy is not the opposite of disabled?</td>
</tr>
<tr>
<td>Kholood: Yeah, but it is common.</td>
</tr>
<tr>
<td>Hussain: Not a bother?</td>
</tr>
<tr>
<td>Kholood: No, it is not, because we are disabled people; why should we be bothered by the truth?... We have needs and [non-disabled people] do not. I need a wheelchair because I cannot walk... which means I am disabled... They talked a lot about changing the word ‘disabled’; the problem is not with the name but with how they look at disabled people. Change your look.</td>
</tr>
</tbody>
</table>

(Kholood, female, aged 24. Focus group date: 6 May 2014.)
By defining herself by her biological characteristics and by accepting the word ‘healthy’ as a synonym for non-disabled people, Kholood is demonstrating explicitly the limitations of the social modellists’ work in terms of the neglect of the role of the biological body in their analyses (Williams, 1999). However, one could also argue that she is, in contrast, reinforcing the work of the social modellists. From a social model perspective, one could say that the widespread use of ‘disablist’ language in Kuwaiti society causes Kholood to understand her ‘reality’ as a disabled person resulting from within her body. Thus, society is at fault, not the bodies of disabled people (Shakespeare, 2014). From my critical realist-informed perspective, however, I am mindful of both possibilities and would suggest that the ‘problem’ of disability cannot be reduced to one level of reality but requires multiple levels of explanation, including the recognition of the body as well as society. Kholood, in line with the other co-researchers, recognises the role of the body as well as the disabling barriers in society. This shows how complex disability issues in Kuwait can be.

Moreover, it can be noted from this extract that Kholood suggests that changing words such as ‘healthy’ is not important, as what is important for her is changing non-disabled people’s perception of disabled people. Kholood seems to suggest that simply changing words or the way of talking about impairments would not change the reality of being an impaired person. Although Kholood stated explicitly that changing the language or the words is not important, she was talking specifically about the word ‘healthy’. As will be shown later, she criticised the use of words such as ‘disabled’ as a slur. She also criticised the language of
the Imam and described it as inappropriate. Kholood’s conflict regarding the language suggests the importance of both language and concepts.

Changing one’s language and way of thinking are both important to Kholood. She seems to suggest that language reinforces negative ways of thinking; however, changing words does not necessarily reflect an enlightened way of thinking without changing the negative connotations engrained in the mind (Shakespeare, 2014). Although changing their way of thinking can lead people to change their words, if the words are changed without changing their ways of thinking, “people will use new words just as they used the old ones” (Reinders, 2008, p.46). This brings to the fore issues pertaining to the relationship between signifiers and signified that is rooted in constructionism (Sayer, 2000). Words (signifiers) do reinforce negative ideas (signified). It has been argued, however, that by simply changing those words or terms, one can never be fully liberated from the negative associations. For example, the term ‘mental handicap’ was introduced to replace the term ‘idiot’ as it had become an insult. As time went by, however, the replacement term simply took on the same negative connotations. This question is asked by Blyth et al. (2016, p.294): “Does every label instigate a kind of accumulative politics that eventually corrupts its good intentions?”

Moreover, it can be noticed in Extract 7.13 that Kholood uses the terms ‘disabled’ and ‘unhealthy’ interchangeably and that she uses and accepts the term ‘healthy’ when referring to non-disabled people as it is common. In fact, terms such as ‘healthy’ and ‘normal’ are common in the media and among people, including
academics and professionals in the field of disability. It is evident throughout all of the data collected that the terms such as ‘normal’ and ‘healthy’ are operationalised frequently when referring to non-disabled people. For example, the use of these terms was evident in the interviews with the politicians and the lecturer working in the field of disability. The next extract (Extract 7.14) shows some examples from the interviews with Dr Rashid, the Assistant Undersecretary of PAPDA (education and rehabilitation sector) and with a disability lecturer at Kuwait University.

**Extract 7.14**

| There are inclusive schools where there are normal students and disabled students. |
| (Rashid, male, aged 53. Interview date: 3 June 2014.) |
| Not only disabled… even normal children can make trouble in the classroom. |
| (Hayfaa, female, aged 43. Interview date: 14 July 2014.) |

In this extract, Rashid and Hayfaa were talking about inclusive schools and referred explicitly to non-disabled people as ‘normal’. It is evident that the widespread use of this term by politicians, academics, and the media has influenced the collective mind-set and led people in society to use the term in their daily language. The use of this sort of language, specifically among professionals
and academics, reflects how new the study of disability in Kuwait really is. As shown in Chapter two, most of the disability research in Kuwait is quantitative and medically focused (see, for example, Shah et al., 2011; Al-Hashel et al., 2014; Al-Temaimi et al., 2015). Indeed, language suitability issues in the disability field are entirely absent in such research. Moreover, I have shown in Chapter two that even studies that can be categorised as cultural studies were not interested in language. This demonstrates the nascence of disability studies in Kuwait, unlike disability studies in the UK where an interest in language has evolved since the emergence of the social model and peaked through a postmodern-inspired model (see Chapter two). In the UK, “the theoretical maturity of disability theory is evident” (Goodley, 2014a, p.661). However, one could argue that this would give the opportunity for disability studies to develop much quicker in Kuwait as they can draw upon the years of work already done in other countries.

The power that politicians and academics in Kuwait have through their discourse will result in maintaining the use of ‘disablist’ terms such as ‘healthy’ or ‘normal’ in society. These professionals practice their power through their discourses in institutions and media. It is clear from the data, that some people in Kuwait have, in part, formed their thoughts regarding disability as a result of the influence of powerful discourses propagated and maintained by politicians and academics who are practising a form of Foucauldian biopower/biopolitics closely interconnected with knowledge.

It can be concluded from the above that although all of the co-researchers
confirmed the notion of their potential to do many things to a similar or even a higher standard than non-disabled people, at the same time, they also recognised themselves as a certain type of person, one who is disabled in differing ways but most definitely disabled by their impairments (I use the term ‘disabled’ in a very deliberate sense here). The belief that impairment has a role to play in disablement is not limited to these co-researchers and has been discussed in depth by Watson (2002) and Shakespeare, Thompson and Wright (2010).

7.3.2 Politicising and Medicalising Disability

The construction of ‘normality’ is reinforced by politicising and medicalising disability in Kuwait. This issue was demonstrated by Khalid, the Head of Tests and Measurements at PAPDA. Khalid talked about disabled people being assessed by several committees to determine those who have ‘inaccurate’ disability identifications and to categorise the impairments of disabled people based on the degree of their impairments so that they can receive disability benefits and an ‘accurate’ disability identification.
As discussed in Chapter two, the PAPDA is a political body concerned with the issues of disabled people in Kuwait. It covers everything from diagnosing impairments to providing people with the necessary support to live their lives to ensure their accessibility and inclusion within society. In Extract 7.15, Khalid discussed the issue of those who have ‘inaccurate’ disability identifications as they were assessed by the medical committee when the old disability law was in force in Kuwait. He criticised the old law because of the medical errors in diagnosis and praised the new law for revealing many of these errors. He confirmed that under the new law, numerous committees by which disabled people are examined before receiving their disability identification have been
established. These committees determine the type, level, and proportion of the impairment. Based on the decision of these committees, disabled people can obtain a disability identification as well as financial benefits.

Moreover, Khalid confirmed that disabled people in Kuwait are required, at intervals, to report to the Public Authority to have their bodies re-examined to update their information about the status of their impairments. Although the work of these committees aims to ensure the allocation of appropriate disability allowances and pensions, the frequent examination of disabled people’s bodies, some would argue, highlights the issues of power relations and the role of the medical gaze of the professionals and doctors to which disabled people in Kuwait are exposed. Reeve (2002) and Thomas (2004a) believe that applying these medical standards (setting a form of standardised ‘normal’ body) when claiming disability benefits through an institutional power not only reinforces the issue of ‘normality’ but also affects the disabled people’s psycho-emotional well-being.

These constant medical examinations, some would argue, are evidence of the domination of the individual model in the Kuwaiti context. These examinations on disabled people’s bodies are an example of Foucauldian regulatory controls that have led to the creation of new norms/standards (Reeve, 2002). This means that disabled people in Kuwait are constructed, in opposition to ‘normal’ as ‘abnormal’ as a result of deviating from these norms.

The question that remains is “Why has Kuwait been influenced only by the individual model in particular?” In other words, why have the officials in Kuwait
not been influenced by other models, such as social or cultural models? The answer to this question could be related to the domination of the individual model globally (see, for example, the definition of WHO). As discussed in Chapter two, Kuwait was one of the countries that signed the UN Convention on the Rights of Persons with Disabilities. In the UN convention, disabled people are defined by their impairments:

Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (UN, 2006, Article 1)

Similarly, part of the definition of the World Health Organisation (WHO) also focuses on the bodies of disabled people. This global medical view of disability may have influenced the officials in Kuwait and led them to define disabled people as,

…all those suffering from permanent, total, or partial disorders leading to deficiencies in his/her physical, mental, or sensory abilities that may prevent him/her from securing the requirements of life to work or participate fully and effectively in society on an equal basis with others. (Law number 8 of 2010: C1 (1))

The word ‘suffering’ in this definition is repeated constantly in the disability rights law in Kuwait. The usage of this word is evidence of the adoption of the individual model (Iriarte, 2016). One should note that while the global medical view of disability has influenced Kuwait, it is also well established in Global North countries, as seen in the UK and US Disability Discrimination Acts.

Although the adoption of the individual model is clear in the Kuwaiti system, as
Assistant Undersecretary of PAPDA, Dr Rashid revealed that they are not following any particular international system:

**Extract 7.16**

Actually, we have not searched [any particular system] whether American, British or Australian, but it is the international terms that we use... They are not terms we created, but they are international terms we translated and applied.

(Rashid, male, aged 53
Interview date: 3 June 2014.)

It is clear from Rashid’s words that PAPDA is not following any international systems but has only translated disability terminologies and applied them. It was not clear whether these terms were exposed to scrutiny by disability specialists in order to examine their suitability to the Kuwaiti context. In fact, the international terminology referred to by Rashid, as discussed above, is internalised with a medical view of disability. This can be seen through the preferred use of the international term ‘people with disabilities’ by the PAPDA and the Kuwaiti disability law.

The consequence of the work of medical professors that aims to define disabled people by their impairments could, from a Foucauldian perspective, be considered a form of biomedicine. As shown in Extract 7.15, however, professionals in Kuwait understand these medical procedures and diagnoses (not conflating them with the ontological existence of impairment) as a necessary process in enabling
the rights of disabled people in Kuwait. Because of the financial abundance and privileges allocated for disabled people in Kuwait, some non-disabled individuals are perpetrating fraud in the welfare benefit system and depriving disabled people of their civil rights. Therefore, these procedures seem to be necessary to protect them from oppression and should not be seen as “a sinister apparatus of power/knowledge; as Foucauldians point out, this can be a liberating and empowering process which facilitates functioning and inclusion” (Shakespeare, 2014, p.64).

Nevertheless, although these procedures can be helpful to detect those who are perpetrating fraud in the welfare benefit system, I find them unnecessary when this problem is resolved. Thus, these procedures are temporarily needed because Kuwait is currently experiencing ‘legislative chaos’ caused by those who, according to the state and disabled people, commit fraud in the welfare benefits. As a result of this chaos in legislation, many disabled people in Kuwait are robbed of their rights. It appears that until now, according to the former General Director of PAPDA, the procedures of re-examining disabled people’s documents were fruitful as he found that around 13,000 persons were misusing the system and they have been transferred to the public prosecution (Alrai, n.d).

The work of poststructuralists (for example, Tremain, 2005) is, without a doubt, helpful in examining power/knowledge relations, the discursive construction of ‘normality’, and the binary dichotomies between disabled and non-disabled people. Owing to the current Kuwaiti situation, however, the work of
poststructuralists that aims to deconstruct the binary dichotomies between disabled and non-disabled people does not seem helpful for two political reasons. The first reason is the co-researchers’ recognition of the needs that make them different from non-disabled people (see Extracts 7.9 and 7.24). Therefore, disabled people in Kuwait would find deconstructing the binary dichotomies between disabled people and non-disabled people a form of deprivation of their ‘special needs’. The second reason is that deconstructing the binary dichotomies is unhelpful, practically, in pursuing those claiming benefits fraudulently. The co-researchers raised the issue of those claiming fraudulently on several occasions and demanded that PAPDA should find those claimants who take their privileges and should not do favours for them during the medical procedures.

Extract 7.17

| Kholood: Now, there are many people who wish to be disabled… they have fake disability ID, they are healthy; they fake it to get financial aid; they take our privileges; they don’t deserve it. |
| Abdullah: Yeah, there are many of those – they claim disability benefits but they are not disabled. |
| Hussain: Does the Public Authority of Disabled Affairs know about them? |
| Abdullah: Their families know. |
| Kholood: Leave their families; the Public Authority knows they should organise the medical committee without favouritism… our medical committees always... |

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Moreover, on some occasions during the regular meetings with the co-researchers, the issues regarding the ‘real’ number of disabled people in Kuwait were raised. This is consistent with the on-going debate among politicians, the media, social activists, disabled people, and their families in Kuwait, which places them in a ‘tug-of-war’ to determine the ‘real’ number of disabled people (see Chapter two).

Some would argue, from a Foucauldian perspective, that the examination of disabled people, medical diagnosis, categories, and welfare assessment highlight the issues of biopower/biopolitics between disabled and non-disabled people. It is evident in the data from this project, however, that these processes are necessary so that disabled people can receive their disability allowances and pensions as well as other public services (see Extracts 7.15 and 7.17). The medical recognition of impairment and categories can also be a positive step in the development of laws and policies that protect the rights of disabled people (Vehmas and Watson, 2014). Although it is crucial to make a correct diagnosis and have a good understanding of the medical condition, one should not deny the psychological effects that might be caused by, for example, misdiagnosis or unnecessary bureaucratic procedures. Therefore, doctors should be careful about how they diagnose people and how they respond to those who are diagnosed (Shakespeare, 2003).
Medical Testing Before Marriage

There is another, significant, sign of how biopower operates in Kuwait in genetic testing before marriage. This issue was clear in Khalid’s discussion when he addressed the aim of the Public Authority to raise people’s awareness about disabled people and disability:

Extract 7.18

One of our projects is raising awareness. We should have continuous awareness, a census of disabled people... ah, ah, the early examination before marriage; it is applied now to reduce impairment... raising people’s awareness through media. When you raise society’s awareness, they will acknowledge how to deal with impairment and how to reduce this problem.

(Khalid, male, aged 36.
Interview date: 15 June 2014)

Although Khalid views himself as a disabled person, interestingly, he is campaigning, along with the Public Authority to reduce the number of disabled people. This is consistent with the law in relation to disabled people in Kuwait:

The government is committed to providing precautionary, counselling, and rehabilitation services in all the country’s health centres, taking into account the special needs of persons with disabilities. It shall also work to reduce the causes of disability before and during pregnancy, and after childbirth, and also provide them with medical treatment abroad if
One way to reduce impairments is through the application of a medical examination before marriage. The law requiring a medical examination before marriage is active in Kuwait: all couples who are hoping to get married are obliged to have this test done. The test serves as an examination for both genetic and sexually transmitted diseases. One would argue, however, what does this have to do with the state? The state would justify this procedure as a means for protecting the next generation from genetic disease. Also, because the state of Kuwait provides its citizens free health services, testing before marriage would reduce the high costs of treatments on the state budget.

The results of the test are such that if, for example, the couples are genetically unsuited to each other, they will still be able to get married but will accept this matter as their own responsibility. This test is also available in other Arabian countries, such as Saudi Arabia. In Saudi Arabia, however, if the couples are genetically unsuited to each other, they cannot get married; couples are considered genetically unsuitable when they have common genetic diseases.

I had to do this test myself before I got married. The result of the test indicated that I have thalassemia trait, which means I carry the genetic trait for thalassemia, but I am not carrying the disease itself. In other words, I am not experiencing any health problems related to thalassemia. However, carrying the genetic trait for thalassemia means I can pass the disease to my children if I were to get married to
a person who has or carries the same genetic trait. Because of the results of my wife’s test indicated that she was neither had nor carried the genetic trait for thalassemia, the ministry of health in Kuwait ‘accredited’ that our marriage was safe. This is an example of how the test works before marriage in Kuwait.

The medical examination before marriage has emerged as a reaction to cultural phenomena. Arab societies, especially the countries that overlook the Persian Gulf, are based largely on the sanctification of Arab habits, such as pride about genealogy. One form of pride about genealogy is consanguineous marriage, a phenomenon that is manifested clearly, particularly in Bedouin communities. The phenomenon of consanguineous marriage can be understood by identifying the classes that form Kuwaiti society. A mixture of people with different genealogical backgrounds forms the Kuwaiti society. A small proportion of the people in Kuwait are of Persian origin, whereas the larger proportion consists of those whose ancestors come from different Arab tribes, some from Iraq and others from Saudi Arabia. Many people who came from Saudi Arabia (especially those called as Bedouins today) adhere to Arab traditions, including consanguineous marriage. The high rate of consanguinity in the Arab world has led to an increase in genetic impairments (Turner, 2015).

The application of the medical tests before marriage is an example of biopower in Kuwait. Although this issue is not addressed explicitly in the work of critical realists such as Shakespeare, Watson, and Vehmas, they all tackle the difficulties associated with impairments and with preferences to avoid them. For example,
Vehmas and Watson (2014) state that some disorders, such as motor neuron disease, depression, or spinal cord injuries, are the types of conditions that every person would prefer not to have because of the cultural representations linked to them, as well as the medical difficulties associated with them. Furthermore, reflecting on his personal experience, Shakespeare points out:

The predicament of impairment – the intrinsic difficulties of engaging with the world, the pains and sufferings and limitations of the body – means that impairment is not neutral. It may bring insights and experiences that are positive, and for some these may even outweigh the disadvantages. But that does not mean that we should not try and minimise the number of people who are impaired, or the extent to which they are impaired: I would very much like to turn back the clock to before the onset of my paraplegia. (Shakespeare, 2014, p.86)

It is clear that the social policy in Kuwait (see Extract 7.18) is attempting to minimise the number of disabled people through the application of medical tests before marriage. This tendency by the state seems necessary, as the accounts of the participants and the co-researchers did not show resentment towards this form of biopower. In contrast, as shown in Extract 7.18, Khalid is a disabled person and has campaigned for minimising the number of disabled people through the application of the tests before marriage. Furthermore, in Extract 7.11, Saja thanked God for having a non-disabled sister, which demonstrated her awareness of the medical difficulties and the cultural stereotypes associated with impairments. However, I am not suggesting here that I believe that testing before marriage is necessary just because a handful of disabled people think it is okay. I am aware that they by no means can be understood as talking for all disabled people. I will show below why I believe testing before marriage is necessary for
the Kuwaiti culture.

Accepting this form of biopower is a challenge for critical disability studies (CDS). From a CDS perspective, testing before marriage is ethically problematic at best as it is based on ‘ableist’ ideas. Critical disability scholars such as Campbell (2008) and Goodley (2014b) employ the concept ‘ableism’ instead of ‘disablism’, believing that by turning the focus away from disabled people and disability, the negative cultural images of disability and disabled people can be challenged. Critical disability scholars, however, have failed to deal with practical solutions, the role that impairment might play in day-to-day activity, and the ethical dilemmas regarding, for example, the connection between living with impairment and people’s well-being (Vehmas and Watson, 2014). Vehmas and Watson (2014) provide an example that shows how CDS failed to engage with these ethical considerations:

Imagine, for example, a pregnant woman who has agreed, possibly with very little thought, to the routine of prenatal diagnostics, and who has been informed that the foetus she is carrying has Tay-Sachs disease. She now has to make the decision over whether to terminate the pregnancy or carry it to term. The value judgements that surround Tay-Sachs include the fact that it will cause pain and suffering to the child and he or she will probably die before the age of four. These are morally relevant considerations to the mother. Whilst CDS would probably guide her to confront ableist assumptions and challenge her beliefs about the condition, considerations having to do with pain and suffering are nevertheless morally significant. (Vehmas and Watson, 2014, p.642)

Nevertheless, in Kuwait and other Islamic states, these ethical issues are more complex. Testing before marriage is accepted in Islam, but termination of a foetus is only possible before the soul is ‘blown’ into the foetus. Termination of a foetus
after the passage of 120 days from the beginning of pregnancy is prohibited in Islam (Islamqa.info, 2016). Therefore, the mother’s decision about whether she wants to continue with the pregnancy depends on cultural/religious restrictions. This view is in contrast to the view adopted in some countries where the abortion of disabled foetuses is acceptable. Thus, in these countries, the need for genetic testing is lessened. However, in contrast, because abortion is prohibited in Islamic states, I find testing before marriage a useful solution that gives prospective couples the choice to go ahead with their marriage or reconsider their decisions.

**The Application of IQ Testing**

Another practice of biopower in Kuwait is the application of IQ tests (see Extract 7.19).

**Extract 7.19**

<table>
<thead>
<tr>
<th>There are two kinds of committees: medical committees where you talk about the whole disability, the physical, medical, and health aspects, and there are educational committees, where we apply tests on him, such as an IQ test, difficulties test, achievement tests, and look at intellectual tests and his comprehension and ability, and then give him a certificate or educational decision that shows the kind of disability he has to see if it is educational.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Rashid, male, aged 53. Interview date: 3 June 2014.)</td>
</tr>
</tbody>
</table>

From his position as an official at the Public Authority, Rashid was talking about
the procedures that he follows to determine the type of impairment and its degree. These procedures are applied through the calculation of IQ scores that can be understood to “objectify the body of the student (high or low IQ) to render them pliable (normal or SEN child)” (Goodley, 2011, p.107).

The Public Authority is employing different types of tests to determine the type of support that students need. As Kuwait has established a special school for each type of impairment, these techniques seem intuitive to conclude which school is the most appropriate for the student. It is clear that Rashid is dealing with the IQ differences between people as a ‘real’ thing, and, accordingly, he decides whether the student needs a general or special school. It does not seem, however, that Rashid distinguishes the existence of a mild learning disability, such as dyslexia, as a social phenomenon which can differ based on the context. For example, dyslexia would disappear in countries where illiteracy is widespread. Thus, mild learning disability may be socially constructed (Shakespeare, 2014). However, at the same time I believe that learning disabilities are not solely “a creation of culture, politics and society – a category of mass education, differentiation, testing and auditing” (Goodley, 2011, p.59); they are real things too.

It can be concluded from the above that the government is practising a form of biopower through the application of medical and educational procedures. From a Foucauldian perspective, this is considered a form of a dissipated power. These procedures, given the current Kuwaiti situation, are necessary to help disabled people integrate into society. In Chapter one, I talked about my interview with the
Deputy General-Director of the PAPDA, as he stated that people in the past used to hide their disabled children and keep them at home because there were no special schools available to accommodate them. He confirmed that the establishment of special schools helped people take their children out and enrol them into these schools. Throughout my journey investigating disability in Kuwait I found a number of disabled people and their parents preferring special schools over general education. Thus, the elimination of special schools suddenly may lead to the danger of isolating disabled children again. Nevertheless, I am fully in support of inclusive schools once they have a good chance to flourish.

The idea derived from the above is that what is seen as a governmental biopower in the UK should not be the case in Kuwait. For example, reflecting on my personal experience, when I first came to the UK, I had to register with a general practitioner as a necessary bureaucratic procedure required for anyone who wants to live in the UK. Following the registration, I had to undergo general medical examinations and report my family history, including the history of diseases. As a result of these procedures and because my family has a medical history of high blood pressure and diabetes, I needed to undergo medical check-ups at regular intervals. From a Foucauldian perspective, this may be considered a form of biomedicine. If these procedures existed in Kuwait, however, people would say that we have a very good health system.

7.3.3 Language suitability

Here, I will discuss another issue related to language that also reinforces the
notion of ‘normality’. Across many societies, many people commonly use words (historically) related to disability as an ‘insult’ (words such as ‘retard’, ‘spastic’, ‘idiot’, and even ‘special’). Within Kuwaiti society, however, the contemporary disability discourse would also appear to possess negative connotations:

**Extract 7.20**

<table>
<thead>
<tr>
<th>Saja: One time, I was walking in The Avenues last week; there was a girl who wasn’t holding her sister’s bag properly. She didn’t know I was walking behind her; then her sister said to her, “Why are you carrying my bag like this? You look like a disabled person – hold it properly”.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kholood: Yeah, they use this word a lot – it is like an insult.</td>
</tr>
<tr>
<td>Saja: Why do they say that? What’s wrong with disabled people?</td>
</tr>
<tr>
<td>Yagoub: I usually say it amongst my disabled friends; I say, “You are disabled...”</td>
</tr>
<tr>
<td>Kholood: Ha, ha… it is ok when you are a disabled person and say it… but it affects them when a normal person uses “disability” to insult someone.</td>
</tr>
</tbody>
</table>

(Focus group date: 10 April 2014)

This extract shows the use of the word ‘disability’ as an insult, in a similar fashion to that of other minority groups (as opposed to being labelled as ‘disabled’ in a factual way) such as being gay or having a mental health problem. When examining the transcripts, however, it is clear that the co-researchers tend to
accept the use of the word ‘disabled’ as an insult or even a joke when used by their disabled friends. This is parallel to the acceptance of some black people of the use of the ‘n-word’ within their community and the strong rejection of its use outside their community (other similar examples include terms such as ‘crip’, ‘queer’, and ‘dyke’). This process of ‘reappropriation’ or ‘reclamation’, i.e. a “phenomenon whereby an ostracized group revalues an externally imposed negative label or symbol by self-consciously referring to itself in terms of that label or symbol” (Galimsky et al., 2003, p.231), would appear to be in existence here. Through ‘reappropriation’ or ‘reclamation’, one can, as Bhaskar (2011) believes, ‘reclaim reality’. Reclaiming reality can be the basis for emancipation and social change (Corson, 1991). For example, the term ‘queer’, which had been used historically as an insult gay people, began to be ‘reclaimed’ in the 1990s by many to represent a form of ‘resistance’ to the dominant homophobic discourse prevalent during this period (Galimsky et al., 2003).

Whilst the reclaiming of certain terms may be common across various minority groups, when it comes to disability, it has been argued that the reclaiming of terminology is more complex, as Shakespeare and Watson (2010, p.64) observe:

It is harder to celebrate disability than it is to celebrate Blackness, or Gay Pride, or being a woman. ‘Disability pride’ is problematic, because disability is difficult to recuperate as a concept: it refers either to limitation pain and incapacity, or to oppression and exclusion, or else to both dimensions.

Generally, although the co-researchers criticised some non-disabled people who frequently use people’s impairments to insult disabled people, they were,
themselves, found to use this ‘disablist’ language in their speech. For example, Saja and Omar used the words ‘crazy’ and ‘demented’ when referring to learning disabled people on different occasions. Furthermore, Khalid used the word ‘incomplete’ when referring to learning disabled people (see Extract 7.21).

**Extract 7.21**

Maybe you know that… sometimes you find one person in a family… his *rupiah* is incomplete.

(Khalid, male, aged 34.

Interview date: 15 June 2014)

Khalid, a physically impaired person who works for the Public Authority, was found to use these disablist terms in a similar fashion to some of the coresearchers, for example, Saja and Omar. In the above extract, Khalid uses the metaphor ‘*rupiah* is incomplete’. *Rupiah* is the currency used in India and Indonesia and was the currency used in Kuwait before the introduction of the Kuwaiti dinar. Therefore, this is an old expression used in the Kuwaiti dialect in reference to learning disabled people. The phrase ‘*rupiah* is incomplete’ means that one’s ‘mind is incomplete’. A similar old English phrase has the same meaning: ‘a shilling short of a ten bob note’.

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7.4 The Psychological Effects and the Role of the Body

As stated earlier, some non-disabled people stare at disabled people when they go out:

**Extract 7.22**

<table>
<thead>
<tr>
<th>Here, they look at you and make you feel like you are a strange being… They stare a lot… Disabled people who get used to it just ignore it, but people who do not get used to it, they get upset.</th>
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<tbody>
<tr>
<td>(Yagoub, male, aged 21. Focus group date: 10 April 2014.)</td>
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</tbody>
</table>

Yagoub’s experiences demonstrate how some disabled people may feel uncomfortable when someone stares at them in public places. It indicates that disabled people, like all people, are affected psychologically in two different ways when being stared at. The effect of the extrinsic factors (e.g. staring) on the intrinsic factors (e.g. getting upset) forms the foundation of what Thomas (2004a, p.22) refers to as ‘social relational understanding of disability’. Thomas (1999, p.60) defines disability as “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being”. Thomas defines oppression on two levels: the micro or ‘inside’ level (the intrinsic factors) and the macro or ‘outside’ level (the extrinsic factors).
As shown in Chapter two, however, the effectiveness of the extrinsic factors on the intrinsic factors presents the ‘problem’ of disability as dual systems rather than as the complex and interwoven system it actually is (Watson, 2012). Whilst I am considering Thomas’s approach, I want to go further than she does and argue that even if, for example, staring were taken out of the picture, disabled people would still face some psycho-emotional challenges merely because of their impairments (Shakespeare, 2014).

Yagoub expanded on his experience with his impairment and talked about the psychological consequences that might be caused by having an impairment. He talked specifically about how having an impairment, especially at an older age, can have negative psychological influences on disabled people’s lives and thus keep them isolated from the mainstream. Yagoub, who became disabled because of a car accident, provided an example from his experience of how having an impairment at a later stage of his life had a negative psychological impact on him:

**Extract 7.23**

[It was] not necessarily [the fact that I was] old or young when I became disabled. I was younger. The only question I was ever asked was if I could play football. All my thoughts were about football because I had been a football player at the Alqadesia club… For the first period I stayed at home and I did not go out; but the people around you [still] have an effect. My friends said, “Come out with us”… [In this] first period [I would say] “No”… Then [my friends] came to my house and took me out. Without this I would still be at home [now].
In this extract, Yagoub shows how having an impairment impacted him psychologically and made him live in isolation for a while. It also demonstrates how having an impairment changed his life as a football player, meaning that he could no longer play football. Yagoub’s story can be linked to the discussion of Shakespeare and Watson (2010) on how intrinsic factors related to impairments have an effect on disabled people’s quality of life. This is an example of how impairment can have negative psychological impacts on disabled people’s lives, isolating them from the mainstream. Yagoub is a positive example, as (with the help of his friends) he could re-engage with society. He is now a table tennis player on the Kuwaiti national team. Conversely, there might be other disabled people who find it difficult to be included in society again. It is important to note here that from my critical realist-informed perspective, although inclusion does not necessarily remove all of the psychological factors associated with impairments, it might reduce them.

7.4.1 Social Gaze

Now, I would like to return to the discussion on the social gaze that disabled people are exposed to by some non-disabled individuals in public places. Some
disabled people prefer to use a wheelchair in order to avoid, or at least reduce, the social gaze:

**Extract 7.24**

<table>
<thead>
<tr>
<th>The problem here – when I go to a shopping mall, for example, I feel that people’s look when I am in my wheelchair is much better than when I walk… When I walk, they make me feel that I am a strange being; they get surprised – how do I walk like this? Well, OK, I am disabled: my ability and my walking are limited.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Saja, female, aged 22. Focus group: 6 May 2014.)</td>
</tr>
</tbody>
</table>

Saja clearly prefers using a wheelchair as this stops people from staring at her body. Saja’s preference for using her wheelchair provides a classic form of psycho-emotional disablism (Thomas, 1999, 2004a). Shakespeare, Thompson and Wright (2010) explore how, in a similar way to this study, some of their respondents who had restricted growth, especially those with spinal stenosis, used their wheelchairs in similar ways as a tool to reduce staring. Using wheelchair to lessen the social gaze alludes to Goffman’s notion of ‘passing’. Goffman (1963) writes about how some disabled people negotiate their impairment by attempting to ‘pass’ as non-disabled people. However, the example above highlights how some disabled people are attempting to ‘pass’ by appearing to have specific impairments (that require a wheelchair). This shows an example of Foucault’s regulatory power on how some disabled people behave in a certain way through
the power of the gaze. It would suggest that there are some ‘acceptable’ and ‘non-acceptable’ impairments. It appears that some people in Kuwait are more open to seeing disabled people using their wheelchairs (and thus reduce their gaze) than seeing them limping.

Furthermore, this extract shows that while Saja sees her wheelchair as a means of managing her life (Extract 7.4), she describes herself as disabled because of her impairment and her limited ability to walk, adopting, again, a more individual model. This finding also reflects what some of the disabled informants in Shakespeare and Watson’s projects revealed in relation to their incapability to manage things in life (Shakespeare and Watson, 2010).

Saja’s discussion in relation to her preference for using a wheelchair raises an important question here: Why does she think that people stare more when she walks than when she uses a wheelchair? This question reintroduces the discussion on imagery, discourse and power. It seems that people in Kuwait have formed a mental image linking the existence of disabled people with the use of a wheelchair. Therefore, it is more acceptable for them to see a person using a wheelchair than to see him/her limping (in the case of Saja). This mental process can be understood as what Van Dijk (2006) calls ‘mental models’. For Van Dijk (2006, p.169), a

…mental model is a subjective representation of the events or situation that discourse is about. That is, understanding text or talk not only involves constructing a mental representation of its (intensional) ‘meaning’, but also and ultimately, a mental representation of its (extensional) ‘referent’ as the participants subjectively define it by constructing a mental model for it … Mental models represent people’s
experiences, and people’s episodic memory is thus populated by mental models.

With this in mind, it is possible that people in Kuwait have formed a mental model that is linked to the presence of disabled people using a wheelchair. It appears that this correlation has been formed (mentally) through the frequent exposure to the wheelchair users in reality and their cultural representations in the media, as well as wheelchair signs on the car parking spaces, toilets, and door buttons allocated for disabled people. This frequent exposure has made people more used to the presence of wheelchair users and thus reduced the social gaze on them (but this depends on the type and degree of impairment).

7.4.2 The Role of the Body

I would like to go back to Saja’s discussion when she referred to the ‘problem’ of disability in her body by saying that her ability and walking are limited. The reference to the ‘problem’ of disability in her body was very clear when she criticised the state for ‘drowning’ disabled people with money as compensation for their impairments:

**Extract 7.25**

Why? Can money compensate for my leg? I want my leg to take all the money… Give me a healthy leg and take anything you want. I could live with one piece of bread; I would be satisfied.

Yeah, sure, I am willing to live with just one piece of bread for the whole of my
Therefore, although Saja sees herself as a person who is capable of doing many things that non-disabled people can do, she does not hide her strong desire to walk, as she is willing to dispense with all of her money to achieve this desire. This poses a challenge to the social model. Perhaps, this desire made her think about receiving treatment abroad, as after a period of working with us on this project, she left for treatment to the US. In fact, Saja was not the only person who travelled abroad for treatment, as shown in Chapter four. Abdullah also left our group for treatment to the US. These are practical/pragmatic or extra-discursive examples of the role that impairment might play in the lives of disabled people. Moreover, the role of impairment was evidenced throughout the research process, as on some occasions, the co-researchers could not attend our meetings because of health problems related directly to their impairments.

Whilst further investigation about the role of the body will continue as this chapter progresses, Saja’s criticism of the country for giving disabled people many financial benefits that cannot compensate for their impairments is important. She developed her argument later and showed the limitation of money in changing social behaviour. Her criticism is compatible with the views of the other co-researchers. Their criticism, which stemmed from the socio-economic level,
centred on the lack of focus of the government on disabled people’s needs and its exaggerated focus on financial benefits at the expense of other services:

**Extract 7.26**

Hussain: Are you asking for equality?

Saja: In everything.

Abdullah: Why do you have sympathy with me?

Saja: Here in Kuwait, they think everything can be fixed by money: increase for disabled people, increase their salary; ok, we don’t want money.

Hussain: What do you want?

Abdullah: Really, they think that disabled people only want money.

Saja: We don’t want money… money is not everything… can money compensate us for the way people treat us and pity [us]!?

Abdullah: Why do you give money to disabled people and show them charity then… disabled people can give you!

Hussain: What do you want if you don’t want money?

Kholood: No, no one hates money, but we also need other things… we mean they fix buildings for us… they apply the law that was established by the previous Amir of Kuwait, Sheikh Jabber… since when this law was established!

Omar: That is right.

(Focus group date: 6 May 2014)
This extract shows the interaction between three co-researchers, Saja, Abdullah, Kholood and Omar. Saja and Abdullah reported their explicit rejection of the state policy for giving disabled people money that cannot compensate for the negative social attitudes towards disabled people. On the other hand, Kholood and, at the end, Omar confirmed that the financial allowances allocated for disabled people are good but not enough, as equality and making buildings more accessible are also important aspects. This is a materialist account regarding the foundation of the social model. As shown in Chapter two, the material base that is rooted in Marxism was behind the emergence of the social model (see, for example, Oliver, 1990b).

The differing views among the co-researchers in relation to financial welfare and materiality can be understood by comparing the economic structure in the UK and Kuwait. Furthermore, exploring extra-discursive practices such as social life and the financial status of the co-researchers and of Kuwaiti citizens in general is necessary. Such explorations might provide a logical justification regarding why the co-researchers, especially Saja and Abdullah, chose those particular traits in their language.

As shown in Chapter two, Kuwait is considered one of the most powerful economic countries in the world. In this socialist state, Kuwaiti citizens generally enjoy a high standard of living and welfare by obtaining secure government jobs and free access to public services such as healthcare and education. Kuwait’s economic prosperity and welfare are certainly reflected by the disabled people’s
lives. PAPDA has established a disability law that gives disabled people in Kuwait many financial benefits. According to the Deputy Director-General of the PAPDA, these financial benefits include a 100KD servant/driver allowance, 10,000KD for house adaptation and a monthly salary based on the type and severity of the impairment. In the UK, the economic structure is different. Currently, the UK is experiencing welfare system changes that are having negative impacts on disabled people’s lives (Duffy, 2013; Grover, 2015; Roulstone, 2015; Beresford, 2016; Dodd, 2016).

Because of this financial abundance, it might not be surprising that the co-researchers criticised the state for exaggerating financial resources over other disability issues or declared their rejection of money and its limits in compensating for their physical impairments. The recognition of the limitation of financial benefits in compensating for impairments constitutes a challenge to the social model and highlights the inappropriateness of the imposition of a Western model. At the same time, however, the co-researchers are aware of the importance of having a law that protects their rights and services and makes buildings more accessible.

Their choice of discourse regarding financial aids, however, might have been different if they were living in a country where basic biological needs are totally unmet (see, for example, Thomas, 2005; Grut, Olenja and Ingstad, 2011). This illustrates the temporal nature of ‘disability’ and how this social construct changes according to place and time. This makes grand narratives that are associated with
modernism fragile, giving way to a more postmodern approach that creates “a shift from meta-narratives to local narratives and from general theories to pragmatic strategies … [allowing] multiple minds, subjects, and knowledges reflecting different social locations and histories” (Corker and Shakespeare, 2002, p.5).

From the above, one can appreciate how difficult it is to analyse disability from a single approach. Analysing disability from a limited/reductionist approach would neglect many aspects of disabled people’s lives. Disability is a complex and distinct phenomenon which cannot be explained solely by the individual or the social model: “Both the medical and the social model seek to explain disability universally, and end up creating totalizing, meta-historical narratives that exclude important dimensions of disabled people’s lives and their knowledge” (Corker and Shakespeare, 2002, p.15).

7.5 Cultural Representations and the Role of the Media

The domination of the individual model can be seen in the way in which the media in Kuwait portray disabled people:
Extract 7.27

The media plays a role. Everyone has a television. Everyone watches television during Ramadan. When you get an actor to play the role of a disabled person, he puts white sheets on his legs in a dark room; he is sad all the time and he doesn’t study or go anywhere.

(Saja, female, aged 22.
Focus group data: 6 May 2014.)

Here, Saja criticises how some TV shows portray disabled people as useless and non-productive, considering this to be a misconception of the real lives of disabled people. In this extract, Saja documents overtly her rejection of the tragic view of disability. It is interesting to note here that Hunt suggested, as far back as 1966, that non-disabled people see disabled people as representatives of tragedy, loss, and darkness. It is also an echo of the observation of the disability rights lawyer, activist, and storyteller Harriet McBryde Johnson, who pointed out that what people usually recognise when they look at her is “unbearable pain, insurmountable adversity, a diminished life, and a fervent desire for a cured body” (Garland-Thomson, 2010, p.202). In this extract, Saja is using her adoption of a social model conceptualisation through a Foucauldian ‘technology of the self’ to resist the tragedy narrative that is being constructed in the media (Beckett and Campbell, 2015).

On the other hand, although none of the co-researchers endorsed any TV shows as reflecting the real lives of disabled people, Fahad, who was shown in the disability
awareness film, mentioned one good show called “Jarh el zeman”:

**Extract 7.28**

We don’t see the correct awareness from the media regarding disabled people. I address what I’m about to say to the Ministry of Information. You should have more programmes and increase awareness about disabled people. All my life, I have just seen one show that did this; it is called “Jarh el zeman”. It focused on social problems and also on deaf people and the problems that they go through from psychological issues to social issues and so on.

(Khad, male, aged 28. Interview date: 22 October 2014.)

The media may be responsible for the formation of how both disabled and non-disabled people look at and perceive learning disabled people:

**Extract 7.29**

Yeah, and when they play the role of a person with an intellectual disability, even [the disabled person’s] family and people around him say he is crazy. He is crazy, so everyone looks at him… “Intellectual disability means crazy”. So, the media is delivering a false message.

(Kholood, female, aged 24. Focus group date: 6 May 2014.)
In fact, as stated in Chapter two, a number of Kuwaiti TV shows and plays refer to learning disabled people as ‘crazy’ or ‘demented’. In comedy shows, the cast ‘use’ learning disabilities and dwarfism as a ‘tool of ridicule’ in order to make jokes. Portraying disabled people as an ‘object of ridicule’ is not restricted to Kuwaiti culture and can also be seen in Western societies (Barnes, 1992; Clark, 2003). Sara, who has restricted growth, talked about how disabled people are being exploited in the media as a ‘tool of entertainment’:

**Extract 7.30**

> As disabled people, we don’t like to be made fun of, playing the role as you see us. If you want to play the role accurately, then you should show us the way we are. Don’t take the role just for the money. I hope the media spreads a positive image to society that we are not there just so they can make fun of us.

(Sara, female, age 22.
Interview date: 25 October 2014.)

Conversely, the notion of ‘supercrip’ that is often related to how the media depicts a disabled person as extraordinary, someone who can overcome his/her impairment with miraculous abilities and become successful in his/her life, was not evident in the data (see Barnes, 1992; Harnett, 2000). On the other hand, indications within the recollections of the co-researchers and the disabled participants in the disability films support their impressions regarding this notion. For example, Fahad, who participated in the disability awareness film talked about
his impairment as a non-barrier for getting on with his life and becoming successful:

**Extract 7.31**

I have had a disability since birth that was caused by lack of oxygen and that gave me cerebral palsy since birth. However, since this did not affect me, I continued to university and continued in life in the best possible way, thank God Almighty. But, some people look at disabled people in a sympathetic way, and we don’t ask for their sympathy. We are well-educated and have abilities and achievements; with that in mind, you sometimes see these people who have a sympathetic view of disabled people are not educated or anything. We are better than them, we have achievements, and, speaking for myself, I’m a member of the Kuwait national team in shot put at the Kuwait club for disabled people. I have also competed in many places like the United Arab Emirates, Tunisia, and I have earned 4th place in the world rankings, thank God.

(Fahad, male, aged 28.
Interview data: 22 October 2014.)

Sara confirmed the same notion:
These two extracts clearly show the participants’ confirmation of success in their lives despite the ontological presence of their impairments. This is relevant to what Silva and Howe (2012) referred to as the ‘achievement syndrome’. The achievement syndrome addresses the success of disabled people in spite of their impairments (Silva and Howe, 2012, p.174). Both Fahad and Sara used their success in life and achievements to prove their presence, demonstrating that such abilities are not limited to non-disabled people. By confirming that their physical and mental abilities are at an equivalent or higher standard than any other non-disabled individuals, however, they are destabilising the attempts of those who have different abilities to challenge the oppression they experience.

The fact that the informants raised these ideas recalls the notion of classification and preferences among different groups of disabled people. Deal (2003) noticed this notion of classification in the early 1980s, when the term ‘supercrip’ was used by a group of young men with Duchenne muscular dystrophy. The group used this

<table>
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<th>Extract 7.32</th>
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<tr>
<td>OK, we are disabled but we can also be creative. Creativity can’t just be from a non-disabled person, we can also be creative in other ways... God took something from us, but he also gave us something else instead. We have many talents; for example, I am an artist, a photographer, and a student. What do you call that? I am displaying my talents, and now I am an athlete too.</td>
</tr>
<tr>
<td>Sara, female, aged 22.</td>
</tr>
<tr>
<td>Interview date: 25 October 2014.)</td>
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</table>
term in a disparaging way to describe other wheelchair users who participated in marathons, drove cars, and used their upper body strength to the full. Thus, this group of young men created a hierarchy by considering themselves to be ‘genuine’ disabled people and distanced themselves from other more athletic groups of disabled people.

It can be seen that Deal’s (2003) observations took disability to a more complex position by showing that the ‘more abled’ person is not necessarily the one who wants to distance himself from the ‘less abled’ person, as it can be the other way around. For example, I have shown how Saja perceived herself as part of a disabled upper class, an equal to non-disabled people, because of her ability to do similar things, and at the same time distanced herself from learning disabled people, whom she viewed as part of a lower class. Deal (2003) showed the issue in an opposite way, however, by discussing the views of the young men (lower class, based on Saja’s classification) with Duchenne muscular dystrophy who wanted to distance themselves from the athletes (upper class, based on Saja’s classification). Therefore, this opens up the possibility that learning disabled people who are considered to be in a lower class by many informants in this project preferred to distance themselves from other groups of disabled people.

Moreover, by returning to the ideas raised by Fahad and Sara, it can be noticed that their ideas are implicitly supportive of the ‘extraordinary’ disabled characters being represented in television and cinema. Let us take two examples here: the first one is from the series of X-men films and the second one is from the Stephen
The second example is from the film *The Theory of Everything* that narrates the life of the cosmologist Stephen Hawking. Although the film shows how his impairment impacted him throughout the different stages of his life, the film makes the audience wonder how Stephen Hawking could, despite his condition, manage his work and be a father of three children. In other words, the film raises ‘supercrip’ questions in relation to Hawking’s achievements with his work in cosmology as well as managing his ordinary life, more specifically his sexual life.

Furthermore, as stated earlier, the media is responsible for how the general public perceive learning disabled people. Given how the media portray learning disabled people, it is clear that the depictions of these people in the media, to a large extent, not only formulate the views of the general public but also reach those who are in political positions (see Extract 7.21).

It is clear from the data that learning disabled people are represented in negative terms from different directions (i.e. politicians, the media and disabled people
themselves who have other types of impairment). The findings from this study suggest that learning disabled people could be amongst the most oppressed disabled group in Kuwaiti society.

The general public in Kuwait has apparently formed their ideas about learning disabled people in a way that is similar to that in the Western societies (see Chapter two). From a Foucauldian perspective, as the notion of ‘madness’ started to be recognised as a mental illness in the 18th century, it is clear that some people in Kuwait still perceive learning disabled people as ‘mad’ or ‘crazy’. This was clear from the discourse of some co-researchers and in the discourse of Khalid, the decision maker in the Public Authority. Moreover, the presentation of learning disabled people as ‘mad’ or ‘crazy’ is obvious in the media. Learning disabled people in Kuwait are confined to their own homes, and there is no evidence from the past and, of course, at the present time in the Arab world of the Foucauldian ‘great confinement’ of learning disabled people in institutions (Turner, 2015, p.1300).

I will now move on to discuss disability and its link with culture and religion.

7.6 Disability and the Role of Culture and Religion

As stated earlier in this chapter, there are groups of non-disabled people who use explicit words when they see disabled people, for example:
The first phrase, as stated by Kholood, shows how people sympathise with disabled people by praying and asking God to help and heal them. The second phrase demonstrates how non-disabled people use disabled people’s bodies as a reminder of their own ‘healthy’ or ‘normal’ body and therefore pray to God to grant them the grace of a ‘healthy body’.

In fact, this phrase, as discussed in Chapter two, is common among local people in Kuwait, as it can either be used as an expression of gratitude, as in the example above, or be used sarcastically, for instance, when someone does a ‘foolish’ or ‘weird’ thing. This phrase, however, in its first meaning (i.e. gratitude), can be seen clearly in the speeches of Islamic spiritual leaders and Imams:

<table>
<thead>
<tr>
<th>Extract 7.33</th>
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<tr>
<td>Oh, poor [people]… God heal them. (Kholood, female, aged 24)</td>
</tr>
<tr>
<td>Thanks and praise be to God. (Saja, female, aged 22)</td>
</tr>
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<td>(Focus group date: 10 April 2014)</td>
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Extract 7.34

So this is our duty. When I see a stricken person, first of all, I praise God Almighty within myself that I am free from this plague and ask God Almighty to heal him and this is sympathy… Sympathy means kindness in helping him. For example, helping someone get into his car, or if you find a blind person, you take him to a [particular] place.

(Imam Abdurrahman, male, aged 74. Interview date: 9 June 2014.)

This extract from my interview with Imam Abdurrahman confirms the importance of praise and thanks when non-disabled people see disabled people in public places. He also thinks that impairment is a plague from God; therefore, non-disabled people should feel grateful, as they have avoided God’s plague. As shown in Chapter two, Imams and Islamic scholars differentiate between the terms ‘plague’ and ‘punishment’. For Imams and Islamic scholars, plague, or test, is a word to be used when referring to ‘good Muslims’ whose belief is being tested, while punishment can be used to refer to ‘disobedient Muslims’ and those who are considered atheists, polytheists or infidels by Muslims. The Imam clarifies these differences:
Extract 7.35

If someone is a believer, a disabled person, then [his impairment] is a plague or a test; and if he is a disbeliever, then it is a punishment as a result of his sins.

(Imam Abdurrahman, male, aged 74.
Interview date: 9 June 2014.)

Obviously, extracts 7.34 and 7.35 show a view that is opposite to what the co-researchers suggested earlier. Whilst the co-researchers emphasised that helping and sympathising with disabled people are behaviours that are unacceptable to disabled people, the Imam argues about the importance of these actions. This may give an indication of the Imam’s lack of knowledge regarding disability and the lives of disabled people, as Kholood stated:

Extract 7.36

He should live with disabled people so he can know more about their views.

(Kholood, female, aged 24.
Interview date: 4 November 2014.)

Thus, Kholood suggests that this view should be eliminated permanently and that the Imam should realise that the terms he uses, such as ‘deformity’, are not acceptable to disabled people. Moreover, during the collaborative analysis with the co-researchers regarding my interview with the Imam, both Abdullah and
Abdurrahman wondered how the Imam knew whether an impairment was a plague or a punishment from God, and if the latter, they wondered what the guilt was of those who were born disabled.

The notion of ‘God’s plague’ or ‘test’ may be related to people’s education and culture, as Saja pointed out:

Extract 7.37

Parents play a role as well… For example, maybe without realising, when a child sees a disabled person, he asks his father: “Dad, what is this?” “This is a disabled person, say thank God”, his father then replies. So [the father tells the son] to say thank God, so that God will keep this plague away from [him]… This is [the view of what it is to be] disabled… so I put the blame on the parents.

(Saja, female, aged 22. Focus group: 6 May 2014.)

The origin of this belief (i.e. perceiving disabled people as suffering God’s plague) is deep-rooted in the discourse of the Imam, which is fundamentally derived from Islamic heritage and religious teachings (I have provided examples from Hadiths and the Quran in Chapter two), demonstrating a coherent connection between his discourse and how non-disabled people in society perceive disabled people. Broadly, however, it seems that this belief, as shown in Chapter two, is not limited to Islamic culture – it is historically/culturally entrenched in different societies (Treloar, 2002). For example, the idea of perceiving disability in a
person as a punishment for sins can be seen in Greek and Roman civilisations as well as in different religions, such as Judaism and Christianity (Barnes, 1997; Snyder and Mitchel, 2001).

It seems that the views of the Imam and some disabled people in the Kuwaiti society consistent in terms of the importance of praising and thanking God for their own ‘healthy’ bodies when they see a disabled person. Likewise, all of the co-researchers agreed that non-disabled people can say phrases such as ‘praise and thanks be to God’ but not too loudly or in front of disabled people, as uttering such words would be hurtful and thereby have a negative psychological effect or create in them a negative view of themselves:

**Extract 7.38**

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<thead>
<tr>
<th>You can praise and thank God in your heart but not in front of us, because when you say it in front of disabled people, you make them feel that they have a flaw, and you say in front of them, “Praise be to God I am healthy, not like you”.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Kholood, female, aged 24. Focus group date: 10 April 2014.)</td>
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</tbody>
</table>

Uttering this expression in front of disabled people and its effect on their psychology reflects Thomas’s “social relational understanding of disability” (Thomas, 2004a, p. 22). Such disablist terms uttered by non-disabled people, including praising and thanking God in front of disabled people, can affect
disabled people’s psychology, such as resulting in a feeling of being flawed. It can be noticed here that the co-researchers only rejected uttering this phrase in front of them. This raises an important question regarding whether if people stopped thanking God in front of disabled people, would this change people’s outlook towards disabled people? The phrase and its negative connotations will persist. It seems that people see disabled people’s bodies as a ‘reminder’ of God’s grace and health. They link ‘the disabled/unhealthy body’ and their own ‘abled/healthy body’. The ‘disabled body’ becomes a representation of ‘abnormality’ or ‘illness’ while the ‘able body’ becomes a signifier of ‘normality’ and ‘health’ (Davis, 1995; Dorn, 1997; Garland-Thomson, 2002). This poststructuralist view “demonstrates modernity’s privileging of one (abled, sighted, independent) over the other (disabled, blind, dependent), in which the one is upheld as the transcendental signifier: the ideal sign around which all others can be anchored” (Goodley, 2011, p.104).

Although many people say the phrase ‘praise and thanks be to God’ when they see disabled people, many others say it to show gratitude without referring to disabled people. This means that the phrase can carry different meanings based on the situation or the way people say it. When someone says the phrase when he sees a disabled person, this means ‘thank God I am non-disabled’. The phrase would have different connotations if someone said it without linking it to the existence of a disabled person. For example, if a person succeeds in his life, he will say, ‘thank God I am successful’.
Although, as shown above, the co-researchers rejected the use of this phrase in front of them, it is evident that disabled people themselves praise and thank God for their relatives or friends who are non-disabled (see, for example, Extract 7.11). Furthermore, Saja, Sara, and Abdullah believe that they are disabled as a result of God’s will, and they can do nothing but accept it:

**Extract 7.39**

People will say, “Your child is disabled”… He feels shame [and asks himself] “How did I beget a disabled child?”… It is from God though!

(Saja, female, aged 22.  
Focus group date: 10 April 2014.)

OK, we are disabled... God took something from us, but he also gave us something else instead.

(Sara, female, aged 22.  
Interview date: 25 October 2014.)

One of the students confronted me at the college today. I do not know him, but he asked me: “Are you satisfied with God’s destiny [for you being] like this?” I said, “Yes, what can I do? It is God’s destiny”.

(Abdullah, male, aged 21.  
Focus group date: 6 May 2014.)
Generally, Kuwait is considered a conservative Muslim society that believes in God’s will, fate, and destiny; anything that happens to people has been written and predestined by God, and objecting is forbidden, so they have to accept matters as they are, thank God, and be patient. This idea was clear in the discourse of the Imam:

**Extract 7.40**

We are talking about lesions in terms of them being like, for example, cholera or swine flu; these are all lesions or epidemics. Without a doubt, they are all God Almighty’s creations. This is a disaster that comes to humans; for example, when a person is born in a place where one of these communicable and infectious diseases is spread, but it is not his choice. How can he accept this, I mean this disease? It shouldn’t lead him to infidelity or leaving his religion, but he accepts this is a calamity that he has been infected with. He must be patient and, as this thing happens by God’s will and destiny and he can’t get rid of it, he must accept and deal with it.

(Imam Abdurrahman, male, aged 74.
Interview data: 9 June 2014.)

In this extract, the Imam is talking about impairments as lesions, similar to any disease, and confirms the notion that anyone inflicted by such lesions should be patient, accept them, and deal with them, and this should not lead him to infidelity or atheism.

Returning to the responses of Saja, Sara, and Abdullah in Extract 7.39, exploration
of their social status (extra-discursive practices) is needed here in order to understand why they have formulated such discourses. Their choice of language might stem from their upbringing in a conservative Bedouin or tribal environment, which is consistent with the traditional beliefs of the general public. The traditional common belief in Kuwaiti culture makes parents believe that it is God’s will to have a disabled child, and the reason behind this may be punishment, a test, or the fact that God has selected these particular parents for unknown reasons (Al-Kandari and Salih, 2008). It is possible that people in Kuwait have formed their thoughts regarding disability as a result of the influence of Imams and other religious leaders who are practising a form of Foucauldian power closely interconnected with knowledge. This form of Foucauldian power/knowledge is maligning. Unlike the previous forms of biopower/biopolitics, which I found necessary to support disabled people in Kuwait, I find this form of religious power as damaging and hurtful. This was clear from the co-researchers words, as discussed above; they revealed that uttering, for example, the phrase ‘praise and thanks be to God’ in front of them makes them feel that they have a flaw (see Extract 7.38).

As a Muslim living in a conservative society, I can claim that Islamic traits have a powerful influence on people, and they might be ‘the source engine’ for other forms of power. Islamic scholars adhere strictly to what the heritage books say about Islamic jurisprudence, and any attempt to criticise these books is a threat to the power of those scholars and Imams.
In this project, by opening up a dialogue on disability issues and by producing a disability awareness film, we can challenge some of the disablist attitudes associated with Islamic culture and religion, such as the traditional belief in destiny and disablist heritage terminology. Perceiving/accepting impairments as ‘God’s plague’, punishment or destiny, however, would leave these disablist attitudes unchallenged, making emancipation and social change that disabled people desire more difficult. This raises the question of whether Kuwait is ready to consider or embrace a perspective/model that is rooted in critical realism.

7.7 Accessibility to Buildings and Communication

As shown in Chapter six, what motivated the co-researchers to participate in this project was not only the social attitudes of non-disabled people towards disabled people but also the possibility of this project opening the door for further research, bringing change in social structures and policies as well as making buildings accessible for disabled people in Kuwait:
Extract 7.41

Yagoub: Here, sidewalks are not prepared; for example, even here at The Avenues, you go and you have to remove the rubbish bin because there is no way to enter the mall.

Kholood: Yeah, The Avenues is considered one of the most elegant malls in Kuwait; if a disabled person wants to enter, he has to remove the rubbish bin so he can enter and then put it back.

(Focus group date: 10 April 2014)

All of the co-researchers confirmed that when they travel to Europe or the US, they do not face any problems in terms of the accessibility of buildings; as Kholood in Extract 6.9 stated, she could move anywhere she wanted on her own. By asserting this view, they are embracing a social model perspective that locates the problem in society/environment, not in the body/impairment. This views disability as a socio-economic creation (Danemark and Gellerstedt, 2004; Bhaskar and Danermark, 2006). This issue was the preoccupation of the “purist social modellists” (Blyth, 2009, p. 191) such as Finkelstein, Barnes and Oliver (see, for example, Finkelstien, 1980; 2007; Oliver, 1990b; 2013; Barnes, 1991; Oliver and Barnes, 2006). However, the co-researchers went beyond the “strong social model” (Shakespeare, 2014, p.11) to “a social relational kernel” (Thomas, 2004a, p.22):

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2 The Avenues is the largest shopping mall in Kuwait.
It is clear from the co-researchers’ words that facing inaccessible buildings can cause negative psycho-emotional effects. This form of discrimination gives disabled people the impression that they are different (Shakespeare and Watson, 2010). Given that all of the co-researchers use wheelchairs, being predominantly
physically impaired, there is a need to improve the accessibility of buildings for them, although this might not be the case for people with different impairments, such as learning disabled people and deaf people:

**Extract 7.43**

<table>
<thead>
<tr>
<th>Kholood: The rest [of disabled people], like hearing impaired and intellectual disabled, do not proceed to university.</th>
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<tbody>
<tr>
<td>Saja: They do go, they do.</td>
</tr>
<tr>
<td>Kholood: They go now?</td>
</tr>
<tr>
<td>Saja: Yeah, we have two hearing impaired students in the same year as me.</td>
</tr>
<tr>
<td>Hussain: Why can’t people with hearing impairment go to university?</td>
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<tr>
<td>Saja: How do lecturers communicate with them, if lecturers don’t know sign language?</td>
</tr>
<tr>
<td>Kholood: It is unfair – they can’t continue their studies.</td>
</tr>
</tbody>
</table>

(Focus group date: 10 April 2014)

In this extract, the co-researchers were discussing the exclusion of learning disabled people and deaf people from the mainstream at Kuwait University as it is difficult for staff and students to deal with and communicate with them. The exclusion of deaf people was also evident in the data generated from my interview...
with Hayfaa, who is a disability lecturer at Kuwait University:

**Extract 7.44**

Currently, we have 65 disabled students; most of them are blind and physically impaired... Last year, two hearing impaired students registered online; we didn’t know they are hearing impaired. We suspended them for one semester, then we got them back and offered them sign language interpreters... but we have few sign language interpreters, so we asked the registration office not to register any more until we find solutions...

Now, we are excluding deaf people from university because we don’t have the facilities that help us to communicate with them... We have met a delegation from the club of deaf people. They came along with people from a foreign company from America. They offered us a full programme that contains screens and interpretations for deaf people but it was very expensive: it costs $10,000.

(Hayfaa, female, aged 43
Interview date: 14 July 2014.)

When I asked about solutions, she replied as follows:

**Extract 7.45**

They study abroad; the Public Authority for Disabled People gives them scholarships out of Kuwait... but, the problem with girls is that they don’t study abroad, so you find all the female students who graduated from the hearing
It can be noticed in these extracts that Hayfaa adopted a social model conceptualisation by locating the problems facing deaf people via the lack of preparation by the university to meet their needs and ensure accessibility. At the same time, she attributes this failure to the university’s failure in including learning disabled people and deaf people. This issue highlights the notion of discrimination and power relations that inspired the social model advocates in the first place (see Chapter two). Hayfaa is talking not only as a disability lecturer but also as the Assistant Dean for disabled people’s affairs at Kuwait University. Thus, she is responsible for this failure of the university to include these groups of disabled people. Moreover, in this interview, Hayfaa commended countries such as the US and the UK for having the necessary technologies to eliminate the barriers facing deaf people:

**Extract 7.46**

<table>
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<th>The other countries have technologies, screens, and [sign language] interpreters.</th>
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(Hayfaa, female, aged 43

Interview date: 14 July 2014.)

impaired schools staying at home; they don’t have university degrees.

(Hayfaa, female, aged 43

Interview date: 14 July 2014.)
In most Global North countries, a solution for deaf people would be to provide interpreters during lectures and technology sessions to help the students engage in the classes. In some Global North countries which seek to provide distance education, a solution for hearing impaired students might be more traditional distance learning methodologies where the emphasis is on text. Whilst Hayfaa realised that providing a sign language interpreter is very expensive, I imagine that sub-titled videos are cheaper than sign language interpreters.

From my critical realist-informed perspective, assuming that using technologies would eliminate all of the disabling barriers faced by deaf people would not be appropriate. For instance, the University of Manchester includes people with different impairments, and the advisor at the Disability Support Office at the University of Manchester confirmed her office’s role in providing technological support for disabled students and facilitating communication between the students and their tutors. Yet, the office faces difficulties with deaf students in terms of offering sign language interpreters, who cost around £250 per class session, as the funding allocated for this does not cover that cost. This issue, in particular, reinforces the social model, e.g. if they made the money available, the students could be supported effectively. Other problems are related to the inappropriateness of some courses, such as engineering and medicine, for individuals with particular impairments. She also stated that some students with
autism, specifically Asperger’s syndrome, face difficulties in communicating with their instructors. This provides an example of the effect of impairment or the role that impairment plays in restricting the activity of some disabled people to join particular courses.

This demonstrates that the problem is more complex than simply offering up-to-date computer technologies. The heterogeneity of disabled people and the diversity of their impairments make it difficult to offer a ‘universal design’ solution that is accessible to everyone. This makes the work of researchers such as Burgstahler (2002; 2012) and the Center for Universal Design at North Carolina State University that aspire to create environments accessible to everyone difficult to implement, given the disabled people’s realities. While offering good support and using the most recent computer technologies can reduce problems faced by disabled people, even these approaches cannot remove them completely (Shakespeare, 2014).

Thus, the problem can take two forms. The first form is related to the impossibility of a barrier-free world or to the idea of a ‘universal design’ that eliminates all of the disabling obstacles faced by disabled people. The second form is related to the role that impairments might play in restricting the activities of disabled people (Thomas, 1999; 2004a). These two forms undermine the social model of disability, the notion of a ‘universal design’, and the lack of recognition of impairments and diversity. (For a full critique of the social model, see Chapter two). As discussed in Chapter two, the idea of a ‘universal design’ takes the social
model from materialism to idealism. Therefore, designing accessible environments that accommodate everyone in society is a utopian idea.

Moreover, the problems faced by deaf people are not restricted to communication with their lecturers in the university, as even if these problems were solved, deaf people would still face problems in communication in the wider society:

**Extract 7.47**

The Deaf Club is one of the oldest... they omit some categories of deafness impairment... their services are very modest. It is a category of [deafness] that is neglected... okay, how many people know sign language... If a person is [deaf] and wants to go anywhere, he must be accompanied by someone, so where is his privacy?

(Khalid, male, aged 36.
Interview date: 15 June 2014.)

In this extract, Khalid is criticising the role of the Deaf Club people in Kuwait in providing appropriate services to ensure the inclusion of deaf people in society. In this extract, he agreed with Hayfaa (Extract 7.44) regarding the lack of sign language interpreters in Kuwait. He also stated that even if there is a person who knows sign language accompanying a deaf person when the deaf person goes out, this will be a form of privacy violation. Although Khalid asks the Deaf Club to find solutions for deaf people in Kuwait, it seems that it would be difficult to do
so. To clarify this issue, I would like to refer back to Groce’s historical study of Martha’s Vineyard in 1985. The population of Martha’s Vineyard experienced a high rate of profound genetic deafness, which led to both hearing and deaf people on the Island learning sign language. Thus, deaf people were included in all aspects of life, including politics and different kinds of jobs. The study concluded that when hearing people were able to learn sign language, the disabling barriers facing deaf people were removed. This could be seen as supporting evidence of the social model of disability.

In his comments on this study, however, Shakespeare (2014) demonstrates that deaf people used one form of communication while people who could hear used two forms of communication, speech and sign language. This made it difficult for deaf people to communicate with the world outside their community. Moreover, as they had lost one of their major senses, deaf people would have been deprived of a variety of experiences and interactions with the world. This is an example of the impossibility of providing a design that is suitable for everyone in society.

The lack of accessibility to buildings in Kuwait may be affecting the choices of the co-researchers and the participants in the disability film and their preferences for going to certain places rather than others. Fahad made this argument clear:
Fahad cited one inaccessible place, Al-mubarakiya market. Al-mubarakiya market is an old market in Kuwait, unlike most modern shopping centres, e.g. the Avenues mentioned earlier by the co-researchers (see Extract 7.41). As Fahad stated, although there are many inaccessible buildings in Kuwait, their accessibility levels vary. Some buildings are more accessible than others. The co-researchers revealed earlier that The Avenues is not accessible because of the presence of the rubbish bins in front of the building’s entrance. It can be noted that this problem is not caused by the design of the building itself, but rather it is the fault of the building management. Anyone can see many disabled people in this shopping mall, while very few disabled people visit Al-mubarakiya market. It is obvious that The Avenues mall, because of its modernity, is more accessible than Al-mubarakiya market. Furthermore, I have noticed this issue in my personal

Extract 7.48

When it comes to inclusion, I fully support it but not at the present time. Hopefully, in the future, we can have this inclusion in the best way, but under one condition: that they make the roads more prepared. For example, Al-mubarakiya market, I go there a lot and every time I do, I struggle because there are no ramps for disabled people. I address my words to the government. They should make Al-mubarakiya market more accessible for disabled people. Not just this market but all the places in Kuwait should be well prepared for disabled people.

Fahad, male, aged 28.
Interview date: 22 October 2014.)
experience with my niece, as my sister prefers to take her daughter to The Avenues rather than to Al-mubarakiya market because of its accessibility. In fact, Maha (my niece) enjoys going to The Avenues more than any other place in the state.

The law regarding disability in Kuwait states that any new public building should be accessible to disabled people. This idea is evident in the discourse of the Undersecretary of the Public Authority, Dr Rashid:

**Extract 7.49**

<table>
<thead>
<tr>
<th>The law of the state says that any new building, whether governmental or a general public place, should have facilities for disabled people; for example, if you enter any complex... you will see special corridors for disabled people... you will see special toilets for the disabled... you will see special elevators for the disabled.... You see these especially when [you] enter the modern complexes... they don’t get permission [to build] if these features are not available, as this is the law and they are obligated to follow it.</th>
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<tbody>
<tr>
<td>(Rashid, male, aged 53. Interview date: 3 June 2014.)</td>
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</table>

Nevertheless, one should note here that Rashid is talking only about new buildings. There are many old buildings in Kuwait that are still inaccessible to disabled people.
7.7.1 General, Inclusive and Special Schools

It seems that the inaccessibility of buildings in public places in Kuwait is reflected in schools and in general education as well. Many disabled students and their parents prefer special schools over general schools as they are more accessible:

Extract 7.50

They [disabled people] must mix with society but the problem is what can you do if the buildings of the government schools are not well prepared? Right? Their parents would say it is better if I put them in a special school... they put them in a special school because they are worried about them because of the negligence in the government school... Do you agree with me?

Are the government schools able to mix impairments, or at least mobility impairments... mobility impairments, hearing and visual? Hearing is a bit difficult, but not all hearing impairments... I told you because the government sector that we have is weak...

(Khalid, male, aged 36.
Interview date: 15 June 2014.)

Khalid, who is a decision maker at the Public Authority, thinks that the parents of disabled student prefer to enrol their children in special schools as they are more accessible than the governmental schools in the general education. This preference was clear, as all of the co-researchers were enrolled in special schools. Based on his friends’ request, however, Yagoub tried to enrol in a general school, but he could not as the school building had no arrangements for his wheelchair:
This extract shows that Yagoub is supportive of inclusive schools, as he preferred to go to the general school to study with his friends. The school was not well prepared for him, however; this made him decide to go to a special school. Yagoub was not the only one who was supportive of inclusive schools; all of the other co-researchers, except Omar, were also supportive of an inclusion system in schools:

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3 Surrah is an area in Kuwait City.
Kholood: … if they want [to create] awareness, they should start with children of course… but how you make inclusion happen. I mean, this is the first issue, the first step they must take… they have been talking about it [inclusion] for ages and no one is doing it… inclusion in schools.

Omar: … all disabled people together?

Kholood: … No, disabled people and healthy people [together].

Omar: That is wrong. It does not work.

Kholood: Why does it not work?

Omar: Ok. For disabled students who are blind, how can they see the board?

Kholood: It is not necessary that they see it. You have Braille display and you can hear what the teacher says and use Braille [to follow it]. Do you not know how to use it?

Omar: The teacher says to write what is on the board.

Kholood: … write what he is saying.

Omar: Ah, ah…

Kholood: Teachers will have to understand if they apply [a policy of] inclusion… If he wants you to write something, he would say I want you to write “this this this”… He would not write it silently.
Omar: … but the [Braille] device is loud. They [students] cannot hear if “six”, “seven” or “eight” are using the device and he [the teacher] is talking. No one can hear [him]. No, I don’t think it will work if they do it [like that]. I went to school here [special] and there [general]. I felt that the special school for blind people was better.

(Focus group date: 6 May 2014)

This extract shows the interaction between a supporter and an opponent of a system of inclusion in schools. Kholood, along with the other co-researchers who are physically impaired, was a supporter of inclusive schools that can pave the way to raise the awareness of non-disabled people. This is consistent with what Ferrante (2012) suggests, i.e. inclusive education can improve the awareness of a school as a community and challenge stereotypes. Kholood and Saja were aware that inclusion is not applied in a proper way in Kuwait:

Extract 7.53

Kholood: Inclusive education is important but not applied in Kuwait. This issue can solve all problems; through inclusion you can raise children’s awareness from kindergarten. But, unfortunately, our schools are not prepared for inclusion.

Saja: Here, if they want to mix, they put disabled students in a segregated classroom.

Kholood: This is not inclusion.
Saja: It is like private schools here; my sister is healthy, thank God; she goes to an English school; she says they don’t mix disabled students with the rest of the school – they put them separately in a classroom and they don’t get out even between classes.

Kholood: This is not inclusion.

(Focus group date: 10 April 2014)

In this extract, Saja was talking about the experience of her sister in a private English school that seeks to include all students. She confirmed, based on her sister’s observation, that disabled students are segregated in a separate classroom and never mix with their non-disabled peers. This extract clearly shows the rejection by the co-researchers of this type of mainstream school.

Omar (Extract 7.52), on the other hand, who is partially sighted, rejected inclusive schools altogether because he thinks that it is impossible for visually impaired people to be included with their non-disabled companions. This extract shows an example of how having a certain type of impairment affects people’s formation of ideas and preferences. Physically impaired people might not have any problems if the school building is accessible, but this would not be, at least for Omar, the case for visually impaired people. Omar goes on with his rejection and provides another example of why inclusion cannot be possible for blind people. His example is related to the school curriculum:
Extract 7.54

The problem we have is that some lessons are removed from the curriculum, for blind people, but you find it available elsewhere [in general education and some special schools]. So, if it is cancelled for blind people, what are we going to do? Do we just not study it or not attend the class? There are some practical experiments in the science books where you have to put something on something else. How can a blind person see it?

(Omar, male, aged 18.
Focus group: 6 May 2014.)

This might not be the case for all visually impaired people, however. Metab, who participated in the disability awareness film, is a blind person. He had a different point of view:

Extract 7.55

I went on with my life normally and attended elementary school and high school all in special education schools. When I reached university level, it became a whole new environment for me, which led me to think how I was going to be able to fit in this new environment. At the beginning, the way that society was looking at me was different. How I’m disabled... there were instances where other students would do something as a kind-hearted gesture, dropping you and taking you to places, or asking if I needed something. They were just kind-hearted gestures from the students and it was all normal for me, as you know Kuwaitis are kind-hearted by nature so it was normal that they would offer to help me. But, there are things that I would rather do myself, and other students would insist on helping me.
Metab showed how the transition from special schools to an inclusive environment such as a university allowed him live different experiences with non-disabled people. Although he confirmed his preference for doing things on his own, he found the behaviour of non-disabled students towards him, such as helping, normal and not bothersome. He emphasised that he went on with his life normally, graduated from the university, and got a job. Metab did not show any restrictions related to his impairment in his activities, unlike Omar, who sees his impairment through a medical lens. The differences between these two people may be due to their education levels. For example, Omar is still in high school, and it is common knowledge that in high school, one cannot choose one’s subjects. This might be the issue that led Omar to talk about an inappropriate curriculum. It is not the case for university students, as they are able to choose any area of interest that is suitable for them. The other issue revealed by Omar was related to Braille display devices (Extract 7.52) that help blind people type. These devices can be a cause (because of their sound) of distraction to the other students if there are many visually impaired students in one classroom. This issue might only exist in a school or university where blind students outnumber the non-blind students. When Omar raised this issue and talked about the large number of

Thank God I graduated from university. After I was employed by Kuwait University, I later resigned, and I now work at the Ministry of Information.

(Metab, male, aged 26.
Interview date: 19 October 2014.)
visually impaired students in a classroom, he was talking about his school, which is only for visually impaired students. Therefore, this might not often be applicable to a university or an inclusive school. This does not mean the absence of conditions that are incompatible with each other in a classroom. Therefore, as discussed earlier, in light of the presence of a wide range of impairments, designing an environment that is to everyone is a utopian dream. Accessibility is about people, not about technology; therefore, it is inappropriate to look for a universal solution. Instead, it is necessary to consider an individual’s specific needs (Kelly, Phipps and Swift, 2004). This brings the importance of providing the right medical diagnosis to the fore once again. Diagnosis in school is important for showing the differences between students and for deciding whether further special adaptations, assistance, and communication technology are needed (Shakespeare, 2014). This view was clear in Rashid’s discourse:

Extract 7.56

The inclusion system... actually any parent would prefer to put his son in an inclusive school... but ah ah what decides this is not the parents nor us, [it is] the type of disability [that decides] if the disability ah ah allows the student to be included... we and his parents are with this direction... but if sometimes his disability doesn’t allow him, like severe intellectual disabilities, it is difficult [for him] to mix [because] he needs special care... the committee examines [his condition] and the school prepares a report if the student can mix or not... based on his disability, yes.

(Rashid, male, aged 53.)
In this extract, Rashid expresses an opposite view to Khalid (Extract 7.50), who confirmed the preference of disabled people’s parents for enrolling their children in special schools. In this extract, Rashid demonstrates that the parents of disabled children prefer to keep their children in an inclusive school, but this is a decision that should be made based on each condition separately. By expressing this view, some would argue that Rashid is adopting a critical realist perspective that recognises the existence of real differences among individuals. Based on medical diagnosis and these differences, one can decide whether inclusion would be suitable.

To sum up, disabled students can have different learning experiences in education. Some of them may find difficulties not because of their impairments, but because of a lack of support. Other students might attribute their problems to physical or learning disabilities. A study by Jacklin et al. (2007) that aimed to explore the educational and social experiences of disabled students found that the majority of disabled students reported positive attitudes towards learning and social experiences in higher education. Some students reported some negative experiences related to their impairments although these experiences were affected by an absence of support or a delay in receiving it. I believe that the ‘problem’ of disability is more complex than reducing it to a lack of support. As shown throughout this project, regardless of support, some disabled people may report
difficulties merely because of the presence of their impairments. As a result, the ‘problem’ of disability is very complex. Disabled people are heterogeneous and their experiences vary.

7.8 Summary

In this chapter, I have presented data regarding disability issues in a Kuwaiti context. This chapter has discussed the social attitudes of non-disabled individuals towards disabled people in Kuwait. It has also dealt with social structures, policies, and buildings as they relate to disabled people in Kuwait. I have focused on how the variety of attitudes of non-disabled people has caused the co-researchers (as the central informants in this project) to adopt different identities. In general, the chapter has shown how difficult it is to reduce the issues of disability to exploring just one or limited levels of reality. It has shown how complex/interwoven the disability issues in Kuwait can be. It can be concluded that an appropriate model/conceptualisation should deal with disability at different levels, from the biological, physiological and psychological to the socio-cultural and socio-economic levels. The next chapter will discuss the potential model for understanding disability in Kuwait.
Chapter Eight

Developing a Model for Understanding Disability
Issues in the Kuwaiti Context

8.1 Introduction

This chapter discusses a potential model for conceptualising disability in the Kuwaiti context. As the findings of this project illustrate, the lives of disabled people are complicated. The model that I want to propose, therefore, explores disability from different dimensions: from the individual level (including the biological, physiological and psychological levels) to the contextual level (including the political, socio-economic and socio-cultural levels).

In the first part, I will draw upon four positions for analysing disability and showing how disability in Kuwait can be understood in relation to these positions. I will argue that exploring disability at various levels would pave the way for theorising disability in Kuwait. This chapter ends with a discussion of the proposed relational/interactional model for Kuwait to consider.

8.2 Theorising Disability in Kuwait

Priestley (1998) differentiates between four positions for understanding social phenomena. The first two positions are more concerned with the individual or agency (nominalist positions), while the next two positions are more concerned
with the collectivity or structure (realist positions). The first position is subjective materialism, which includes the existence of social phenomena in relation to material individuals (empiricism and biological determinism). The second position is subjective idealism, which concerns the experience of voluntaristic individuals (individuals’ beliefs and attitudes). The third position is objective materialism, which concerns political and socio-economic structures, while the fourth position is objective idealism, which is related to an idealist society, including social values and socio-cultural aspects.

Priestley (1998) also suggests, in his paper, that these four positions are useful in explaining and theorising disability. The first two positions are related to studying the disability phenomena at the individual level. The individual position includes individual materialist models (position 1) and individual idealist models (position 2). Individual materialist models are concerned with analysing disability at the biological level, while individual idealist models are concerned with analysing disability at the psychological level. This includes exploring the experiences, ideas, and identities of disabled people. Positions 3 and 4 involve exploring disability at the social level, and they include social creationist models (position 3) and social constructionist models (position 4). Social creationist models are related to the analysis of disability at the socio-economic level, and this includes the disabling barriers faced by disabled people in society, while social constructionist models are concerned with the analysis of discourse and cultural representations.
As my conceptualisation is rooted in critical realism, studying each of these four positions is equally important in order to theorise disability in Kuwait. The findings of this project explored these four positions and showed the intersection between them. For example, the accounts of the co-researchers and the participants show interaction between individual essentialism (the role of the biological body), individual idealism (the role of the phenomenological body), contextual essentialism (the role of society and economy), and “discursive essentialism” (the role of discourse and culture) (Bhaskar and Danermark, 2006, p.278). Based on the findings of this study, table 6 shows how disability in Kuwait can be understood in relation to the four positions suggested by Priestley (1998).

Table 6. Four Positions for Understanding Disability in Kuwait

<table>
<thead>
<tr>
<th>Individual</th>
<th>Position 1</th>
<th>Position 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Materialist</td>
<td>Individual materialist models. Disability is the physical product of biology acting upon the functioning of material individuals (bodies). Exploring disability in Kuwait in relation to the biological and neurological levels. The units of analysis are impaired bodies. In this position, the focus is, for</td>
<td></td>
</tr>
<tr>
<td>Idealist</td>
<td>Individual idealist models. Disability is the product of voluntaristic individuals (disabled and non-disabled) engaged in the creation of identities and the negotiation of roles. Exploring disability in Kuwait at the psychological and psycho-emotional levels. Exploring the identities, social values, and cultural attitudes of both disabled and non-disabled people regarding disability in Kuwait.</td>
<td></td>
</tr>
</tbody>
</table>

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example, on analysing the potential remedial treatment (in Kuwait or abroad).

The units of analysis are beliefs and identities. In this position, the focus is on analysing the linguistic features used by both disabled and non-disabled people in Kuwait in relation to disability.

Social | Position 3
Social creationist models.
Disability is the material product of the socio-economic relations developing within a specific historical context.
Exploring materiality, power relations, and economic, social, and political factors in Kuwait.
The units of analysis are disabling barriers and material relations of power. This position focuses on analysing disability rights law in Kuwait as well as the physical environment and accessibility.

Position 4
Social constructionist models.
Disability is the idealist product of societal development within a specific cultural context.
Exploring the role of the Kuwaiti culture and the role of religion.
The units of analysis are cultural values and representations. This position focuses on analysing the cultural representation of disabled people (e.g. the depiction of disabled people in the Kuwaiti media) as well as analysing/deconstructing ‘normality’ in historical and religious texts.

Source: Adapted from Priestley, 1998, p.78

Now, I will discuss how these four positions can be applied when developing a model to analyse and conceptualise disability in Kuwait. As my conceptual framework, which is rooted in critical realism, considers multiple explanations of disability, the next section will provide a model that explores disability in Kuwait.
at various levels/domains of reality showing how disability issues in Kuwait are complex and entangled. The model suggests that it is not possible to study disability without exploring its multifaceted levels of reality. I would argue that by studying these multi-layered levels/domains, disabled people in Kuwait can step forward towards emancipation and social change.

8.3 Disability Model for Kuwait

From the discussion above, the model that I would suggest for Kuwait to consider operates at two main levels: the individual level and the social level. The individual or micro level is related to medical, biological, physiological and psychological aspects. This level involves medical diagnosis, treatment, surgery (if needed), and psychological support and counselling. However, I am not suggesting here that all disabled people need or want these things. For example, in this project, only two co-researchers sought treatments (Saja and Abdullah) and went abroad to receive these treatments. Also, as shown in Chapter seven, Yagoub needed psychological support when he met with an accident and became a disabled person. In relation to surgery, Kholood said that the doctors told her she needed to undergo surgery and this would help her walk, but she does not want to do go ahead with surgery because she scared. Other disabled people in Kuwait may want or need other things than those suggested by the co-researchers and the participants of this project. Thus, the model that I am suggesting gives disabled people in Kuwait autonomy to decide how they want to be supported by the state at any level whether individual or social.
The model also explores disability at a social level. The social or macro level operates in two domains: the external domain and the internal domain. The external domain includes observable phenomena such as discrimination, prejudice, oppression, and cultural stereotypes, while the internal domain includes the underlying structures/mechanisms that produce these phenomena. These underlying structures or mechanisms are often related to economics, politics, culture, and religion. For example, the phrase ‘praise and thanks be to God’ that non-disabled people use when they see disabled people stems from a deeper level that is often related to cultural and religious mechanisms. Also, how disabled people are portrayed in the Kuwaiti media stems from a deeper level that is related to Kuwaiti culture and the influences of other cultures.

Understanding the underlying structures that work on the individual and social levels is crucial, as I believe that, when these structures are understood, emancipation and social change become possible. In addition to these two levels, I would add an intermediate or ‘meso’ level related to the psycho-social and emotional levels that look at the relationship between psychological factors and environmental or social factors. In other words, this level concerns the influence that both psychological and environmental factors can have on people’s physical and mental well-being. For example, when disabled people face discrimination at work and are turned away from jobs, this will have an influence on their psycho-emotional well-being (Thomas, 2004a). Other examples can be derived from the discussion of the co-researchers on how inaccessibility of buildings can have a negative influence on people’s psychology and make them feel inferior and sad.
Figure 8 shows an interactional/relational model which operates at three levels of reality.

This model is interactional and non-reductionist, as it explores disability at different levels rather than focusing solely on an individual level (as in the individual model), a socio-economic level (as in the social model), or a socio-cultural level (as in the cultural approaches to disability). It provides a broader explanation of disability, so I would argue that it can be appropriate not only for the Kuwaiti context but also other similar contexts. Any social phenomenon can be explored within these various levels/domains, and then it becomes an empirical question (differing from case to case) about where the most analytical weight of a particular case can be found. This enables the disability theory to be generated empirically (Gustavsson, 2004). For example, if a person believes that he/she does not need or want physiological or psychological support and believes that the ‘problem’ of disability is, in large part, social, then the analysis will be focused on the lower part of the diagram.

Therefore, the model I put forward for Kuwait to consider is sensitive to the complexity, circumstances, and the nuances of the experiences of the individuals and deals with disabled people as a heterogeneous group (Watson, 2012). In short, from the above discussion, I am aware that “the relative importance and specific role of these components [or domains of reality] varies from disability to disability, and often from case to case, and is always an empirical question” (Bhaskar and Danermark, 2006, p.292).
8.4 Summary

In this chapter, I have discussed four positions for analysing disability by drawing upon the work of Priestley (1998). I then showed how disability in Kuwait can be understood in relation to these positions. Then, suggested a relational model for Kuwait to consider. This relational/non-reductionist model, which is rooted in critical realism, explores disability issues in an interactive way at two main levels: the individual and social levels. This chapter concludes that an appropriate model for understanding disability in Kuwait should consider the complexity of the lives of disabled people and analyse disability at multiple levels of reality. This suggests that one cannot study disability without considering all the connected disability issues which emerge at different levels.
Figure 8: Disability Model for Kuwait: Operation of Three Levels of Reality
Chapter Nine

Further Discussions, Conclusions, and Recommendations

9.1 Introduction

In this chapter, I will return to the research questions that were explored throughout my entire journey in the field of disability. By revisiting my research questions, I intend to summarise the findings of the project in relation to these questions. I will then talk about the potential of this study to provide a substantial contribution to the wider knowledge. At the end of this chapter, I will conclude the thesis by suggesting areas for future research and explaining how the findings of this project will be disseminated.

9.2 Research Questions 1, 2, and 3

By the end of the journey described in Chapter one, a number of research questions had emerged in relation to the nature and the process of the research:

- What are the co-researchers’ motivations behind participating in this research?
- Do the co-researchers believe that they will benefit from this process and if so, how?
What are our (i.e. the researcher and the co-researchers) experiences of the process of participatory research?

It is clear from the data that the main factor that motivated the co-researchers to participate with me in this project was changing the views of non-disabled people towards disabled people and disability. The co-researchers believed that people in Kuwait generally have negative attitudes towards disabled people; therefore, they saw this research as a vehicle to contribute to changing these negative views. They also believed that this project would contribute to changing societal structures and policies in Kuwait and open the door for further research.

The co-researchers also believed that participating in this project helped them to develop research skills such as preparing interview schedules, data analysis, and critical thinking skills. In line with Abell et al. (2007), O’Brien et al. (2014), Stevenson (2014) and Strnadova et al. (2014), the co-researchers developed a range of necessary research skills throughout the research process and even acquired some of the skills I, as a researcher, have. At the same time, I provided them support and allowed them to decide how they wanted to participate. For example, they welcomed the opportunity to participate with me in the data collection phase of the project (a stage that is often considered ‘difficult’ for ‘non-academic’ researchers) (Strnadova, et al. 2014). It is worth noting that, initially, the co-researchers were reticent about taking on this aspect of the process, but they became more involved over time and decided to participate not in conducting interviews but in preparing schedules for these interviews. They were more
enthusiastic about participating effectively in preparing the interview schedules for the interviews conducted with the non-disabled individuals of this project. They also participated effectively in the data analysis.

Another benefit of this research project, per the co-researchers, was hearing about the experiences of disabled people who have different impairments from theirs, such as visual impairments and learning disabilities. This project also gave them an opportunity to listen to views about disabled people and disability from the non-disabled people’s perspectives. This was through the interviews which were conducted with the non-disabled participants.

This project faced a number of difficulties, however, including the co-researchers’ commitment and time constraints. I have discussed these difficulties in detail in Chapter six. As explored throughout the thesis, I was aware of the power relations and the complexities that are often associated with participatory nature of research (Chapman, 2005; McClimens, 2008) throughout the process. As the principles of participatory research are based on a partnership between the researchers and the disabled participants in the entire research process (Kitchin, 2000; Walmsley, 2001), I would consider this research neither emancipatory nor fully participatory. It drew upon the spirit of participatory research, however, and the process stressed the importance of active and effective participation rather than the extent of participation. Therefore, as the co-researchers participated in some of the research process, such as preparing interview schedules and data analysis, this project may be seen as semi-participatory. However, on the other hand, the co-researchers
believed that these processes would pave the way towards emancipation and open
the door for further projects.

9.3 Research Question 4

In relation to the exploration of disability issues, one general question has emerged:

- What are the most significant issues facing disabled people in Kuwait?

The disability issues in Kuwait were explored through the lens of the co-
researchers, the people who participated in the disability film, and the non-
disabled participants. The most significant disability issues in Kuwait were related
to the experiences of disabled people due to their impairments and their
experiences with people in society and the societal structure. These experiences
show how complicated and multifaceted the identities and lived experiences of
disabled people in Kuwait can be. For example, the data reveals how Saja draws
upon two opposing identities spontaneously: one associated directly with her
impairment and the other locating the ‘problem’ of disability within society.
Saja’s adoption of these different identities demonstrates how complex the lives of
disabled people can be as well as the impossibility of reducing the issues of
disability merely to the body or to society. Adopting these unstable/changeable
identities illustrates the limitation of the social and individual models. For
instance, the limitation of the social model was evident when Saja reduced her
disability to her body as well as when she distanced herself from learning disabled
people, confirming that disabled people cannot be dealt with as a homogeneous group but rather as a heterogeneous group. On the other hand, the limitation of the individual model was clear when she criticised how, for example, disabled people are being depicted in the Kuwaiti media in a ‘tragic’ way and when she referred to the issue of disability regarding social attitudes. I would suggest that this demonstrates that the social and individual models individually do not adequately reflect the complicated and multi-layered lived experiences of disabled people in Kuwait and thus fail to reflect the experiences of all disabled people. Moreover, even the works of social constructionists within disability studies, whose work centres on the historical and cultural investigations and the role of discourse, are insufficient. Such works neglect the biological in their analyses, favouring discussions relating to ideas about objects over discussions related to the objective presence of objects (Williams, 1999; Bhaskar and Danermark, 2006; Shakespeare, 2014).

Generally, the discussion in Chapter seven has clearly shown a desire among the co-researchers to challenge some of the disablist discourses and attitudes within society, which could be viewed as the adoption of a social model/conceptualisation. At the same time, however, they viewed themselves as disabled people as a consequence of their impairments, and this could be viewed as the adoption of an individual model/conceptualisation. The co-researchers were also aware of the role the body might play in disablement. Locating the ‘problem’ of disability in the body and recognising the role of the body, some would argue, highlight a weakness or limitation of the social model of disability (see Williams,
1999; Danermark and Gellerstedt, 2004; Bhaskar and Danermark, 2006; Shakespeare and Watson 2010; Shakespeare, 2014). Thus, from a critical realist perspective, the social model of disability is producing a “disembodied” conceptualisation of disability (Hughes and Paterson, 1997, p.330) or, in other words, “writing out of the body” from disability discussion (Williams, 1999, p. 803) focusing instead on limited levels of reality (Bhaskar and Danermark, 2006). Therefore, I would argue in this thesis that bringing the body in its complexity and its various forms, including the ‘discursive’ and ‘biological’, back into the analysis of disability is necessary:

The body, in short, is everywhere and nowhere today: the more it is talked about and studied, the more elusive it becomes; a fleshy organic entity and a natural symbol of society; the primordial basis of our being-in-the-world and the discursive product of disciplinary technologies of power/knowledge; an on-going structure of lived experience and the foundational basis of meaning, imagination and reason; the wellspring of human emotionality and the site of numerous ‘cyborg’ couplings; the physical vehicle of personhood and identity and the basis from which social institutions, organisations and structures are resisted or reproduced. (Williams, 1999, p.798)

In conclusion, in order to have a better understanding of the lives of disabled people in Kuwait, an appropriate conceptualisation should include mechanisms at the medical, social and cultural levels. From here, the need arises for a model that combines the best aspects of individual and social models as well as social constructionism, namely, a model rooted in critical realism. Through the adoption of a model/conceptualisation that is rooted in critical realism, one can gain a better understanding of the multifaceted lives of disabled people in Kuwait. In short, the model I propose in this thesis brings “minds back into bodies, bodies back into
society and society back into the body” (Williams and Bendelow, 1998, p.3). This model has been discussed in Chapter eight.

Furthermore, although I have discussed in Chapter two and Chapter seven the issue of non-disabled people who are ‘benefitting’ from ‘passing’ as disabled people, I believe that it is vital to provide a further discussion on this topic. I believe that this issue gives Kuwait ‘singularity’, as this phenomenon is not widespread in the Global North. In his book *Stigma* (1963), Goffman talks about disabled people who ‘pass’ as non-disabled because of the stigma and cultural representation linked to impairments. Little has been written about the reverse situation.

According to the accounts of the co-researchers, one of the reasons why the problem of ‘impairment claimers’ surfaces is the fact that the state guarantees to offer those who desire treatment a chance to go abroad with all expenses paid by the state:

**Extract 9.1**

Saja: There are people who leave the country for treatment without a diagnosis, nothing apparently wrong with them, and they get it [the necessary approval].

Omar: [That is] favouritism.

Saja: They ignore disabled people here.
This extract shows four co-researchers discussing the issue of some non-disabled people who ask for acts of ‘favouritism’ from a decision maker in the state in order to help them travel with their expenses paid for by the state. In this context, favouritism means prioritising someone who does not deserve/need treatment at the expense of someone who does deserve/need treatment. By looking at this issue more closely, it almost becomes common knowledge for anyone who lives in
Kuwait that favouritism is widespread in the country. It happens everywhere in Kuwait, for example, prioritising someone who is not eligible for a particular political position at the expense of someone who deserves that position. This problem may reveal the extent of corruption in the state.

An indication of corruption can be seen from the extract above. Omar’s brother got his papers signed without him having to meet the committees but with the assistance of a parliament member. Moreover, when Saja tried to get approval from the legal medical committees to travel abroad, she was rejected, whereas she was accepted when her father asked for favouritism. She clarified this in a further discussion:

**Extract 9.2**

| Saja: He says to my father: “How much can you give me? I will provide her documents!” |
| Hussain: Who said that – a doctor? |
| Saja: A doctor… wait, it is a doctor in the [the name is anonymised] Hospital, in the physical therapy department. |
| Hussain: Is he from the committee? |
| Saja: Yeah, he said [my father]: “My daughter is sick and tired. I want to take her for treatment out of the country”. He said [the doctor]: “How much do you want to give me?!”. My father said, “I do not give bribes”. Then, he was able to arrange an act of favouritism and he made it [happen]. |
Hussain: Favouritism is [a lesser sin] than a bribe?

Saja: Favouritism is the lesser, as at least then God will not curse us.

(Focus group date: 6 May 2014)

One should note from the accounts of the co-researchers that they are not rejecting favouritism itself as they do it for themselves, but rather, they reject it when non-deserving (often non-disabled) people are using it. The next extract clarifies this issue:

**Extract 9.3**

Saja: There are people who go for treatment out of the country without a diagnosis. They go for the purpose of tourism for three months. They say “Let us go for a summer holiday”.

Kholood: Yeah. He goes with two members of his family. I swear I know someone who takes newlywed couples. He says it is “to make them happy on their honeymoon”.

Abdullah: … with all travel expenses paid.

Saja: By the way, travel expenses are paid not only for the patient but also for his companions. Everyone gets 3,000 KD.

Abdullah: … but they don’t pay for two companions.
Saja: They do.

Omar: They travel to get the money and then they go back.

Abdurrahman: Yeah, this happens.

Saja: Yeah, this happens. They go back and buy a car.

Omar: My relative has just bought a car using government money.

(Focus group date: 6 May 2014)

This extract demonstrates that some non-disabled people arrange an act of favouritism to travel for tourism and get money from the government. Therefore, the main reason behind doing this is the money.

Nevertheless, non-disabled people who have, according to disabled people, claimed money fraudulently do not exist only in Kuwaiti society. The Glasgow Media Group and the Strathclyde Centre for Disability Research conducted a study to analyse how the media reported disability and its impact on public attitudes towards disabled people (Briant, Watson and Philo, 2012). The researchers compared and contrasted media representations of disabled people and disability in 2010-2011 and 2004-2005 and carried out a number of focus groups with people from the general public. The researchers found that the people in these focus groups were quite influenced by the information they received from
the media, especially information related to disability benefits and fraud. The strong focus of the articles on disability benefits and fraud, which increased from 2.8 per cent in 2005 to 6.1 per cent in 2010/2011, made people in the focus groups claim that there was a higher level of fraud (up to 70 per cent) than there was in reality. The focus group members suggested that more than 70 per cent of disabled claimants were fraudulent and referred to articles they had read in newspapers. The way the media showed disabled people in a less sympathetic way, as an economic ‘burden’, had influenced the study participants’ thoughts. Although the researchers suggested that the people in the focus groups (under the influence of the media) were exaggerating the percentage, this does not negate the reality of the phenomenon of those claiming fraudulently in British society.

Furthermore, I want to mention other types of scroungers who, I believe, are far more dangerous than those who use the money for disability allowances. During an informal talk with my sister, who has a learning disabled daughter, she told me about a group of parents of learning disabled children who arrange for their children to marry to get a free house from the government. She stated that the disability law in Kuwait allows a disabled person who marries another disabled person to get a free house from the state. She supported her claim by referring to two incidents that she witnessed. The first incident took place when the father of a son with Down’s syndrome asked whether his son could marry her daughter for his son to get a house. The second incident occurred when she was asked by an employee at the Public Authority to provide evidence that her daughter was not married. Although this issue was not evident in the data, the head of tests and
measurements in the Public Authority, Khalid, explained about the penalty that parents who take care of a disabled child might face if they abuse their child:

**Extract 9.4**

| Look, this law primarily serves the disabled and their parents and relatives... and also it protects the disabled if there is any problem or any abuse by the parents of the disabled. Look, the Public Authority here has the right to judge the person who is in charge of taking care of the disabled... this is covered by article 24 and is followed by other articles up to article 28... the Public Authority has the right to appoint someone to be in charge of care of the disabled person and specify who deserves to be in this position, the mother, father, wife, husband, son, daughter or grandfather... but people see what they want... most of them, they want the material features... they don’t want the awareness aspects or the aspects that serve the disabled people themselves. |
| (Khalid, male, aged 36. Interview date: 15 June 2014.) |

In this extract, Khalid asserts, as an official in a political body, that disabled people’s parents are preoccupied by the financial features and lack awareness of the other laws that serve and protect disabled people. I have expanded on these issues in Chapter two and Chapter seven.

I would like to clarify here that I am not suggesting that these political issues related those ‘claiming fraudulently’ are more important than religious issues and media representation of disabled people which I have discussed in detail. I have
prioritised discussing the issues of ‘claiming fraudulently’ here because, as discussed earlier, they give distinctiveness to the Kuwaiti context, unlike the issues of culture and religions that can be well found (as discussed in Chapter 2) in any other context whether in the Global South or the Global North.

9.4 Research Question 5

As stated in Chapter two, other questions emerged as a result of a thorough exploration of the literature concerning both disability studies in Kuwait and the disability perspectives in the Global North. These questions may contribute to the development of the field of disability studies:

- Which disability perspective/analytical tool is more suitable for adoption in Kuwait?

In relation to this question, the exploration of the literature review and data analysis enabled me to develop a model for understanding disability in Kuwait. The model I proposed for Kuwait to consider is rooted in critical realism. I have introduced this model in Chapter eight. It is important to note here that although all of the participants and co-researchers in this study are Kuwaitis, I would claim that the model proposed can also be applied to the situation of disabled non-Kuwaiti citizens. However, this does not suggest that the experiences of disability of non-Kuwaitis are similar to the experiences of Kuwaitis. I would argue that the experiences of disabled non-Kuwaiti citizens are far more complex than the experiences of disabled Kuwaiti citizens.
Generally, the number of non-Kuwaiti residents, as shown in Chapter two, is higher than the number of Kuwaiti citizens in Kuwait. According to the Human Right Watch report (2016), migrant workers from countries of low-income economies and stateless residents in Kuwait generally experience a degree of abuse and exploitation in the Kuwaiti society. These treatments include discrimination at work such as withholding of their salaries as well as continued exposure to physical and sexual abuse. This kind of treatment by the state would certainly reflect negatively on the experiences of disabled non-Kuwaiti individuals. Moreover, the financial status and the standard of living of disabled non-Kuwaiti nationals differ from those of disabled Kuwaiti nationals, and this would reflect in different experiences with disability issues. For example, if disabled non-Kuwaiti nationals were not supported financially by the state, this would indeed result in the reporting of different experiences from the experiences reported by the Kuwaiti co-researchers in this study in the light of the financial abundance. Furthermore, disabled non-Kuwaiti people may provide deeper insights than those reported by the co-researchers in relation to identities and the relationship with the ‘other’. This will, generally, produce more complex accounts of disability issues than those recounted by the disabled Kuwaiti people. Although the model that I have proposed in this study is based on the economic and cultural situation of Kuwaiti nationals and the experiences of disabled Kuwaiti individuals with disability issues, I would suggest that it can be also applied to the situation of non-Kuwaiti nationals. Thus, in the case of non-Kuwaiti nationals, the focus of disability analysis would be on the economic and political dimensions (the lower
part of figure 8). However, this takes disability analysis to a very complex position showing an intersection of disability, nationality, and identity (Hanisch, 2007).

9.5 Research Question 6

Another research question in this thesis related to the previous research question is whether the state is ready to consider the perspective/model that I have proposed:

- To what extent is the state ready to consider a disability perspective/model rooted in critical realism?

My honest answer to this question is that, at this point, it is not possible to give a comprehensive answer. I believe that answering this question is beyond the capability of this thesis, but I have included it to show that I am aware of the gap that often exists between the theoretical frameworks suggested by the academics and their practicality in government policies. What I have proposed in this study is a theoretically sound tool which should not be conflated with the readiness of the state to adopt it. Some would argue that the ideas that often come from scientific research are rarely adopted by the state and rarely find their way towards action (Shakespeare, 1996). For example, when the social model of disability was developed, the UK was not ready to accept it, and it was only the work of disabled people that campaigned for its adoption by the government (Oliver, 2004). However, ultimately, the social model now, after more than 30 years of work, is dominant within the UK.
Nevertheless, in the presence of the challenges related to, for example, favouritism and fraud in the welfare system in Kuwait, it is possible to see a glimmer of hope towards adopting some ideas to resolve these political/cultural dilemmas. Therefore, the model I have proposed in this thesis can at least begin the conversation about disability issues in Kuwait. I will show later on in this chapter how I am going to disseminate the findings of this project. When the findings are presented at international conferences and published in journals, this would help start a conversation about disability issues in Kuwait and thus ‘plant a seed’ towards social change and emancipation of disabled people.

Moreover, talking to officials and decision makers is possible in Kuwait. As discussed earlier in this thesis, Kuwait is a small community, and therefore, it is not difficult for anyone to access officials and decision makers. For example, I have shown in this project how I was able to conduct three interviews with officials at the PAPDA. The on-going interactive communication with the officials would help this project to achieve practical application. Thus, in addition to presenting and publishing findings at conferences and academic journals, I will also send a summary of the findings to the politicians and the decision makers I interviewed. Additionally, I will present my works to disabled and non-disabled people in Kuwait through local conferences, seminars, and workshops. All these practical actions I believe, at least, can begin a conversation about disability issues and the possibility of social change can be realised. However, providing a wide-ranging answer to whether Kuwait is ready to adopt the model I suggested is not attainable until further exploration has been taken place. I will show later in the
chapter how this issue can be traced as an area for future investigation.

9.6 Contribution to Knowledge

This thesis consists of nine chapters. I believe that every chapter of this thesis has a potential to contribute to the wider knowledge:

- **Chapter one:** This chapter discussed my journey into the field of disability and how the current research topic was decided through a series of events and transformations. This shows how deciding a research topic is not always a straightforward or an easy task. This experience illustrates the complexity that is central to qualitative research in general (Denzin and Lincoln, 2011) and in participatory research in particular (McClimens, 2008), and thereby, would be useful to novice researchers looking to understand how the research process works.

- **Chapter two:** The first section of this chapter addresses the broader exploration of the Kuwaiti context and disability in Kuwait. There is a dearth of literature on Kuwait and disability, thus, this chapter provides a wider analysis of the Kuwaiti situation in relation to disability issues. It includes exploration at various levels in the Kuwaiti context: the political, socio-economic and socio-cultural levels. This will help disability researchers in Kuwait to use this chapter as a starting point to open up the issues related to disability and seek for improvement of the lives of disabled people in Kuwait. The second section of this chapter talks about disability studies in the Global North where some broad discussions by
disability authors in Global North (which would be covered in many introductions to texts and theses in disability studies) were explored. However, the aim of this exploration was to develop a conceptualisation that is appropriate when exploring and analysing disability issues in Kuwait. I concluded the chapter by discussing the inappropriateness of importing disability perspectives from the Global North and applying them as they are to the Global South without subjecting them to scrutiny. This will be considered as a reference to those ‘colonisation supporters’ who tend to import anything from the West without taking into consideration the context sensitivity (Bazna and Hatab, 2006).

- **Chapter three:** This chapter discusses the conceptual framework that I believe is the most appropriate perspective to be adopted in the Kuwaiti context. The conceptual framework adopted in this study is rooted in critical realism. As the conceptual framework adopted in this study analyses disability at individual and social levels, this will help those who have interest in disability studies, whether in the Global North or Global South, to start thinking more about the complexity of the lives of disabled people.

Another contribution is the use of religious text in understanding theories of knowledge such as empiricism and constructionism. Although there have been some attempts to use the same verses to understand Darwinism and evolution (Hassan, 2007) and to understand the development of language theory (Shahrur, 1990), none of these attempts linked these
verses directly to the development of empiricism and constructionism. This will help to bridge the gap in the historical conflict between religion and science.

- **Chapter four:** This chapter talks about the methodological approaches adopted in this study. Spending a considerable amount of time in research, I would argue that this project is likely to be the only one in Kuwait (if not in the region) that gave disabled people an opportunity to play an active role in the research processes as co-researchers. In this chapter, I narrated the detailed practicality that is often associated with this kind of project. This will encourage disability researchers generally and in Kuwait particularly to invite disabled people into their research and report the complexity and details of participatory projects. Moreover, the outcome of research processes (i.e. the disability awareness film) can contribute to raise the awareness about disability issues among people in Kuwait and in other similar contexts.

- **Chapter five:** This chapter discusses the process of analysis and how the themes and sub-themes emerged from the data. This can help the readers identify the detailed analytic process in thematic analysis. As some researchers ignore showing how they have arrived to the themes emerged from their data, this chapter would encourage them to show how the process of analysis is conducted in a qualitative research.

- **Chapter six:** This chapter shows the findings and discussion related to the process of participatory research. Detailing the process of participatory
research will help those who are aspiring to conduct similar research in future. It also ensures that in this kind of a research, these details have to be in place, discussed, reported, and not ignored, no matter how painful and difficult these detailed processes are (Oliver, 1997).

- **Chapter seven:** This chapter shows the findings and discussions related the experiences of disabled people in Kuwait. In particular, this will help people in Kuwait to have better understanding of the lives of disabled people in Kuwait, thus raising awareness among the general public. This chapter will also help professionals and decision makers in Kuwait identify the issues of disability and disabled people. This may lead them to think about how to improve the lives of disabled people in Kuwait. Moreover, this chapter can be useful for those who want to conduct disability research and conduct an in-depth analysis on the lives of disabled people. This chapter can also contribute to knowledge in terms of the possibility of using ideas such as the work rooted in the social model and postmodern thoughts that are mainly cultivated in the Global North to analyse disability in a country such as Kuwait. This indicates the existence of common factors between societies globally, and thereby, employing various analytical approaches can help conceive better understanding of disability issues. This realisation led to the key contribution of this thesis, a model for understanding disability in Kuwait.

- **Chapter eight:** In this chapter, I developed a model that I believe is appropriate for analysing disability at different levels (i.e. individual and
social levels). As far as I can determine, this is the only study that has proposed a model to analyse disability in the Arabian region. I argue that this model, if adopted, in the long term, can improve the lives of disabled people in Kuwait and in other similar contexts.

- **Chapter nine:** The first section of this chapter provides further analysis of the key findings of this study. The next section will show the ways for future exploration, namely how disability can intersect with other fields of study such as gender and sexuality studies. This chapter generally emphasises that the experiences of disabled people are varied, so it is important to invite other people with different experiences into disability research. This shows how complex the field of disability is, as one study can open the door for many other studies.

### 9.7 Areas for Future Research

Although this thesis has explored disability in both the Global North and the Global South, I would like to suggest areas for future research in the context of Kuwait given the lack of disability studies in this region. I believe that there are a number of key areas and issues arising from this project that require further in-depth research.

#### 9.7.1 Exploring Disability Issues Among Non-Kuwaiti Residents

I have already addressed this issue above and shown in Chapter two that it is unclear from the Kuwaiti disability rights law whether disabled non-Kuwaiti
residents are being supported by the state. The non-Kuwaiti residents in Kuwait, as shown in Chapter two, include ‘Bidun’ or stateless people and people of other nationalities from different places in the world, mostly from Arabian and Asian countries.

In relation to ‘Bidun’ residents, I have shown in Chapter two the conflict about whether their settlement in Kuwait is legal or illegal. Despite the varying explanations about the legality of their presence in the state, the reality of the ‘Bidun’ residents is that they are deprived of their most basic rights. They are deprived of the right to citizenship (nationality) and Civil IDs that would enable them to access the basic life requirements enjoyed by Kuwaitis, such as the right to attend free public schools, access free health care, work in the government sector, and own a property. Moreover, they are deprived of the right to acquire official marriage and divorce documents and the right to travel between countries with a passport.

Although there are variations in opinions regarding the accurate number of ‘Bidun’ residents, it is clear that they comprise a significant number of the overall Kuwaiti population. Indeed, there are disabled people among this significant number, and the problems faced by non-disabled people among the ‘Bidun’ residents are certainly reflected by disabled stateless people. Therefore, further in-depth research is required in order to explore the experiences and the situation of disabled people in the ‘Bidun’ community in the light of this human rights crisis.

Other parallel research can focus on disabled individuals among the migrant
workers in Kuwait. According to the Human Rights Watch report (2016), there are about 2.9 million migrant workers in Kuwait. The report states, as discussed above, that migrant workers experience physical and sexual abuse and exploitation at the hands of the state. There is a lack of information about how the disabled people among the migrant workers are being treated in Kuwait. Therefore, further research is required in order to explore the experiences of disabled non-Kuwaiti people who are living in Kuwait and whether they have access to services and support from the state.

9.7.2 Disability and Marriage Rights

During the exploratory phase discussed in Chapter one, in the focus group with students in higher education, two participants raised the issue of marrying a non-disabled partner:

**Extract 9.5**

Fahad: I want to get married but I can’t. Every time I go to a family in order to ask to marry their daughter they say, “You are disabled, we don’t want you”. Even marriage [is difficult], I am not deficient!

Salma: Even the man’s idea I am sorry to say. My aunt said to me, “If you were non-disabled, I would take you for my son but he is the elder”.

Saja: It is shameful that she says this and she is your relative. Tell her there are a lot of disabled people who have married healthy people. There is a fat actor who married a disabled woman. Most [disabled] guys marry healthy people.
Salma: I would take a disabled person. I don’t want to take a healthy person because he would make me feel it’s out of sympathy.

Hussain: Maybe it is not sympathy.

Salma: No. This is the ideal man; where can you find him?!

(Higher education students’ focus group.
Focus group date: 14 August 2013.)

Some interesting issues were raised by the participants here. I hoped that this discussion about marriage rights would continue in the main study; however, perhaps the participants and the co-researchers in the main study decided not to follow up these issues. I did not feel that it was ethical to coerce them to talk about disability issues that they chose not to reveal. Perhaps, one of the reasons why they did not want to talk about this issue was that they may have regarded it as very personal and did not want to talk about it in front of the others in the focus groups. Therefore, if I had had an opportunity to conduct one-to-one in-depth interviews, this may have given the co-researchers more freedom to express their very personal feelings. I would consider my inability to conduct one-to-one interviews with the co-researchers a limitation in this study.

From the extract above, one can take the thread and continue to explore, for example, why the participants thought about marrying a non-disabled person. This
explains how the participants view themselves compared to non-disabled people. For example, the fact that they use the term ‘healthy’ here tells us a great deal about their own ‘disablist’ assumptions. Indeed, further exploration of this issue will provide an interesting contribution to disability studies in the Global South.

9.7.3 Disability, Gender and Sexuality

This project may pave the way for further exploration of disability and other parallel and interdisciplinary research within gender and homosexual studies. In Chapter seven, I showed how Saja created a classification system predicated on learning disabled people being not representative of disabled people. In relation to this, Kholood challenges Saja, saying,

**Extract 9.6**

<table>
<thead>
<tr>
<th>You seem very racist when you say this... All of these are disabilities but in different categories.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kholood, female, aged 24.</td>
</tr>
<tr>
<td>Focus group date: 6 May 2014.</td>
</tr>
</tbody>
</table>

Kholood’s acknowledgment of Saja’s prejudiced view highlights the assertions of Deal (2003), who emphasises the importance of acknowledging disabled people’s own prejudices if they want to be fully included in society. The way Kholood responds to Saja made me think about the connection between the concept of
‘disability’ with other concepts such as sexism, racism, and homosexuality. Hurst, Gordon, Rosenblum, Vernon and Thomas are some of the disability researchers who show a connection between disability, gender, and race. For example, Hurst (2000) explored the intersection between disability and gender, rejecting analysing both women and disabled people based on their personal characteristics. Furthermore, the work of Thomas (1999), Vernon (1999) and Gordon and Rosenblum (2001) demonstrated a connection between the oppression that women and minority groups, such as gay men and lesbians, are exposed to and the oppression that disabled people experience. Although I argue that the lives of disabled people are more complex than the lives of the other minority groups because of the existence of impairments (Shakespeare, 2014), the lives of the other minority groups may be as complex as the lives of disabled people in the Kuwaiti context.

In a conservative Muslim society such as Kuwait, I would argue that it is more difficult to remove the oppressive barriers faced by women and homosexuals than in Western societies. In strict patriarchal Muslim societies, because of the power of religion and culture, women are frequently not able to marry without the permission of their father. Moreover, in Kuwait, at the political level, women who are married to non-Kuwaitis do not have the right to apply for housing loans from the bank, while men who are married to non-Kuwaitis can do so. One could argue, however, that women in Kuwait can at least vote in parliamentary elections and can reach important leadership positions in the state. Nonetheless, in my opinion, this is insufficient, as women should be treated the same as men in all fields.
Homosexuals are far more oppressed than disabled people and women in Muslim societies. In Kuwait, for example, gay people and lesbians are vulnerable to harassment that frequently reaches the level of raids into their homes and private spaces by the police. Furthermore, according to the Human Rights Watch report (2016), in Kuwait, men engaging in same-sex relations are subject to up to seven years in prison. The report also states that transgender people can be arrested according to the Kuwaiti law that prohibits one from imitating the opposite sex in any way.

These acts of the state are derived fundamentally from an Islamic heritage through the interpretation of religious texts such the Muslims’ holy book and the hadiths that are attributed to the prophet Muhammad. Through such religious interpretations, Islamic scholars perceive homosexuality as ‘perverted’ practice that provokes God’s wrath; thus, it deserves maximum punishment (although ironically, at least in part, some of them believe it is God’s creation).

From this standpoint, I acknowledge, along with Shakespeare and Watson (2010) and Shakespeare (2014), how complex the lives of disabled people are in Muslim societies and, more specifically, in the Kuwaiti context, the lives of women and homosexuals are equally complex. Therefore, gender studies, sexuality studies and even race studies need to receive the same attention as disability studies in the Islamic states and in particular in Kuwait. Drawing attention to the similarities and differences in the lives of disabled people and other minority groups in Kuwait
can take disability studies to a more complex level by exploring, for example, the experiences of disabled black people and disabled gay people with ‘disablism’:

As disabled Other, disabled black people struggle altogether with white disabled people against disablism while they also struggle against the racism of white disabled people. The same is true of disabled women and gay men and lesbians’ experience in that they struggle altogether with other disabled people against disablism while they also struggle against the sexism and heterosexism of other disabled people as, indeed, they do in mainstream society which is a commonality they also share with non-disabled women, gay men and lesbians. (Vernon, 1999, p.389)

Nevertheless, exploring these complex disability issues is not without risk and they may expose the researcher to legal repercussions. These issues must be handled with caution. Therefore, because of the sensitivity of the context, the current models around disability that arose from disability studies in the Global North may be seen as problematic when dealing with disability in the Global South.

### 9.7.4 Experiences of Diverse Groups of Disabled People

It is worth taking advantage of the methodology of this study and continuing to explore disability from the perspective of other groups of disabled people along the lines of the collaborative research conducted in the Global North. As the participants and co-researchers in this study were predominantly physically impaired people, exploring the experiences of other disabled groups would provide different insights into the lives of disabled people in Kuwait. For example, according to the accounts of the disabled and non-disabled participants, learning disabled people are the most oppressed group in Kuwaiti society. Therefore,
future research could examine, for example, how learning disabled people perceive their experiences compared to the other groups of disabled and non-disabled people. Furthermore, the co-researchers and participants in this study talked about how deaf people experience difficulties in communication which results in their exclusion from the study community. This realisation can lead to a useful study on how deaf people can be supported in a more effective way (e.g. using assistive listening devices or subtitled videos) so that they can be included in the mainstream and higher education community.

9.7.5 State’s Readiness to Adopt a Disability Model

It would be useful to conduct further research in order to gauge the readiness of the state of Kuwait to adopt the disability model I suggested as a key outcome of this thesis. This can be done by summarising the main findings of the thesis and showing the model to a number of politicians and decision makers including politicians working at the PAPDA, parliamentary members and ministers. By doing this, one can begin to gauge to what extent the state might be ready to adopt the model, and thus grasp a more comprehensive answer to the last research question.

9.8 Dissemination of Findings

The findings of this project can be disseminated in a variety of ways, including presenting the key findings of this project at international conferences and publication in journal articles and books. I was supposed to present a paper
entitled ‘Developing a Model for Understanding Disability-related Issues in a Kuwaiti Context’ at the Pacific Rim International Disability and Diversity in Hawaii this year, but because of the unavailability of the funding support from the university for my travel, I was not able to do so. Therefore, I aim to present the paper at the same conference next year. I will also aim to present some of the findings of this study at the annual Disability Studies Conference at Lancaster University next year.

I will seek possible venues for publication such as the journals *Disability & Society* and *Disability and the Global South*. I will particularly discuss topics such as:

- The political identities of disabled people in Kuwait.
- The role of media in depicting disabled people in Kuwait.
- The influence of religious discourse on disability and disabled people in Kuwait.

Moreover, I will develop the key findings of this project into a book chapter. For instance, I believe that the theme ‘being differently different’ and the issues related to impairment hierarchy discussed in Chapter seven have potential to be developed into a book chapter.

Furthermore, as the model proposed in this study is rooted in critical realism that provides a broader exploration of several disciplines, I am planning to benefit from this feature and conduct in-depth joint interdisciplinary research. For
example, my friend is currently studying for a doctoral degree in counselling psychology; therefore, it is worth writing a joint paper that combines the disability and psychology fields in Kuwait. We could benefit from the findings of this project, for example, and examine the relationship between the environmental and the psycho-emotional factors in the lives of disabled people in Kuwait.

### 9.9 Final Words

At the end of this long journey, I very hope to be returning to my home country with a PhD that identifies me as a nascent disability researcher. Entering the field of disability was not as easy a task as I expected at the beginning of the journey. Throughout the journey, I found myself moving between different disciplines. As I stated in Chapter one, I started researching disability and linked it to distance education, trying to provide an open distance learning course for disabled people in Kuwait. I then (based on the findings of the exploratory phase) narrowed my research and focused on the exploration of disability issues in Kuwait through participatory research. Exploring the field of disability led me to explore philosophies such as Marxism, postmodernism, and critical realism, trying to find the most suitable theoretical tool that can provide a better understanding and an in-depth analysis of the lives of disabled people in Kuwait.

All of the experiences that I have had on this journey were new and challenging for me. A challenge related to, for example, my own attitudes towards disabled people. It is shameful to admit (but important to recognise) that when I was younger, disabled people disgusted me. I still remember the boy with no limbs I
used to see in the school cafeteria when I was in middle school. The image of that boy remained in my mind until the first meeting with disabled people in this project. The image appeared in my head again when I was heading to my first meeting with the disabled pupils in the secondary special school. A number of questions arose in my mind at the time: How am I going to meet disabled people? Will I accept them? How am I going to deal with them? Am I qualified to deal with their issues? How am I going to deal with those who have no limbs (like the disabled boy in middle school)?

I also asked myself: Why am I worried about this meeting? My niece is a disabled person and I often deal with her and she’s my favourite among my nephews and nieces. After thinking carefully, I realised that the same questions arose when my sister decided to move and live with us in our family home. I remember how at the beginning, I distanced myself from my niece and did not accept her presence. As time passed by, however, I got used to her presence and she became my favourite niece. I realised that we fear things that we do not understand and that we do not often see. Thus, it is an issue of familiarity with things. The co-researchers emphasised this notion in the focus groups and revealed that the frequent presence of disabled people in society will make non-disabled people accept them and deal with them. This is exactly what happened with me, as my frequent meetings and my presence in the places for disabled people, such as special schools and the sport club for disabled people, made me more familiar with the presence of disabled people in society and more qualified to deal with their issues. Thus, all my worries diminished over time.
Moreover, another challenge I encountered in this journey was the difficulties I faced with the English language. This is the first time that I have used the English language in its four components, reading, listening, writing, and speaking, at this educational level, as all my previous studies were in the Arabic language.

Now, at the end of this study, I feel more confident in dealing with disabled people and disability issues, and I hope that the ideas addressed in this thesis will be applied and implemented by the state of Kuwait.
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Appendix 1: Participants/Co-researchers Sheet

You are being invited to take part in a research study as part of my PhD in Education. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please do not hesitate to ask if there is anything that is not clear or if you would like more information.

Who will conduct the research?
Hussain Alenaizi - School of Education, University of Manchester.

Title of the research
Exploring Participatory Research Processes with Disabled People in Kuwait through the Development of an Open Online Course.

What is the aim of the research?
This research will be conducted in collaboration with disabled people in Kuwait on building an open online course to raise people’s awareness of disability issues.

Why have I been chosen?
You have been chosen to participate in this project as co-researcher because the study intended to collaborate with disabled people in the creation of the course.

As a participant, you have been chosen because the course is primarily intended for the use of non-disabled people, and we need people to try out the course.
What would I be asked to do if I took part?
If you decide to take part in this study as co-researcher, you will be asked to take part in focus group interviews. You will also be expected to participate throughout the research process from data generation, to analysis, to the evaluation of the whole process.

If you decide to take part in this study as a participant, you will be asked to take a part in interview aims to explore your attitudes toward disabled people and disability. You will be also expected to share your experiences with the online course in an interview after you try it out.

What happens to the data collected?
The data that you provide will be analysed and discussed as a part of my thesis.

How is confidentiality maintained?
The data you provide will be confidentially stored and kept secure; access will be limited to the researcher and the supervisors of the study. The results will be anonymous and it will not be possible to identify you as a participant.

What happens if I do not want to take part or if I change my mind?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any point for whatever reason.

What is the duration of the research?
As a co-researcher, you will be expected to take part in 17 meetings if you decided to take a part in the whole research process. You will also expected to participate in four focus groups (one to one and half hours each).

As a participant, you will be expected to take a part in two interviews before and after you try out the online course (each interview may take up to 30 minutes).

Will the outcomes of the research be published?
The results of the study will primarily be used for my PhD thesis. The results may also be published in academic journals or presented at academic conferences. However, all data will be anonymous and linking the data to you will not be possible.

Contact information
If you have any questions or concerns, please do not hesitate to contact either myself, or my supervisor at the following email addresses:
Hussain Alenaizi: hussain.alenaizi@student.manchester.ac.uk
Gary Motteram: gary.motteram@manchester.ac.uk
If you are happy to participate, please complete and sign the consent form below:

1. I confirm that I have read the attached information sheet on the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily. 

2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason.

3. I understand that the interviews will be audio-recorded.

4. I agree to the use of anonymous quotes.

5. I agree that any data collected may be passed to other researchers.

6. I agree that any data collected may be published in anonymous form in academic books or journals.

**I agree to take part in the above project:**

______________________________________________________________________________
Name of participant                  Date                  Signature

______________________________________________________________________________
Name of person taking consent         Date                  Signature

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## Appendix 2: Summary of Co-researcher Meetings (CRMs)

<table>
<thead>
<tr>
<th>CRMs</th>
<th>Research Questions/aims</th>
<th>Agendas</th>
<th>Activities</th>
<th>Estimated time per day</th>
<th>Data type</th>
</tr>
</thead>
<tbody>
<tr>
<td>CRM1</td>
<td>RQ1: What are the co-researchers’ motivations for participating in this research?</td>
<td>Recruiting the participants as co-researchers and identifying the agendas and process.</td>
<td>Discussion of research topic, procedures and ethical issues, and running the first focus group.</td>
<td>1.5 hours</td>
<td>Audio recording and field notes.</td>
</tr>
<tr>
<td>(10&lt;sup&gt;th&lt;/sup&gt; April 2014)</td>
<td>RQ2: Do the co-researchers believe that they will benefit from this process and, if so, how?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRM2</td>
<td>Exploring qualitative research strategies and participatory strategies.</td>
<td>Exploring qualitative methodology and participatory strategies.</td>
<td>Presenting information about qualitative methodology, participatory strategies, and data collection methods, for undertaking this project.</td>
<td>1.5 hours</td>
<td>PowerPoint presentation</td>
</tr>
<tr>
<td>20&lt;sup&gt;th&lt;/sup&gt; and 21&lt;sup&gt;st&lt;/sup&gt; April 2014</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRM3</td>
<td>Analysing the data of CRM1.</td>
<td>Analysis process (workshop).</td>
<td>Working jointly on analysis and discussing results.</td>
<td>1.5 hours</td>
<td>Coding all of the extracts from the dataset.</td>
</tr>
<tr>
<td>CRM4</td>
<td>RQ3: What are the most significant issues facing disabled people in Kuwait?</td>
<td>Specifying disability-related issues.</td>
<td>Focus group with co-researchers.</td>
<td>1.25 hours</td>
<td>Audio recording and field notes.</td>
</tr>
<tr>
<td>CRM5</td>
<td>Analysing the data of the second focus group.</td>
<td>Analysis process (workshop).</td>
<td>Working jointly on analysis and discussing results.</td>
<td>1.25 hours</td>
<td>Discussing and generating initial ideas in both first and second focus groups.</td>
</tr>
<tr>
<td>CRM6</td>
<td>Co-constructing interview schedule.</td>
<td>Co-constructing interview schedule for</td>
<td>Constructing interview schedule.</td>
<td>2 hours</td>
<td>Note taking.</td>
</tr>
<tr>
<td>CRM/Date</td>
<td>Activity</td>
<td>Duration</td>
<td>Notes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>------------</td>
<td>------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRM7 8th June 2014</td>
<td>Analysing the data generated from non-disabled people.</td>
<td>Analysis</td>
<td>Discussing and generating initial ideas</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRM8 17th June 2014</td>
<td>Analyzing the data generated from non-disabled people.</td>
<td>Analysis</td>
<td>Discussing and generating initial ideas</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRM9 25th June 2014</td>
<td>Discussing the data generated from non-disabled people.</td>
<td>Discussion</td>
<td>Discussing and note taking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRM10 17th August 2014</td>
<td>Discussing the research process and plan.</td>
<td>Discussion</td>
<td>Discussion of the research plan and note taking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRM11 8th September 2014</td>
<td>Discussing the content of YouTube videos.</td>
<td>Discussion</td>
<td>Discussion of the research plan and note taking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRM12 16th September 2014</td>
<td>Discussing the ideas of the YouTube videos, with members of Kuwait University.</td>
<td>Discussion</td>
<td>Discussion of the research plan and note taking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRM13 2nd November 2014</td>
<td>RQ4: What are our (i.e. the researcher and co-researchers) experiences with the process of participatory research?</td>
<td>Evaluation</td>
<td>Audio recording and field notes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRM14 4th November 2014</td>
<td>RQ4: What are our (i.e. the researcher and co-researchers) experiences</td>
<td>Evaluation</td>
<td>Audio recording and field notes</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 3: The Co-researchers’ Commitment in the Project

<table>
<thead>
<tr>
<th>Co-researchers</th>
<th>Date of withdrawal</th>
<th>Reason of withdrawal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Saja</td>
<td>25&lt;sup&gt;th&lt;/sup&gt; May 2014</td>
<td>Receiving treatment abroad</td>
</tr>
<tr>
<td>Omar</td>
<td>10&lt;sup&gt;th&lt;/sup&gt; July 2014</td>
<td>No reason stated</td>
</tr>
<tr>
<td>Abdurrahman</td>
<td>16&lt;sup&gt;th&lt;/sup&gt; August 2014</td>
<td>Personal circumstances</td>
</tr>
<tr>
<td>Abdullah</td>
<td>24&lt;sup&gt;th&lt;/sup&gt; August 2014</td>
<td>Receiving treatment abroad</td>
</tr>
<tr>
<td>Yagoub</td>
<td>24&lt;sup&gt;th&lt;/sup&gt; August 2014</td>
<td>No reason stated</td>
</tr>
</tbody>
</table>

*Note: the collaboration work with the co-researchers started on the 10<sup>th</sup> April 2014*
Appendix 4: Participants Information Sheet of the Disability Film

You are being invited to take part in a research study as part of my PhD in Education. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please do not hesitate to ask if there is anything that is not clear or if you would like more information.

Who will conduct the research?
Hussain Alenaizi - School of Education, University of Manchester.

What is the aim of the research?
This research explores disability issues and the process of participatory research with a number of disabled people in Kuwait.

Why have I been chosen?
You have been chosen to participate in this project as participant because the study intends to explore the experiences of disabled people with disability issues in the Kuwaiti context.

What would I be asked to do if I took part?
If you decide to take part in this study as participant in the film, you will be asked to talk about a number of topics related to the behaviour and attitudes of non-disabled people towards disabled people, their views about social inclusion, their views about the political decisions with regard to disabled people and disability, and the role of the media (how disabled people are depicted in the media).
What happens to the data collected?
The accounts that you provide in the film will be analysed and discussed as a part of my thesis.

What happens if I do not want to take part or if I change my mind?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any point for whatever reason.

What is the duration of the interview?
You will be expected to take part in one interview that may take about 30 minutes.

Will the outcomes of the research be published?
The results of the study will primarily be used for my PhD thesis. The results may also be published in academic journals or presented at academic conferences.

Contact information
If you have any questions or concerns, please do not hesitate to contact either myself, or my supervisor at the following email addresses:
Hussain Alenaizi: hussain.alenaizi@student.manchester.ac.uk
Gary Motteram: gary.motteram@manchester.ac.uk

If you are happy to participate, please complete and sign the consent form below:

Please Initial Box

1. I confirm that I have read the attached information sheet on the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.

2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason.

3. I understand that the interviews will be video-recorded.

4. I agree to the use of anonymous quotes.
5. I agree that any data collected may be passed to other researchers.

6. I agree that any data collected may be published in anonymous form in academic books or journals.

**I agree to take part in the above project:**

<table>
<thead>
<tr>
<th>Name of participant</th>
<th>Date</th>
<th>Signature</th>
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<table>
<thead>
<tr>
<th>Name of person taking consent</th>
<th>Date</th>
<th>Signature</th>
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Appendix 5: Diary Format

Candidate name:

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Notes</th>
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Appendix 6: Focus Group Schedule

<table>
<thead>
<tr>
<th>Description</th>
<th>The initial focus group interview with six co-researchers: four males, Abdullah, Abdurrahman, Omar and Yagoub; and two females, Saja and Kholood.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research questions</td>
<td>1) What are the co-researchers’ motivations for doing this research?</td>
</tr>
<tr>
<td></td>
<td>2) Do the co-researchers believe that they will benefit from this process and if so, how?</td>
</tr>
<tr>
<td>Location</td>
<td>Kuwait</td>
</tr>
<tr>
<td>Duration</td>
<td>90 minutes</td>
</tr>
<tr>
<td>Date</td>
<td>10th April 2014</td>
</tr>
</tbody>
</table>

Focus group body

(i) Research purpose and rights

(Purpose) This research aims to explore disability issues and the process of participatory research.

(Rights) Ok, now you’ve all agreed to participate with me in this participatory research as co-researchers, right? I would just like to remind you that you can withdraw from this research at any time and even without stating any reasons.

(ii) Questions

a. How do you feel this research can add to you if you work on it?

   a1. What does it add?

   a2. Is it about the process of the research or particular skills you can develop throughout the process, or things that you can benefit society with? Why do you want to do this research with me? Why did you agree?
Appendix 7: Interview Schedule

(i) Opening

(Establish Rapport) [shake hands] My name is ___________ and I am a member of a collaborative research aims to develop an Open Online Course to raise people’s awareness of disability related issues. This research will be conducted in collaboration with disabled people in Kuwait and an academic researcher name Hussain Alenaizi who is doing his PhD currently with the University of Manchester.

You have been chosen because the course is primarily intended for the use of non-disabled people, so that your views around disability related issues would help us to design a suitable online course. Also, you will be expected to try out the course and share your experiences with the course as well as your views and ideas about disabled people and disability in Kuwait after you complete the online course.

(Purpose) I would like to ask you some questions about disabled people and disability related issues in relation to the employment, social life, health and education for disabled people.

(Time Line) The interview should take about 30 minutes. We will arrange to have the interview in your school (e.g. teachers) or in a public place (e.g. disabled club) at a time / date convenient for you.

The data that you provide will be analysed and discussed as a part of the academic researcher’s PhD thesis. The data you provide will be confidentially stored and kept secure; access will be limited to the researcher and the supervisors of the study. The results will be anonymous and it will not be possible to identify you as a participant.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any point for whatever reason.

The results of the study will primarily be used for the academic researcher’s PhD thesis. The results may also be published in academic journals or presented at academic conferences. However, all data will be anonymous and linking the data to you will not be possible.

(ii) (Transition): Let me begin by asking you some questions about yourself first…..
(iii) Interview Body

a. What do you think about the services allocated for disabled people in society?
   a1. To what extent you think disabled people are satisfied about these services?
   a2. Prompt
b. Tell me about your views around social inclusion?
   b1. What are the necessary actions that must be taken by the State to promote the inclusion of disabled people?
   b2. Prompt.