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Complicated Stories: Exploring perceptions of Attention Deficit Hyperactivity Disorder (ADHD) from the point of view of parents raising children with ADHD in Kuwait.

A thesis submitted in partial fulfilment of a Doctor of Philosophy degree requirements

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Zainab Khaled Alshtaili

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# **Abstract**

This research focuses on the experiences of eight Kuwaiti parents raising a child with attention deficit hyperactivity disorder (ADHD) to explore parental perspectives on the category of ADHD and experiences of parenting a child with ADHD. Medical sociology, critical psychology, and disability studies influence the conceptual framework for the research and provide a lens to examine the parents’ experiences and understanding.

The study adopts a narrative approach and parents’ stories were collected using open-ended questions and narrative interviews. Using thematic narrative analysis, the analysis develops three themes. The first theme, ‘Parents’ understandings of ADHD’, explains how Kuwaiti society and culture influenced the social construction of parents’ ideas about their children’s behaviour as ADHD. In this theme five stages in the parents’ journey to understanding ADHD are described revealing complex engagement with ADHD as a disorder and ADHD as a deviant social norm.

The second theme, ‘Disability barriers in social life’, explores the attitudes, environmental and psycho-emotional barriers that parents and their children encountered that led to exclusion from social participation and other disadvantages. The theme is divided into three sub-themes to discuss the idea that, despite the availability of support and services, parents and children with ADHD are still disadvantaged via a lack of information, poor communication and psycho-emotional burden, all of which are in part products of negative social and institutional attitudes.

The third theme, ‘ADHD and impairment’, explores the parents’ personal ideas of ADHD that often conflict with the negative social perceptions in the context of Kuwait. The theme is divided into two sub-themes. The first sub-theme addresses the role of religion and Arab culture in accepting ADHD disabilities and impairments. The second sub-theme focuses on the ways parents positively negotiate the differences in children with ADHD.

The analysis of parents’ experiences as discussed here have implications for policymakers and professionals. parents’ perspectives around ADHD help to build a set of understandings rooted in lived experience which challenge the dominant cultural and medical dogma. Considering ADHD as a disorder, often leads support and services to focus on impairment and to neglect the disability encountered by the children with ADHD and their families. This research concludes that centring the voices and experiences of parents and children with ADHD is crucial to developing more socially just practice and research in disability studies in Kuwait.

# 

# **Acknowledgement**

Many thanks to the people who facilitated my PhD journey and kept me motivated. My primary thanks are to God for his blessings that shine upon me. I would also like to thank my supervisors, Katherine Runswick-cole and Harriet Cameron, for their feedback and suggestions that guide and develop me personally and academically. I also want to show my gratitude to the parents of children with ADHD who participated in the research for the time and the help they offered. They guided me to find better information resources and explore the topic of students with learning difficulties in Kuwait. Lastly, I greatly appreciate my mother and friends for believing in me and supporting me emotionally.

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# **List of Abbreviations**

| American Psychological Association | APA |
| --- | --- |
| Attention Deficit Disorders Evaluation Scale | ADDES |
| Attention Deficit Hyperactivity disorder | ADHD |
| Centre for Child Evaluation and Teaching | CCET |
| Cognitive Behavioural Therapy | CBT |
| Deoxyribonucleic Acid | DNA |
| Diagnosis and Statistical Manual of Mental Health Disorder | DSM |
| Food and Drug Administration | FDA |
| Intelligence Quotient | IQ |
| International Statistical Classification of Diseases | ICD-11 |
| Kuwait Association of Learning Difficulty | KALD |
| Learning Difficulty | LD |
| Motor Neuron Disease | MND |
| National Institute for Health and Care Excellence | NICE |
| Public Authority For Disability Affairs | PADA |
| Rights of Persons with Disabilities | CRPD |
| Strengths and Difficulties Questionnaire | SDQ |
| Test Of Variables of Attention | TOVA |
| Union of the Physically Impaired Against Segregation | UPIAS |
| United Kingdom | UK |
| United Nation | UN |
| United States | US |
| Vanderbilt ADHD Diagnostic Rating Scale | VADHDDRS |

# 

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# Chapter 1

# Introduction

## 1.1 Background to the current research

The current research focuses on attention deficit hyperactivity disorder (ADHD), which is conceptualised as a childhood neurodevelopmental disorder (American Psychological Association (APA), 2013). The ambiguity of ADHD aetiology has attracted a vast amount of attention from academia, resulting in continuous controversies over the validity and management of behaviours seen in ADHD (Conrad and Bergey, 2014; Hinshaw, 2018). However, as I will illustrate in Section 2.1.6, in education, politics and clinical practice, ADHD is seen as negatively influencing a child’s academic life (McDougal et al., 2022). The current research presents a case study from Kuwaiti practice. ADHD is seen as a disorder and learning difficulty which needs educational support (Kuwait Association of Learning Difficulty (KALD), 2010). In this research, I argue that focusing on ADHD as only a neurodevelopmental problem and learning difficulty in children might cause disadvantage and exclusion for such children and their families. This is because families who have children with ADHD encounter many issues that are not only related to the child’s behaviours and academic challenges, but also to the social environment (Oliver, 1996).

Therefore, in an attempt to expand and explore the understanding of ADHD in Kuwait, the current research investigates the perspectives of eight parents of children with ADHD. The focus on parents is underpinned by the belief that parents are responsible for children with ADHD; therefore, they are most experienced with the condition (Ghosh et al., 2016). Following my analysis of the parents’ complex and sometimes inconsistent ideas, I used different models of disability from Western literature to explain and present the implications of my analysis of participants’ ideas about living with ADHD (Oliver, 1996; Conrad, 1992; Thomas, 1999).

This chapter starts with an introduction to the focus of the research with a brief summary of the background. I then discuss my own position and background, as well as the reason for choosing the research topic. I also discuss the construction of the aims and research questions, which changed significantly from the start of the research, as well as the significance of the purpose of the research. Finally, I give the research terminology and discuss the influence of language on this study, which is situated in the field of disability studies. Concluding with a chapter by chapter overview of the thesis.

## 1.2 Position of the researcher

This section presents my background and experience with disability studies to provide a window into the values and ideas that I bring to the research. I also demonstrate the influence of my own position as a non-disabled female researcher from the same culture as the parents who participated in the research. This is important, not only to address a central question in disability studies, about the place of non-disabled researchers (Goodley, 2011), but also to consider how my position affected the entire study process.

At the start of the research, I believed ADHD to be a disorder, but the deeper I got into the literature about ADHD, the more uncertain I became about what ADHD was. Nevertheless, one thing I am sure about is that the label of ‘ADHD’ and the behaviour associated with ADHD affects the lives of children and parents as well as educators such as myself every day. During my undergraduate study, I was taught about ADHD through a ‘special education’ model as part of my degree. I knew how to identify and assess children with ADHD-like behaviour. However, I did not know how to teach children with behaviour like ADHD because special education model lack teaching and social interaction strategies. This put pressure on my reputation as a good teacher who was required to know how to advocate students to sit and listen by my supervisor at work. However, unlike other stages of school, in which teachers are able to report a child with ADHD-like behaviour, I had to figure out a way to teach children with ADHD-like behaviour, because children in kindergarten are often barred from having an ADHD ‘diagnosis’. It was challenging to meet the requirement of the kindergarten to keep children with ADHD-like behaviour still for 20 minutes. Therefore, I often found myself caught between two options, either following the rules and reporting their children’s behaviour to the parents, or being creative with support to help the children engage, without forcing them to sit down. However, this meant facing the consequences of not following the rules of the kindergarten.

The challenges that I observed through my experience teaching children with ADHD and interacting with their parents drove my interest in understanding ADHD and the ways in which it influences people’s lives. I believe this understanding comes from my cultural background. I am Arab and Muslim which affects my understanding of what disability is and the possible ways to ‘cope’ with it. Viewing disability as a biological impairment, and the prioritisation of finding a cure or intervention, is ingrained in my subconscious, and these beliefs have been hard to shake, despite the development of my understanding of ADHD and disability from a social perspective.

I developed an interest in learning difficulties and ADHD in particular because of my work practice. This was as a teacher for five years, then as an educational therapist for two years, helping parents of children with challenging behaviours. Since working as a therapist, I have noticed the importance of listening to parents and understanding their challenges. Specifically, I have worked with parents on improving their children’s learning skills through play therapy. The focus is often on the parent’s role in continuing with certain strategies to enhance their children’s skills.

For two years, I observed how the parents of children with learning difficulties were called ‘bad’ or ‘ineffective’ parents while doing their best to help their children. I also witnessed that many children in school were often misunderstood as lazy or naughty because they were unable to sit the ‘right way’ in class, and it was often the parents who were blamed for the child’s behaviour. I came to the UK wanting to create a programme for parents to help them, because at that time, I thought that (lack of) parenting skills was the main problem. My initial research proposal was to create a parenting intervention that would help parents build the skills needed to help their children. This is because when working with parents, I often explored the parents’ story and perspective of parenting in a familial context, where the focus is often on either the parents or the child. However, as I started reading about ADHD, the research theme started to shift, and I became more interested in understanding the social aspects that challenge parents’ lives. *Naughty Boys* (Timimi, 2005),the first book I read in my PhD journey about ADHD, influenced my understanding of the ‘facts’ and ‘realities’ that differ, not just between cultures, but also historically. This background then influenced my reading of the parents’ narratives in the analysis.

Reading within disability studies also motivated me to question my beliefs about ADHD, as well as the causes of the challenges faced by parents and children. The main challenge I faced when researching studies on ADHD in Kuwait and Arab literature was the lack of available research, which made me increasingly aware of the importance of conducting such research. Over the past four years, I have discussed disabilities, especially ADHD with parents and associations for disabled people, and this has been facilitated by looking at the social and environmental aspects behind the challenges that they faced in everyday practice. I have listened to different sides of ADHD stories, including from being a teacher who were former work colleagues, as well as the parents of children with ADHD, with whom I was able to establish a relationship through discussions of different topics concerning ADHD. This experience was the main reason I continued the research, helping to sustain my motivation to conduct the research.

Thus, the aim of this research is to explore the stories of parents’ experiences of raising a child with ADHD in Kuwait in order to understand different perspectives on ADHD and its implications for parents’ and children’s lives. Implications here refers to the needs and challenges the parents encounter which are linked to social, political and cultural contexts. I highlight the parental view that may be masked by professional understandings of ADHD and challenge the orthodox understanding of ADHD as a learning difficulty or a developmental and cognitive disorder. I represent only some of the many possible ways of understanding ADHD to invite the reader to consider ADHD in a broader way that extends beyond the boundaries of the medical perspective. I also argue that the parents’ perspectives on ADHD are relational and linked to the social and cultural contexts that they and their children experience in everyday life. The parents' experience may support ideas and suggestions for policymakers or activists to improve services and legislation to facilitate the lives of parents of children with ADHD and other disabilities.

## 1.3 Issues in conducting disability research

I faced two main issues when conducting this research. First, the issue of non-disabled researchers conducting research about disabled people has been addressed by disability studies scholars, such as Shakespeare (2013), Morris (1992), and Goodley (2011). The basis of this concern is the apparent authority of non-disabled researchers over disabled people to produce information and knowledge about disabled people, which has led to the portrayal of disabled people as passive and tragic, with the most concern being directed towards their impairment (Oliver, 1993). These kinds of studies have been carried out *on* disabled people rather than *with* them, with the results and suggestions often ignoring the participants’ views and needs. In contrast to such approaches, disability studies often indicate the importance of empowering and collaborating with disabled people (Goodley, 2011). Feminist studies, such as Morris (1992), emphasise the importance of research being led by disabled people, because no one can better understand or present information about them. This argument thus portrays an able-bodied researcher like me as not legitimately conducting research on disability or ADHD.

The current research does not focus on the biological and medical aspects of impairment. Instead, it fits with the orientation of the social model, focusing on the practice and social structures that create a barrier for disabled people. Whether following the social or individual model (Conrad, 1992; Oliver, 1996), the focus is not on impairment, but on exploring the construction of impairment and disability. In exploring the social context and its cultural, economic, and political aspects, even the non-disabled researcher is able to participate in the investigation because the issues of disadvantage and lack of support could have implications for the entire society, not just disabled people. Morris (1992) has expressed concern over the differences in experience and understanding with respect to the challenges of disability, and this is understandable, as I cannot understand disability in the same way as the disabled people do. However, I argue that one does not have to have an impairment to care about the social disability that impacts disabled people; it is an issue that is important for us all (Goodley, 2011). As Goodley (2011) argues, there is a benefit to collaborative research being conducted with both disabled and non-disabled persons:

The expertise of the ‘disabled participant’ and the analytical and reportorial skills of (non)disabled researchers are combined to draw out broader socio-structural, cultural, political and theoretical points (Levine and Langness, 1986, pp. 192–205, cited in Goodley, 2011).

The second issue is related to the legitimacy of parents of children with disabilities, or disabled children engagement, representing an understanding of the disability and impairment of their children, which was discussed in the UK context (Ryan and Runswick-Cole, 2008). The issues of parents participating in studies of disability might be different in Kuwait, but no less important to illustrate, because the position of parents of children with learning difficulties is not addressed by the law of disability in Kuwait (Kuwaiti Constitution, 1962). Scholars in the UK have expressed an interest in developing and understanding parenting a disabled child (Vaughan and Super, 2018; Ryan and Runswick-Cole, 2008). When parents were questioned about the motivation behind participating in the current research, often the answer was to share awareness, although some of them wanted to allow others to benefit from their understanding of raising a child with ADHD. This issue was raised explicitly by one of the mothers who wanted to be a researcher in learning difficulties; however, the challenges faced by raising four children with learning disabilities prevented her from continuing her studies. She said:

I was applying for a master’s degree in learning difficulties in Bahrain years ago. The doctor who interviewed me said, ‘You are not a student; we need you to help us. You could work with us. From the moment you sit with me, you seem to know more things because you face them.’ At that time, I had a young baby, and my husband was studying outside Kuwait. I said, ‘I cannot leave my children because they have learning difficulties’. I have the ambition to work in an academic field to serve my children, but I could not find a place where I could help more with my experience. When you are in an academic space, you can do more. However, every place you try, they ask about your academic qualifications. They do not see your experience in life. (Rawan, a mother of four children with learning difficulties)

In the above passage, Rawan shows that her motivation for wanting to work on these issues was to be a beneficial part of the knowledge about learning difficulties. She believed in the possibility of her knowledge contributing to academia and practice. Rawan’s collaboration in this research on ideas of ADHD in Kuwait and the historical events surrounding learning difficulties was a reflection of her ambition to put her experience in the service of children with learning difficulties. Rawan and other mothers in the study were experts that I went to when I felt lost when searching for information about disability and learning difficulties in Kuwait.

There are many examples of disability studies done by mothers of disabled children who are advocating the rights of parents to address their children’s needs, as well as challenging medical understandings of their children in society (Harry, 2008; Ryan and Runswick-Cole, 2008; Vaughan and Supper, 2019). I agree with Ryan and Runswick-Cole’s (2008) argument that parents can provide a valuable understanding of disability as much as any disabled person might.

Thus, the current research follows Goodley’s (2011) suggestion regarding the benefit of collaboration, in which the researcher’s knowledge combines with the parents’ information through the preparation of a theoretical framework as well as discussion of the results. However, this idea proposes actual collaboration with disabled people, and not just participatory research, through which the participants are invited to engage in the entire process (Goodley, 2011). Ideally my participants would be co-authors in my academic writing, but this was not an option given the confines of a PhD. I am, however, grateful for the time they gave me. Nevertheless, it is important to be clear about the meaning behind the use of the word ‘collaboration’ here, in that the engagement facilitated negotiation between the researcher and the participants over the kind of knowledge that they had obtained from their experience and how this should be represented in the research.

## 1.4 Significance of the study

My own background and experience were the initial motivation behind my growing interest in the topic of this research. However, the lack of studies on ADHD in Arab countries, and especially in the Kuwaiti context, directed my research towards the cultural and social aspects that influence the understanding of ADHD. It was thought that an investigation of parents’ experiences of raising a child with ADHD could generate beneficial ideas for other parents in similar situations. The ideas, views, and attitudes of the parents in the stories could be portrayed as tips and lessons to learn to solve similar challenges that other parents might be facing. The parents’ experiences might be a source of information that could help to answer questions linked to practice, such as issues related to accessing support or alternative ways of handling negative responses to ADHD behaviour in social contexts. Moreover, the research could work as a means of supporting social recognition and awareness among readers who do not have children with ADHD of the impact of social action and appropriate responses to the families of children with ADHD. Accordingly, such readers might reconsider their behaviour towards people with ADHD or disability in general (Cortazzi and Jin, 2006).

The stories of the parents provide practical feedback on the implications of the Law of Disability No. 08 in Kuwait. This can help policymakers and activists evaluate the academic and medical support and services that are provided for children with ADHD. Discussing the barriers and challenges that families encounter with special needs schools and health services could highlight the limitations in service provision and suggest ways to improve services in Kuwait. I am not claiming that the stories could be generalised to all parents’ experiences in Kuwait; instead, such stories might draw attention to the importance of understanding parents’ experiences with these services.

Finally, there is increased interest in global and cultural studies of disability, on the basis that disability is a social entity. The understanding and practices of disabled people might differ from one culture to another (Goodley, 2013). The current research provides a social and cultural perspective on ADHD using models of disability from the Western perspective on disability. This perspective provides a critical way of understanding disability in Kuwait. However, it is important to note that the idea of social movement and the disability models were a product of Western society, and the issues and circumstances in Kuwaiti culture are different. Therefore, I discussed the importance of being sensitive to the research context when using disability studies models of disability (see Section 2.3.3.7). Models of disability were also used in order to inspire scholars from different cultures to improve on my initial ideas gained from adopting the Western perspective.

## 1.5 Research question

The process of writing the research questions started with a basic idea of the topic, but determining and clarifying the focus was influenced by the participant stories and the development of my own understanding of disability studies (discussed in full detail in the introduction to Chapter 3). Additionally, the format and language of the questions changed several times to conform to my theoretical and conventional beliefs about the research. Engaging in disability studies means being very sensitive to the impact of language on parents and children with ADHD, whom I was interested in representing. I intentionally chose broad, open-ended questions to account for the variety in the parents’ experiences (see Chapter 3 introduction for more). I therefore produced the following questions:

- How do parents construct their understanding of ADHD?

- What are the implications of the parents' perceptions of ADHD on their experience raising a child with ADHD in the context of Kuwait?

From these questions, one may ask, ‘Why focus on the parents?’ This focus comes from my belief in the important role parents constitute in the lives of children with ADHD (Ryan and Runswick-cole, 2008). Therefore, they were assumed to be the best people to ask about what ADHD looks like in Kuwait and their perspectives on ADHD. This is not to deny the perspectives of the children themselves, but my interest in the parents comes from my own practical experience with the parents of children with academic difficulties and challenging behaviour. Parents often do their best, but are still blamed for their children’s behaviour and academic issues (Ghosh et al, 2016). While ADHD is still new in Kuwaiti culture, and information on ADHD is thus scarce, it might be even harder for the parents of children with ADHD to find a way to meet social expectations (Ryan and Runswick-Cole, 2008). For this reason, the current research focuses on parents who believe their children have ADHD.

Moreover, from my experience in presenting this research to different audiences, it is important to acknowledge that the research focuses on the parents’ experiences of parenting a child with ADHD and not on ADHD per se. This means that I am exploring the way the parents’ experiences constitute their perspectives on ADHD by looking at cultural and contextual factors indicative of their social experience. I am not presenting or evaluating biomedical information about ADHD. Instead, the research presents a critical analysis of the way parents adopt biomedical (this term is defined in Chapter 2, Section 2.1) ideas about ADHD or the process of seeking a ‘diagnosis’ and opting for ‘treatment’; in doing so, it addresses the role of social and cultural factors in constituting the parents’ ideas about and attitudes towards biomedical perspectives, rather than discussing the legitimacy of ‘treatment’ options, ‘diagnoses’, or ‘symptoms’. The current research is an exploration of how various parents’ experiences could help to illustrate alternative ways of looking at ADHD as more than a disorder and the implications such perspectives have on their everyday lives.

## 1.6 Role of language in disability studies: terminology and definitions

This section turns to the importance of language in disability studies. An important aspect of language is that it is constructed by the way disability is presented socially, and this could have implications for how people with disabilities are thought of and treated in society (Ziegler, 2020). Swain et al (2003) argued that ''We tend to live up to other people’s expectations of us'' (p.12). Negative terms increase surveillance or segregation, which leads to an increase in unacceptable and negative behaviours (Ziegler, 2020). People with disabilities are often labelled by their impairment, which often portrays them as weak or dependent (Oliver, 1996). In a study that focuses on the empowerment and inclusion of parents of children with ADHD, it is important to discuss the language that encompasses the relevant terms and definitions used in the current study.

There are the terms ‘people with disability’ and ‘disabled people’. Within disability studies, there have been arguments on the appropriate use of these terms in studies on disability or impairment (Swain et al, 2003). The term ‘disabled people’ has been advocated by disability studies scholars as a political statement capturing how disability is an imposition upon people (Oliver, 1990). Moreover, the term ‘people with disability’ could be confusing, given the distinction between disability and impairment within the social model. Disability in this sense could also be interpreted as an impairment of part of the individual’s identity (Barnes and Mercer, 2010). However, the term ‘people with disabilities’ also indicates that the people should be put before the disability (Oliver, 1990). The use of such terms is controversial because both terms might not effectively capture the way in which people with disabilities see themselves. Therefore, I will use ‘people with disability' because I want to illustrate that they are people before their impairment, but in the section related to disability studies, I will use the term ‘disabled people’ as it is the language used in the literature on the materialist social model of disability.

While the study starts with a general discussion of disability terminology, the main focus is on ADHD. The terminology used to describe children who are believed to exhibit behaviour associated with ADHD is ‘child with ADHD’. I am using the social model, which advocates owning the impairment and celebrating differences through the use of the term ‘disabled people’ (Goodley, 2007). However, I am not following the social model terminology for children with ADHD for two reasons. First, children with ADHD are understood in Kuwait as having learning difficulties (Al-Kandri, 2009). Many disabled individuals prefer the term people with learning difficulties, as it suggests that people are capable of learning (Swain et al., 2003). Second, following the suggestion in Swain et al. (2003) that the term depends on the aim of the study, my intention is to present children with ADHD as children who happen to have difficulties because of their environment. Third, ‘disabled’ is a characteristic that may not apply in the ADHD case, as it might be grammatically inaccurate to say, ‘ADHD children’, and the term might characterise children with ADHD as having a disorder. Therefore, I used the term ‘children with ADHD’.

Finally, language is also important in conceptualising ADHD because throughout the research, I use terms such as ‘deviant’ and ‘dysfunction’, which might prevent advocating for an alternative understanding of ADHD in Kuwait rather than the biomedical understanding. The biomedical language of ADHD presents ideas about ADHD as a pathology that leads to tragedy and requires help; this devalues the abilities and dreams of children with ADHD compared to those of typically developing children (Wilde and Hoskison-Clark, 2014; Haegele and Hodge, 2016). The descriptions of the behaviours and characteristics of children with ADHD point to developmental disorders. Their excitement or boredom is translated into hyperactivity or inattention. The diagnosis of ADHD underpins moral aspects of normal childhood and highlights the parents’ responsibility for the child’s behaviour (O’Reilly and Lester, 2017).

The dangers of negative biomedical perceptions impact not only the kind of support provided, which focuses only on rehabilitation or removing an abnormality, but also shapes professional and social interactions with the families of children with ADHD (Wilde and Hoskison-Clark, 2014). The influence of language could extend to children’s perceptions of themselves and cause them to doubt their value (Wilde and Hoskison-Clark, 2014). Oliver (1996) showed that focusing on language is not only important because we need to be conscious of when we might offend disabled people, but also because language could shape meaning and impact practice. Runswick-Cole and Goodley (2012) extended this idea, arguing that medical language that often considers ‘objective and scientific’ truth about impairment could create an unequal power relation over people with disabilities.

Thus, I want to acknowledge that by using medical language, my intention was not to pathologise children with ADHD or their parents, but to try to write using the language that is most dominant in practice while illustrating problems with the use of such language to create a space for more affirmative language using the social models of disability. I did not assume that these terms were the most suitable language for presenting children with ADHD or ADHD itself. Childhood is a cultural and historical concept that underpins the economic, social and political factors of a specific context (Timimi, 2005). Medical language might be one way of understanding what is commonly understood as scientific truth.

At the same time, this acknowledgement must be addressed cautiously, as I agree with Runswick, Cole and Goodley (2012) that each perspective (including the medical perspective) may be more useful in one context than the other perspectives. Pedersen and Sandberg (2013) reminded us that speaking the ‘language of the system’ is sometimes even better than the system itself. In other words, it is sometimes necessary to use the language of medicalisation (see Section 2.3.2.3 for definition), as the process of medicalisation is complex. Medicalisation could give some parents the power to gain support and access information (Rose, 2007). Unfortunately, families interact with biomedical language on an everyday basis, such as at school, at hospitals, when acquiring disability services and even at home. However, this should not be done without problematising the use of biomedical language. I still believe and hope that with alternative ways of looking at ADHD and childhood, we can advocate for more affirmative language that makes biomedical language less dominant. This can be made possible by looking at ADHD in a different way, where the needs of the child and the family are the main concerns and not the label (O’Reilly and Lester, 2017).

## 1.7 Structure of the research

### Chapter 2: Literature Review

This chapter reviews the literature related to ADHD, Kuwait, and disability studies. The first section introduces the main concept of ADHD. It defines the term and then explores the biomedical literature related to ADHD causes, prevalence, ‘diagnosis’, social and educational effects and ‘treatment’. This section argues that there is variation in these aspects between the US, UK and Kuwait.

The second section demonstrates the context of the study. It sets out the political, economic and cultural aspects of the Kuwaiti context. It highlights the influence of globalisation on the changing values and perceptions of the culture towards disability, children, and parenthood. Moreover, it outlines disability law as it applies to the learning difficulty that encompasses ADHD, which is mostly supported through academic services, although emotional and social support is often absent for the parents and children with ADHD. It ends with an evaluation of studies on disability in Kuwait that lack consideration of social, political, and economic aspects.

The last section illustrates the conceptual background underpinning the analysis of the study. The study draws on social and individual models (medical sociology and critical psychology) of disability. The main argument is that there is strong potential to combine two different approaches to explore the experiences of parents of children with ADHD. The individual model is used to critically analyse the understanding of biomedical ideas about ADHD and the influence of the social, economic and political structure in Kuwait on the parents’ perspective of ADHD as a disorder. The social model is used to explore the main social barriers that disadvantage and exclude parents from participating in society. It also discusses the cultural impact of stigma as one of the main issues related to ADHD. The chapter ends with a critical discussion of the best way to use models of disability that are widely used in the UK, within the Kuwaiti context. The main argument highlights the importance of considering the differences in social structure in the Kuwaiti context when using these models.

### Chapter 3: Methodology

This chapter discusses the philosophical beliefs and values underpinning the methodological approach of the study. This study’s theoretical foundation lies in social construction ontology and epistemology. It focuses on the multi-reality that is seen as helpful to the divergent understandings of ADHD between medical sociology and disability studies. The chapter then justifies the choice of methodology, which is a narrative. This section also discusses ways to evaluate the research based on the underlying beliefs and values from a social constructionist approach and a narrative approach. The main argument illustrates the different criteria used to assess the value of narrative research. The chapter ends with a summary of the ethical considerations of the research.

### Chapter 4: Research Procedures

This chapter demonstrates the process of conducting the research and the methods used to recruit the participants, including snowballing, narrative interviews, and the thematic narrative analysis process. The recruiting and interview processes were presented with a reflection on the decision-making process and an illustration of the main challenges encountered in conducting the study. The study included eight parents (two fathers and seven mothers, as one of the interviews included the father and mother together) who were interviewed about their experiences of raising a child with ADHD. The chapter ends with a detailed explanation of the reason for choosing the thematic narrative analysis approach to analyse the parents’ stories, as well as an outline of the way in which the analysis was conducted. This section also presents the uncertainties and difficulties involved in narrative research based on the lack of practical guidance.

### Chapter 5: Parents’ understandings of ADHD: medical Sociology, critical Psychology and Disability Studies’ Perspectives

This chapter includes a critical discussion of the parents’ perspectives on ADHD as a disorder. Any parent with a child with ADHD goes through the process of noticing certain differences in their child's behaviours, searching for information, and pursuing a ‘diagnosis’ and ‘treatment’. However, this chapter argues that a critical investigation of the social and contextual aspects of the process would highlight the differences in the biomedical understandings of ADHD. It shows that parents’ ideas are often complex and continue to shift between biomedical and cultural understandings of ADHD behaviours. The social structure plays an essential role in the way parents advocate the ADHD label and limit the acceptance of ‘treatment’ for their children.

### Chapter 6: Disability Barriers in Everyday Life

This chapter focuses on the parent’s experiences of the social practice of raising a child with ADHD. It highlights the material and non-material barriers that parents encounter throughout their journeys. The main discussion focuses on the influence of the social barrier on the parents’ and the children’s everyday lives and the inclusion they seek within society. Parents encounter barriers in special needs schools, health services, and communication with professionals, and they face stigma from society and its social structures. This can be a burden and increases the difficulty of their experience. The chapter ends with suggestions derived from the parents’ stories on the importance of social group support to illustrate the importance of information and communication in empowering the parents through their journey.

### Chapter 7: ADHD, Impairment from a Social Relational Model of Disability

This chapter discusses the experiences of the parents focusing on their personal understanding of ADHD as an impairment. It highlights the influence of Arab culture and the Islamic perspective, which often overlap in the parents’ ideas about their children’s impairment. It also uncovers the complexity of their ideas about the children’s impairment as they differ between fathers and mothers. The main discussion in this chapter focuses on the spiritual dimension of the parents’ experience in accepting the positive and negative effects of the impairment.

### Chapter 8: Conclusion

This chapter started by answering the research questions through a typology of the parents’ experience of ADHD in the Kuwaiti context. The experience of parents can be characterised as being complex and contradictory, with various understandings of ADHD. They constructed their experiences by drawing on themes such as stigma, special school, information and communication, the law of disability, and services. The chapter then discussed the implications of the findings and the contribution of the research to different audiences, for example, parents of children with ADHD or another disability, professionals, policymakers, and scholars from global or Western countries. Last, the decision to adopt a social constructionist position and narrative inquiry does not come without limitations. The importance of acknowledging the limitations increases the value of the research, as it opens up recommendations for future research and studies on ADHD and disability.

# **Chapter 2**

# **Literature Review**

General Introduction

This chapter in general discusses the concepts of disability and ADHD. The objective of this chapter is to discuss ideas from disability studies that show different ways of understanding disability (Oliver, 1996; Thomas, 1999; Shakespeare, 2006; Morris, 1992) and ADHD (Timimi, 2005; Conrad, 1992). Another objective of the chapter is to argue that academic studies on disability stem from Western culture (Grech, 2009); however, cultural differences between Kuwait and Western countries (such as the UK and the US) suggest that it may be inappropriate to apply Western findings to Kuwait.

I begin by discussing ADHD, in Section A, applying the biomedical model to the concept of ADHD. I then, in Section B, describe how Kuwaiti culture conceptualises disability. Lastly, in section C, I provide an overview of Western paradigms of disability using an analytical lens (a social and then an individual model approach (Oliver, 1990)) to understand disability. I also draw on other theories that help to discuss previous models and factors associated with disability, such as stigma, medicalisation and sick role theory (Parson, 1951; Goffman, 1963; Conrad, 1992). After each model is discussed, I consider its relevance in interpreting understandings of ADHD in the context of Kuwait.

A significant note about the chapter structure and terminology is that as the focus of the current research is ADHD, I move between cultures as well as cultural interpretations of disability and ADHD. I start by discussing the broad understanding of disability and then narrow the focus to a discussion of ADHD classification as a mental health disorder’ and/or ‘learning difficulty’. I end with a specific discussion of ADHD. Both mental health disorders and learning difficulties are discussed in relation to ADHD, because although the condition is understood as a ‘child development disorder’ in the mental health guidance DSM-5 (American Psychiatric Association [APA], 2013), ADHD is classified as a learning difficulty under the Law of Disability No, 08 in Kuwait (Kuwait’s Constitution, 1962). (The justification of terms is presented in Section 1.6).

# 2.1 Section A: Literature on ADHD

2.1.1 Introduction

This section, debates ADHD, discussing ongoing controversies surrounding its cause, ‘diagnosis’, implications, and ‘treatments’ (Hinshaw and Scheffler, 2018). The current research does not abide by the biomedical understanding of ADHD, but uses the construction of some ideas from the biomedical model presented by parents of children with ADHD. However, for introduction purposes, this section provides a comprehensive review of the old and current research on ADHD and the main sociological and critical psychology critiques of ADHD from the biomedical perspective. Sociological and critical psychology offer different ways of understanding ADHD than the biomedical perspective. While this section addresses the sociological and critical psychology critiques to give a critical review of the biomedical studies, Section C of this chapter focuses on ADHD perspectives.

The biomedical model of disability is used in most of the current research and understanding of ADHD across the globe (Jones and Wilsdon, 2018). However, as I explained before, the understanding of ADHD from a biomedical perspective varies in cultures (Timimi, 2005). Thus, I highlight the variability in the prevalence, ‘diagnosis’ process, and ‘treatment’ options for ADHD by comparing insights from the UK, the US and Kuwait. This is because, in looking at the history of ADHD, the UK and US are the initial countries of studies of ADHD (Timimi, 2005). Moreover, this research draws on disability studies from the US and the UK, with Kuwait being the context of the present study.

## 2.1.1 Biomedical model understanding of ADHD

The biomedical model, commonly used in psychiatry, was devised in Europe and North America during the 19th century (Deacon, 2013). From the biomedical model, a ‘childhood development disorder’ is understood as a disease, and the cause is located in the brain and/or biological factors (Deacon, 2013). The biomedical model aims to explain the biological causes and to eliminate or reform impairments, understood as diseases, using pharmaceutical ‘treatments’ or rehabilitation interventions (Deacon, 2013). It is the predominant model in the US, UK, and Kuwait for psychiatry. It is scientifically underpinned by medical studies. However, these studies failed to research the personal and social circumstances of individuals with ADHD (Deacon, 2013).

A major resource of the biomedical model is the Diagnostic and Statistical Manual of Mental Disorders (DSM) (DSM, 1952, 2013), a manual that gives account of mental health diseases and ‘child development disorder’ (Deacon, 2013), which is in its fifth edition. ADHD first appeared in the second edition of the DSM in 1986 (DSM II, 1986). The biomedical model paradigm regards ADHD as a ‘childhood neurodevelopmental disorder’ that affects cognitive and behavioural aspects of the child, as well as influences academic performance and social skills (APA, 2013). Pajo and Cohen (2012) indicated that despite ADHD being considered a ‘child neurodevelopmental disorder’, the ‘diagnosis’ does not include any neurobiological criteria. ADHD is often identified through three main ‘symptoms’: inattention (lack of ability to focus), hyperactivity (excessive movement), and impulsivity (rush to action without thinking). The increasing rate of ‘diagnosis’ of ADHD globally has made ADHD the most prevalent ‘child development disorder’. Although there are several studies indicating that ADHD prevalence might increase due to its ‘diagnosis’, it is difficult to be certain whether the ‘diagnosis’ of the condition is a true reflection of its prevalence, as I illustrate below.

## 2.1.2 Inconsistence of global prevalence

According to the latest update, the APA estimates that 8.4% of children might develop ADHD 'symptoms' (APA, 2017). However, through reviewing studies of ADHD prevalence in the UK and US, the rate of prevalence of diagnosis and treatment shows inconsistencies due to differences in methodological approach; ways of classifying children and the guidance on this vary from country to country (Polanczyk et al., 2014). For example, the prevalence of diagnosis and treatment rates in the UK was 3.97% in 2019 (Russell et al., 2019). While in the US in 2016, the prevalence was estimated at 9.4% (Danielson et al., 2018). In fact, until 2019, the main classification used in the UK was ICD 10, which is more restricted than DSM5. This led to a decrease in diagnosis and treatment for children with ADHD-like behaviour (see Section 2.1.4). Despite the differences, some studies highlight the increase in prevalence in the UK and US (Zablotsky et al., 2019; Newlove-Delgado et al., 2019).

This has led to some research (for example, Polanczyk et al., 2014) questioning the validity of diagnosis and treatment prevalence in the studies. The latest meta-analysis of 135 studies from different countries worldwide asserts that there is no significant difference in the prevalence of ADHD in different countries (Polanczyk et al., 2014). Polanczyk et al. argued that the prevalence of ADHD has not changed empirically over the last three decades. They concluded that the prevalence might not reflect the number of children with ADHD, because social conditions, such as the media, the education system, pharmaceutical advertising and social policy in these countries might contribute to a rise in the diagnosis level, more than children actually meeting the ADHD criteria (Polanczyk et al., 2014). Bergey et al., (2018) added more social factors, highlighting the importance of increased awareness of the DSM and psychological theories that might point the parent and teacher to the diagnosis. Lastly, the results of the studies are often based on reports by parents with diverse ethnicities and life circumstances who might misunderstand the ‘symptoms’ in their children (Xu et al., 2018). The previous studies therefore highlight the importance of investigating the social factors that play a role in the prevalence of ADHD.

However, while the prevalence rate in the UK and US is available, there is a lack of statistical research on ADHD in Kuwait (Salem et al., 2014). Prior systematic reviews seldom included a significant proportion of studies conducted on Arab children and adolescents (Polanczyk et al., 2014). The only study found was a general study on all Middle Eastern countries, which gives the approximate prevalence of ADHD in Kuwait. I examined a recent systematic review and a meta-analysis conducted by the Gulf Cooperation Council’s (GCC) COUNDUCINE from the six GCC member states (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, and the United Arab Emirates). Across the GCC, the prevalence of ADHD estimated between 12.83% and 26.135% using methods such as the Vanderbilt ADHD Diagnostic Rating Scale (VADHDDRS), clinical judgments, the Attention Deficit Disorders Evaluation Scale (ADDES), and the Strengths and Difficulties Questionnaire (SDQ) (Chan et al., 2021). The studies offered different results from previous investigations on the prevalence of ADHD in Arab countries, such as Thome et al. (2012), who reported the prevalence to be 7%, and Alkhateeb and Alhadidi (2019), who showed the prevalence to be 1.3%. This difference might be related to using different diagnostic tools in studies in Arab countries (Alkhateeb and Alhadidi, 2019).

From the studies above, I highlighted the importance of the discussion on ADHD prevalence. However, although this research is not interested in providing the prevalence of ADHD in Kuwait, a discussion of the prevalence is essential to highlight the social circumstances that lead parents to ADHD diagnosis and treatment. It might also be important for future researchers who are interested in the prevalence of ADHD in Kuwait, to consider the social factors while exploring the prevalence of children with ADHD.

## 2.1.3 Variation in causes explanation of ADHD

The historical understanding of ADHD as a biologically cognitive dysfunction has been explained from the cognitive, biological, and neurological perspectives (Horton-Salway and Davies, 2018). However, when these perspectives fail to provide evidence for the causes of ADHD, there is typically an orientation towards environmental causes of ADHD. The review of the literature below gives a brief summary of the main research on the aetiology of ADHD, followed by a discussion of the main criticisms of the studies.

Studies of the brain have contributed to a biological explanation of the cause of ADHD, whether psychological studies that focus on tests of mental processes or neurological studies which test brain function and structure (Thome et al., 2012). Thome et al. consider ADHD to have an impact on response inhibition, intelligence, working memory and organisation in children with ADHD. ADHD is considered a neurobiological cognitive dysfunction because children with ADHD show deficits in nervous system functionality and the dopamine transmitter system, resulting in problems with attention and concentration (Maiese, 2012; Thapar et al., 2012). Neuropharmacology studies assume that there is a lack of dopaminergic receptors in the dominant noradrenergic prefrontal cortical area and subcortical area (Thome et al., 2012; Thapar et al., 2012).

Moreover, hereditary factors have stronger evidence in aetiology studies on ADHD, both in twins and adoption studies (Romadona, 2017). Demontis et al. (2019) conducted a genome study analysing the DNA of people with ADHD from Australia, Europe, China, the US and Scandinavia revealing that there are 12 genes that might pose a risk of ADHD. Thus, ADHD is considered polygenic, which indicates that the cause of the condition is a combination of many genetic variants that work to increase the risk of ADHD. These results are similar to those reported in Faraona and Larsson (2019) in the US, Australia, Europe, and Scandinavia, which asserted that ADHD is caused by different genetic variants that combine with environmental factors. The idea is that polygenicity exposes children with ADHD to the risk of developing general psychopathology and ‘psychiatric disorders’, such as autism, conduct disorders, and eating disorders (Lee et al., 2019). There is genetic overlap between ADHD and other psychiatric problems, which was illustrated by Lui et al. (2021). Fourteen genes are associated with the risk of presenting with ADHD. However, as the rate of heredity is low, it could be argued that the causes of ADHD cannot be explained by genetic factors alone, but also by the interactions between genetic and environmental factors (Romadona, 2017). These genes are assumed to interact with the environment, which makes reliance on genetic studies for ‘diagnosis’ difficult. Despite the previous review, a specific genetic cause of ADHD is still unknown (Thapar et al., 2012; Faraona et al., 2021). Thus, these studies and related genetic tests are not used for the ‘diagnosis’ of ADHD (Faraona et al., 2021).

Other studies have described the complex interactions between biological and environmental factors that contribute to the onset of ADHD (Kieling et al., 2008). Despite the fact that ADHD-associated genes might be heritable, the environment sets the genes that will appear (Swanepoel, 2020). Numerous factors have been implicated in caregiver-ascribed aetiologies for children with ADHD. Nilsen and Tulve’s (2020) meta-analysis showed that higher blood lead levels can increase the risk of ADHD. Maternal smoking was associated with a high to moderate chance of having children with ADHD. This was supported by Huang et al.’s (2021) meta-analysis, which associated smoking with a 60% chance of ADHD. Chen et al. (2019) highlighted that using medication during pregnancy might increase the risk of ADHD, while a 12-study meta-analysis (Franz et al., 2018) showed that babies with low birth weight are at risk of developing ADHD. Mother obesity also plays a role as a risk factor for developing ADHD (Jenabi et al., 2019), and low levels of family income reportedly increased the rate of ADHD (Keilow et al., 2020). Parents with lower education levels, in unemployment, and poverty are at higher risk of having children with ADHD (Keilow et al., 2020).

Others have linked the cause of ADHD with a lack of consistency between children and environmental structures, social and cultural constructions, or an evolutionary advantage (Pajo and Cohen, 2012). This reflects a failure to confirm the condition as a biomedical ‘disorder’ or ‘defect’, or its cause stemming from a biomedical model, despite being the first perspective from which ADHD is investigated (Pajo and Cohen, 2012). Most biomedical perspectives are provisional and conjectural, exposing the results to criticisms (Pajo and Cohen, 2012). For example, exposure to trauma could lead to ‘symptoms’ similar to ADHD, such as restlessness or lack of attention (Swanepoel, 2020). Another example is that children at high risk of developing ADHD might demonstrate difficult behaviour leading to the child being abused by the adults around them, leading in turn to increased ‘symptoms’ of ADHD (Swanepoel, 2020). This indicates the complexity of the environmental factors that play a role in the risk of ADHD or ‘symptoms’ similar to ADHD. It is easy to confuse some ADHD-like behaviour, which might be a product of trauma or abuse with ADHD ‘symptoms’.

Studies have shown that the insights revealed from genetic studies might make the use of neurobiological causes as models in the ‘diagnosis’ practice of ADHD very hard (Faraone et al., 2021; Hinshaw, 2018; Thapar et al., 2012). Yet, there is an increase in the global ‘diagnosis’ of ADHD, which will be discussed in the next section.

## 2.1.4 wrangle around the subjectivity of diagnosis

While the diagnostic criteria for ADHD have developed to be less restricting overtime, testing and evaluation procedures have remained fairly consistent (Anastasiadis, 2021). However, the current processes for diagnosing the ‘symptoms’ of ADHD are varied and complicated, reflecting the ambiguous construction of ADHD globally (Bergey et al., 2018).

In general, two tools are used to diagnose ADHD: the DSM-5 and the International Statistical Classification of Diseases and Related Health Problems (ICD-11). ADHD is identified through the persistence and inappropriate rate of three main ‘symptoms’ of hyperactivity, impulsivity and inattention which hinder a child’s ability to function in social and educational environments (APA, 2013). To support an ADHD ‘diagnosis’, these behaviours need to persist for at least 6 months (APA, 2013). The difference between the two tools is the criteria they require to make the ‘diagnosis’. In the DSM-5, six or more ‘symptoms’ must be observed in different settings (APA, 2013), while ICD-11 has a very restrictive requirement of high pervasiveness of the ‘symptoms’ in different settings (NICE, 2021). These differences affect the rate of ‘diagnosis’ of children with ADHD. For example, according to the National Institute for Health and Care Excellence (NICE), which is based in the UK, the estimated prevalence of children diagnosed with ADHD using ICD-10 is 1–2%; with DSM-5, it is 3–9%. These differences are due, in part, to the way these tools are applied. An ADHD ‘diagnosis’ is often made in conjunction with other tests that show the impact of ADHD ‘symptoms’ on specific functions.

Published in 2019, the ICD-11 is a revised version of this classification system. The new criteria classify ADHD and the rules for ‘diagnosis’ are less strict than they were in previous versions. For example, in previous versions of the ICD-10, the age of the onset of ADHD was before 6 years; in the ICD-11, exact age is no longer a determining factor; rather, the onset of ‘symptoms’ should occur within the early child development period to mid-childhood (ICD, 2019). The DSM-5 has also been modified. The age at the onset of ADHD ‘symptoms’ was 7, but in the new version it is any point before the age of 12 (APA, 2013). In the new classification system, the change in the age criteria for ‘diagnosis’ includes combining the ‘symptoms’ and the impairment and rating them as mild, moderate or severe (ICD, 2019).

In the UK, the ‘diagnosis’ follows the NICE guidelines (NICE, 2021). ADHD is assessed using either the ICD-11 or DSM-5 classification systems (Bowling and Nettleton, 2020). The assessment also includes other clinical and development tests as well as reports from parents and schools (Bowling and Nettleton, 2020). In the US, the diagnostic evaluation of ADHD is based on the DSM-5 criteria. This involves several appointments with parents to collect parental, child development, family and home environment data (Belanger et al., 2018). In addition, academic reports on the child, standardised behaviour rating scale data, physical examinations and history, medical examinations and reports from the parents concerning the child’s behaviours are collected (Belanger et al., 2018). In the Kuwaiti context, the method of ‘diagnosis’ follows the same guidelines and tests that are stipulated in the US.

In Kuwait, the ‘diagnosis’ of ADHD requires the use of the DSM-5 classification system, with the appearance of six of the nine criteria related to the child’s behaviours, as well as continuous observation of those behaviours of up to 6 months in different contexts (Shaaban, 2017). Moreover, the ADHD ‘symptoms’ must appear before the age of 7 and they must not be linked to any other cognitive or developmental ‘disorders’ (Shaaban, 2017). The ‘diagnosis’ process consists of a list of tests and reports, such as the clinical history of the child, personal interviews with the parents, IQ tests, physical assessments, achievement tests (including school reports and standardised academic tests), DSM-5 criteria and the test of variables of attention [TOVA] (Shaaban, 2017).

Rydell et al. (2018) found that the ‘diagnosis’ of ADHD is increasing globally; however, as previously noted, the ‘diagnosis’ might not be a ''real'' indicator of the prevalence of ADHD. The literature on ADHD demonstrates many reasons for the increase in the ‘diagnosis’ of this condition. One reason is the increased awareness and knowledge about ADHD among professionals and laypeople (Rydell et al., 2018). Another reason is an increase in expectations to engage in everyday social activities; the failure to fulfil those expectations is often interpreted to be due to the presence of neuropsychiatric issues. Layton et al. (2018) found that the increase in the number of ADHD diagnoses might be related to a child’s behaviour in school. Layton et al. (2018) argued that children might develop inappropriate behaviour in kindergarten and younger children, especially, might be viewed as demonstrating deviant behaviour in a school classroom. As discussed above, the ‘diagnosis’ depends on considering not just the ‘symptoms’ of ADHD, but how the symptoms impair the life of the child, such as lack of management skills or procrastination. However, not all countries consider the impact of impairment in the ‘diagnosis’ (Rydell et al., 2018). This might increase the prevalence of ‘diagnosis’ rate that the studies report due to not considering impairment. Research on teachers’ experience shows that they are more likely to rate children that underachieve as having ADHD because they are aware of the ADHD and the while they are less likely to acknowledge children with a high level of achievement who also happen to have ADHD (Metzger and Hamilton, 2020)

Chaaya and ElKoury (2019) reported that ADHD often being misdiagnosed, over-diagnosed or over-treated. Not every child who is active has ADHD; that behaviour might have a physiological basis. For example, Chaaya and ElKoury (2019) noted that fatigue and stress may trigger changes in behaviour and attention levels that might look similar to ADHD ‘symptoms’. Furthermore, the stress experienced by children in families with disadvantaged circumstances, such as divorce, illness or death, or those who face pressure in school could lead to inattention or behavioural problems (Swanepoel, 2021). Thus, the reasons for the behaviour of a child showing ‘symptoms’ that are similar to ADHD could be due to biological or neurological factors. The danger is that a professional misdiagnosis might lead to prescribing medication instead of investigating the psychological causes that trigger the child’s behaviour. However, not all countries use medication as the first line ‘treatment’; for example, in France, professionals search for the psychological causes of a child’s behaviour before determining the ‘treatment’ (Edward et al., 2012). The criticism related to the ‘diagnosis’ increases doubt over the use of medication as an intervention for children with ADHD. This will be addressed in the next section.

## 2.1.5 Controversy around treatment options

Various medical and non-medical interventions are used for the rehabilitation and ‘treatment’ of children with ADHD despite ongoing debates about its causes and the challenges of ‘diagnosis’ (Antshel et al., 2011). According to Hallowell and Ratey (2021), 34 types of medication are used to treat ADHD. Faraone et al. (2021) noted that the most popular medications for children with ADHD are stimulants (methylphenidate and amphetamine) or non-stimulants (atomoxetine, guanfacine and clonidine). Cortese et al. (2018) conducted a meta-analysis of 36 studies on the 12-month efficiency of using medication for treating ADHD youth; while atomoxetine might have a more positive outcome, methylphenidate has fewer side effects. Pharmaceutical interventions are the most popular among parents and health organisations and are most often included in social policies (Fridman et al., 2017; Edward et al., 2012; Ruiz-Goikoetxea et al., 2018). Psychostimulants, such as methylphenidate, are the medications that are most often used to treat ADHD globally (including in the UK and Kuwait). While, in the US, amphetamine is most commonly used for children with ADHD (Sá et al., 2020).

As previously mentioned, neurobiological studies illustrate that the cause of ADHD is dysfunction in the prefrontal cortex area of the brain (Schmitz et al., 2019). The prefrontal cortex is responsible for attention regulation, working memory and hyperactivity (Schmitz et al., 2019). It has also been argued that the prefrontal cortex and other parts of the brain of children with ADHD lack secretion of norepinephrine and dopamine, which cause the ‘symptoms’ of ADHD (Hallowell and Ratey, 2021). The use of medication aims to increase the levels of dopamine and norepinephrine, as they are neurotransmitters that regulate activity in the brain. It is assumed that the defect in the secretion of the neurotransmitters causes the ‘symptoms’ of ADHD (Hallowell and Ratey, 2021). Stimulating the neurotransmitters to transfer information in the brain decreases the need to move and increases the ability of the person to pay attention (Hallowell and Ratey, 2021). However, Chaaya and ElKoury (2019) reported that the response to medication differs between children with ADHD. Until now, there is no clear evidence for the reason behind the different reactions.

The efficiency and safety of the medication has been reported in many studies and the side effects of psychostimulants are undeniable (Sá et al., 2020). A non-systematic review of 106 studies noted that the side effects of this medication are decreased appetite, weight reduction, insomnia, somnolence, headache and rebound irritability, which is usually assumed to be temporary and mild (Sá et al., 2020). Hinshaw and Scheffler (2018) reported that there are inherent problems in studies that investigate a pharmaceutical intervention, as there are various selection biases. Moreover, medication might not be effective for the long-term ‘treatment’ of ADHD (Bergey et al., 2018).

Psychological interventions are another intervention designed to moderate or prevent behaviours considered to be ‘unaccepted’. ‘Treatment’ may include cognitive behavioural therapy (CBT) and parenting classes to manage so-called ADHD behaviours (Davies, 2018; Antshel et al., 2011). Sonuga-Barke et al. (2013) conducted a meta-analysis of studies published in peer-reviewed journals focusing on non-medical interventions for children between the ages of 3 and 18 with an ADHD ‘diagnosis’. They found that cognitive psychological intervention provided the most effective support for youth with ADHD ‘symptoms’. CBT entails the application of specific cognitive and behavioural therapy strategies including memory training, speech therapy and family therapy for the ‘treatment’ of a variety of psychological illnesses (Dobrakowski and Lebecka, 2020).

Psychoeducational interventions aim to educate children and their parents about ADHD by providing them with support, information and coping strategies (Rafalovich, 2001). Dahl et al. (2019) conducted a systematic review and found that psychoeducation has positive outcomes; it improves the ‘symptoms’ and behavioural problems associated with ADHD. However, psychoeducation is typically used with medical interventions (Rafalovich, 2001). The type of psychoeducational intervention varies according to the child’s age. An intervention often focuses on improving the child’s social behaviour and occupational skills. Some interventions include the parents, training them to interact with and discipline the child; other interventions also include the teachers to improve the child’s behaviour in school (Anastasiadis, 2021).

The effectiveness of alternative/complementary interventions for children with ADHD is still under debate. These types of interventions, such as dietary changes, can also reduce the ‘symptoms’ of ADHD (Heilskov Rytter et al., 2015). They consist of either the consumption of specific dietary supplements (such as fish oil, vitamins, and/or mineral supplements) or the reduction or elimination of certain foods in the diet (such as sugar and artificial sweeteners) (Heilskov Rytter et al., 2015). Alternative/complementary approaches have not yet been approved by the US Food and Drug Administration (FDA), because some research results have shown no significance when testing the effectiveness of these interventions (Sonuga-Barke et al., 2013). A recent meta-analysis of 16 studies (Chang et al., 2018) showed the Omega-3 fatty acid supplement resulted in a moderate improvement in ADHD ‘symptoms’.

However, what is confusing is that most of the studies focused on ADHD ‘symptoms’, even though ADHD might impact the life of the family in many ways. Thus, while it might be true that reducing the ‘symptoms’ will decrease the behaviour and problems associated with ADHD, what if the main problem for parents is the impact of a ADHD ‘diagnosis’ or the children's different behaviour that is seen as deviant, and not the ‘symptoms’?

## 2.1.6 ADHD implications: psychological perspective

ADHD is defined as a ‘childhood disorder’ because the influence of ADHD on the lives of children and their families is mainly studied from a psychological perspective which depends on psychological child development theories (Burman, 2016). The theory of psychological development provides a basis for understanding the behavioural, social and emotional development of a child, and any failure to conform to the norm is considered a ‘disorder’ (Burman, 2016). It is argued that ADHD is associated with a range of negative outcomes in both school and family contexts.

Although some children with ADHD have high IQ scores, they may have poor academic records as they generally pay less attention in class, as reported by teachers and parents (Garner et al., 2013; Fleming et al., 2017; Mayes et al., 2020; Rommelse et al., 2017). Moreover, Garner et al. (2013) reported that teachers and parents stated that the ‘symptoms’ of ADHD lead directly to academic difficulties in writing, reading and mathematics. The researchers suggested that inattention is associated with difficulties in academic functioning, unlike hyperactivity and impulsivity, which are associated with disruptive behaviours which prevent a student with ADHD from concentrating in the classroom (Garner et al., 2013). The latest meta-analysis of six studies of children’s performance in school shows that children with ADHD tend to underachieve at school and have poor communication skills without an intervention compared to children with ADHD with an intervention (McDougal et al., 2022). The meta-analysis conducted by McDougal et al. supports the evidence reported in previous studies on the difficulties children with ADHD encounter in academia in comparison to children without ADHD (Arnold et al., 2020; Dupaul et al., 2016). However, in Garner et al. (2013), although the children with ADHD generally had difficulties with academic performance, only inattention was related to poor academic achievement, while hyperactivity and impulsivity were associated with behavioural difficulties that could affect the children’s academic performance. Thus, the impact of ADHD impairment in children with ADHD might differ based on the child’s ‘symptoms’.

Behaviours associated with ADHD also affect the children’s friendships. Psychological studies have focused on social behaviours in children with ADHD. Mikami (2010) studied the relationships that children with ADHD have with their peers and found that they have difficulties in making and keeping friends. Similarly, Peasgood et al. (2016) found that children with ADHD had poor relationships with their siblings. The findings of these studies are supported by a recent meta-analysis of 16 studies showing that children with ADHD encounter difficulty socialising and in recognising the socialisation signs, which make it difficult for them to make friends (Sibley et al., 2019).

ADHD not only impacts the children until adulthood (Hinshaw and Scheffler, 2018), but the children's behaviour may also affect the parents. Barkley (2005) reported that ADHD behaviour affects children’s lives in different social contexts, particularly within the family (Barkley, 2005). This is because parents are responsible for identifying and managing the behaviour of their children (James and Prout, 2006). The familial environment and lifestyle possibly influence the development of ‘symptoms’ associated with ADHD in children (Weissenberger et al., 2017). Kashdan et al. (2004) found that parents of children with ADHD tended to describe their home environment as stressful and lacking support. Indeed, the irritating and unpredictable behaviours of children with ADHD may disturb the parents’ relationships and increase marital problems (Cussen et al., 2012). A recent meta-analysis (Dey et al., 2019) reviewed 17 studies and found that parents of children with ADHD had a lower quality of life than parents of children without ADHD.

Social psychological studies on parents’ experience of children with ADHD show that ADHD is associated with stigma and derision. The public stigma faced by parents and children is linked to the negative stereotype of ADHD being associated with bad parenting. While labelling ADHD as a biological or brain-related condition could decrease the stigma associated with it (Bergey et al., 2018), labelling or medicating the child might cause the parents to be blamed, resulting in stigma (Ghost et al., 2016). Thus, it is not surprising that psychological studies on parents’ experience of parenting a child with ADHD show that parents often expressed feelings of depression and anxiety (e.g Cussen et al., 2012; Muñoz-Silva et al., 2017; Propper et al., 2021).

## 2.1.7 Summary

This section introduced the definition of ADHD, providing a background from the associated literature. It presented ADHD from the dominant and well-known biomedical perspective. ADHD is understood as a ‘developmental disorder’ that negatively affects a child’s academic and social skills. There is no consensus in the global literature about the causes of ADHD, due to its varying global prevalence, ‘diagnosis’ processes and ‘treatment’ options. These differences were highlighted by discussing its variation in different countries such as the US, UK and Kuwait. The following section explores disability and ADHD in Kuwait concerning the context and culture in that country.

# 2.2 Section B: The Kuwaiti Context

Introduction

This section introduces the Kuwaiti perspective regarding disability and ADHD. The first part presents background information about Kuwait, including geographical, political, and economic aspects. The second part discusses disability, childhood, and parenthood from the perspective of Kuwaiti culture. After setting the groundwork of this section, I discuss the impact of these aspects on the social policy on disability and people with learning difficulties (ADHD). I also review the impact that Kuwaiti culture has on disability and ADHD studies and establish the rationale for the research.

## 2.2.2 General information about Kuwait

Kuwait, a small Arab country in the Middle East, is located in the Persian Gulf between Saudi Arabia and Iraq. Its capital is Kuwait City where most people reside. The population of Kuwait is 4.3 million, of which only a third are Kuwaitis, with the rest comprising foreign nationals (Kuwait population, 2021). Disability and learning difficulties are the focuses of ADHD research in Kuwait. The population of people with a disability in Kuwait is around 45,547 (PADA, 2021), including 5,735 with a learning difficulty (PADA, 2021); however, no detailed statistics show the number of people with ADHD in Kuwait (Alqabas, 2021).

## 2.2.3 Economic system in Kuwait

The economy of Kuwait boomed due to oil exports (Kuwait Ministry of Oil, 2019). Indeed, the Kuwait state heavily relies on the oil sector. For instance, it comprised 89% of Kuwait’s total export revenue in 2019–2020 (Reuters, 2020).

Until recently, the economic system in Kuwait was based on moderate socialism, which respects individual ownership as long as it supports social and public initiatives that develop Kuwait’s economy (Altaqadomia, 2018; Al Sabah, 2011). In addition, Articles 11, 13, 25, 40, 41 and 48 of Kuwait’s constitution stipulate that unlike pure capitalism the State is responsible for providing Kuwaiti citizens with many privileges, such as free education and health care, as well as subsidies to support marriage expenses and child welfare (Kuwait's Constitution, 1962). This suggests that the economic system is moderately socialist - between extreme socialist and capitalist (Altaqadomia, 2018).

However, with increased oil production and participation in the capitalist global market, Kuwait experienced both positive and negative effects. On one hand, globalisation increased Kuwait’s ability to enjoy better access to goods and capital, but on the other hand it became more vulnerable to global and financial shocks and crises. The drop in the world oil price during the mid-2010s created a budget deficit of 5.64 billion dinars (18.44 billion USD); thus creating problems for the rentier state, defined as a state where the government is the primary economic support (Alarab, 2020).

The relative prosperity of the economy and welfare system also affects the lives of people with disabilities. People with disabilities in Kuwait enjoy the same rights and privileges as non-disabled people because of their disability. Although until now, rights and privileges have been given to people with a disability, consideration of the impact of the Kuwait economic crisis on people with a disability is important. This is because the economic crisis might lead to a reduction in financial support for people with a disability. How this economic challenge impacts the lives of people with disabilities is discussed more in the next section.

## 2.2.4 Political system in Kuwait

Kuwait witnessed political development after it became independent from Britain in 1961 (Al Sabah, 2011). The Emir Abdallah Al-Salem established Kuwait’s constitution, which is the fundamental basis underpinning the political and economic system in Kuwait (Al Sabah, 2011). The constitution is based on Sharia law (Islamic teaching) (Al Sabah, 2011), which guides the political system.

The constitution of Kuwait characterises the political system in Kuwait as a cooperative system in which there is a separation of three powers (Article 50 of the Kuwaiti constitution). The three powers comprise the legislative, executive, and the judiciary (Articles 51, 52, and 53). Legislative power is held by the Emir (who descends from the Mubarak Al-Sabah family). The executive power is held by the National Assembly shared by the Emir, the cabinet and ministers, and the courts hold the judicial power. This means that the Emir has ultimate power over the country. Indeed, the Emir can enact any law or legislation (Al Sabah, 2011, Article 4).

The political system is characterised as partially democratic (Article 6), as evidenced by the establishment of the elected National Assembly in the 1960s. As the National Assembly is considered the main way of representing the voices of citizens in the government, political parties are not allowed (Article 44). In the past, Kuwait witnessed political change; however, none of the changes were related to citizens with disabilities. Most political change was initiated by business owners (due to the rise in taxes after the discovery of oil) demanding the right to participate in political decision making (Alshammari, 2019).

In the next section, a brief background to the Kuwaiti context of disability and ADHD is introduced, starting with the economic and political aspects. I then continue mapping the Kuwaiti context by discussing Kuwait’s culture and perceptions of ADHD.

## 2.2.5 Culture of Kuwait

The attitudes of Kuwaiti people towards children, parents and disability, as affected by policies, is described below. The reason for not directly describing attitudes towards ADHD is that it is still a new concept in Kuwait and included within general disability studies. Therefore, I have decided to discuss disability in general (Al-Qimlass, 2015). Moreover, a discussion of the concepts of childhood and parenthood is important, because the study focuses on children with ADHD. Parenthood and childhood are linked: the role of parents is linked to the achievement of childhood expectations (as they may be blamed for not meeting such expectations). Also, the study focuses on the parents' perspective. Therefore, mentioning these concepts gives the cultural background to the parents' perspective on ADHD.

Culture is defined as a “a particular way of life, which expresses certain meanings and values not only in art and learning but also in institutions and ordinary behaviour” (Williams, 2001, p:57). The discussion of ADHD in Kuwaiti culture is a broad one, as the aim of this research is to explore Kuwaiti parents' perspectives on ADHD in order to fill gaps in the ADHD research in Kuwait. Research on ADHD in Kuwait and other Arab countries is scarce (see Section 2.2.6). Hence, discussing ADHD in depth is difficult because there is no foundation to build on and so a broad discussion of disability is a way to understand the complexity of parental perspectives and stories in Kuwait. Before discussing Kuwaiti culture, I give a definition and explanation of some of the terms used below.

Kuwait is considered an Arab and Islamic country (Articles 2 and 3 Constitution of Kuwait). The term Arab is used to describe the native people in 22 countries, from the Atlantic coast to the Arabian Gulf (Hammad et al., 1999). This classification is related to the Arabic Language used in these countries, as well as shared values and beliefs that build and unify the Arab identity (Hammad et al., 1999).

The term Islam refers to a religion that worships a God named Allah and Islam means submission to Allah and peace (Hammad et al., 1999). It considers the Prophet Muhammad as the last messenger of God’s universal laws (Hammad et al., 1999). Islamic teachings come from a book called the Qur'an (Koran) which is considered a guide for Muslims’ actions. As the Qur'an is believed to be divinely revealed by God, its teachings are considered absolute and unchangeable by time or people. The Qur'an provides a system for all aspects of life (Hammad et al., 1999). Muslims take Islamic injunctions from the Qur’an and the Sunnah which mean the actions of the Prophet Muhammad (Al-Aoufi et al., 2012).

While Arab countries have some culture and language in common, the culture is not static (Al-Aoufi et al., 2012). Indeed, Arab countries differ economically, socially, politically and geographically (Al Khateeb, Al Hadidi and Al Khatib, 2015). Moreover, both Arab culture and Islamic teaching seem to be similar between countries, although their understanding of culture and Islamic teaching differs. This creates an overlap of two perspectives within the Kuwaiti context. The culture in any country, including Kuwait, includes many elements such as language, religion, customs and media. The focus of the current research is on religion and customs, with an interest in the language related to Islam and Arab culture. The relationship between Arab culture and the Islamic religion is complicated, because they share the Arabic language (Al-Qaradawi, 2009; Turmusani, 1999). Some words and values Arabic countries use might be traditional, but they are thought to be Islamic teachings and vice versa. This makes it difficult to recognise the sources from which Muslims draw their behaviour and thinking, whether it is Islamic teachings or Arab culture and customs. This might be explained through the use of a language that is shared by two elements of the culture. Language can be a tool for describing and a source of meaning (Al-Amer et al., 2016) (see Chapter 4). While all Arab countries use language to express themselves, interpretation varies between countries because culture involves a person’s awareness of himself/herself and his/her surroundings (Williams, 1961). In looking at the history of Islam, Arab culture is older than the religion and so religion is part of culture. Religion cannot be explained without culture and its tools. The relationships between culture and religion involves the Qur'an, the Sunnah, consensus and analogy. While Muslims believe that only the Qur'an was sent from God, the Sunnah, consensus and analogy depend on the interpretations of a religious leader (Imam) which are controlled by human abilities such as memory and comprehension. Even the Qur'an, which Muslims believe was sent by God, is associated with people’s interpretation, legislation, political authority and education. This is because the Qur'an is the word of God in the traditional Arabic language and the language is tough to interpret, which makes the language involve many interpretations. Thus, different political, social and economic circumstances in different Arab countries lead to different interpretations of Islamic teaching and Arab customs.

Therefore, it is important to distinguish the difference between Arab culture and the Islamic perspective. I discuss Arab and Islamic understanding in general before illustrating the differences in Kuwaiti culture by discussing the impact of globalisation in Kuwait to illustrate the impact of economic, political, and geographical factors.

### 2.2.5.1 Disability from Arab and Islamic perspectives

From the Islamic perspective, the Qur'an does not use the terms ‘disability’ or ‘impairment’ to refer to people with disability. Instead, the term *"disadvantaged people"* in the Qur'an is believed to indicate people with disability (Al-Aoufi, Al-Zyoud and Shahminan, 2012; p.207). This is because disability is considered "a natural part of human nature'' and disadvantages are a social responsibility (Al-Aoufi et al., 2012; p.206). Islamic teaching emphasises that people should care for each other, while insisting that more care be given to disadvantaged people to help them improve their lives (Al-Aoufi et al., 2012).

From the perspective of Arabic culture, ‘disability’ in the Arabic language means ‘different to the norm’ (Hagrass, 2005). It refers to biological limitations (mental or physical) that make a person with disability ‘abnormal’ (Hagrass, 2005). The Arabic language is characterised by its thoroughness in explaining the human state. The Arabic language uses different words to indicate and describe an impairment, but the words are merely descriptive and have no negative connotations attached to them (Al-Thakeb, 1985). The negative connotation is constructed from the cultural meaning attached to the term and the stigma inferred from these terms.

Beliefs about disability are shared between Arab values and Islamic teaching. I explain each one alone, then discuss the implications of both for disability understanding in practice. Muslims believe in two concepts related to disability: *qadar* meaning ‘the justice of God’ and 'reward and punishment', which is based on the idea that our actions have consequences in the afterlife (Al-Thakeb,1985). These two concepts impact the understanding of impairment. An impairment is an act of God and the qadar of the individual, so we should accept it (Al-Thakeb, 1985). This acceptance is based on the belief that no human being is perfect, and that God may take one thing, but recompense a person with other blessings. This impacts the attitude of Muslims towards impairment, making them pragmatic, so that they might accept an impairment, but at the same time work to improve their lives (Hammad et al., 1999).

In terms of the second concept (reward and punishment), Islamic teaching commands people to be kind and to care for people with disability or impairment; violating Islamic principles and teachings about people with a disability or impairment will have bad consequences in this life and the afterlife (Al-Thakeb, 1985). By contrast, the Qur'an declares that both people with disadvantages and those who care for them will be rewarded in the afterlife (Al-Thakeb , 1985).

In Arab culture, the understanding of impairment is linked to concepts of 'honour' and 'shame'. These concepts develop from the nature of Arab society which is a collective society that places great emphasis on reputation and social standing (Hammad et al., 1999). Arab families are very sensitive to societal opinion and criticisms that might impact on or dishonour the family name (Gharaibeh, 2009). Indeed, the actions of one member of the family might impact the whole family and bring them dishonour or shame (Hammad et al., 1999). The honour of the family depends on social status that is known traditionally through generations. Impairment is seen as abnormal, because it differs from the social norm, so it might decrease the social standing of the family (Gharaibeh, 2009). Impairment is viewed as a threat to the family reputation in a society that asserts and values conformity and individual duties towards the family and the community (Hammad et al., 1999).

Attitudes towards people with disabilities and their families vary because they combine both perspectives to different degrees. Arab people might follow the moral and religious perspective; people might think impairment is a blessing and that the difficulty that comes with it is a message from God testing their faith (Bazna and Hatab, 2005). The stronger the faith, the more tolerant a person becomes towards people with disabilities (Turmusani, 1999). People just accept people with disability and take good care of them (Al-Aoufi et al., 2012).

Others might hide and refuse to admit the impairment because they fear social opinion and stigma in their community (Al-Thakeb, 1985). Although Arab people might feel guilt and pity because of these actions, the fear leads them to keep people with disability separate from society and sometimes even to refuse any support that might mitigate their social inclusion (Turmusani, 1999). This is because impairment in the family might be seen as a sign of an hereditary defect, which might impact their social standing and acceptance, especially when finding a suitable partner for marriage (Al-Thakeb, 1985). To some extent, some parents might blame the child or themselves for the negative attitude from society because of the impairment (Gharaibeh, 2009).

Among the two above parent groups, some parents remained confused and puzzled about their children’s disability and were also afraid of society having a negative reaction towards their children. They might try to avoid stigma by situating their child’s disability within a religious discourse. The view of Islamic studies on disability and stigma provides a good example. Hasnain et al. (2008) illustrated that some Muslim parents might interpret disability as part of God’s plan, and consider that they should be patient and compliant towards children with a disability. Other parents might interpret their child’s disability as a punishment from God for their own sins (Hadidi, 1998). Islamic belief protects parents from stigma and supports them with the emotional burden caused by their confusion and bewilderment due to their child’s ‘diagnosis’ (Al-Aoufi et al., 2012).

From the discussion above, I conclude that the definitions do not appear to distinguish between impairment and disability. These terms reflect the social model (see Section 2.3.2.1). In social oppression theory (Hagrass, 2005), impairment and disability are treated as if they were the same concept. Although the Islamic perspective is closer to the social model than the Arab perspective, evidence of the social model's influence on practice is scarce (Hagrass, 2005). The dominant model is an individual, medical and charity model in which people with a disability are objectified, based on their biological impairment, as well as being seen as needing help. However, I agree with the observation of Hagrass (2005) about the different meanings of charity in Arabic society. Charity can be seen as bad in UK and US disability studies, because it can negatively portray people with a disability as victims who are dependent and in need of help; whereas in Arab societies, charity is seen as the moral and religious right of people with disabilities. This is because *zakat* (charity) in Islamic teaching is considered one of the obligations that a Muslim has to the society they live in, for example, providing job opportunities so that disadvantaged people can thrive (Bhatty et al., 2009).

In addition, disability is linked in Arab society with the visibility of an impairment. Arabs may not admit or believe that people with either an impairment that cannot be seen or a learning difficulty are disabled (Turmusani, 1999). Thus, people with unseen impairments may not encounter public stigma, and the nature of their impairment may prevent them from being seen as legitimately disabled and from qualifying for government support and services (Turmusani, 1999) (see Section 2.3.2.1).

### 2.2.5.2 Parenthood from Arab and Islamic perspectives

Arab culture is family-oriented (Hammad et al., 1999). It is believed that establishing a family through marriage and parenthood is necessary, because it increases the social status and respect for the individual (al-Zubair, 2006). In addition, parenting in Muslim societies is a way of thanking God for children, who are considered a blessing. Muslims believe that parenting a child is *amanah* (trust) that God will bless the parents with the ability to raise the child in an appropriate way to be a good Muslim and useful member of society (Hamzah, 2019).

Parenting from the Arabic perspective is providing for all of the child’s wellbeing needs, including their educational and economic needs. It is not only the responsibility of the parents, but all family members, to support and collaborate during the process of raising a child (Hammad et al., 1999). Although the Islamic perspective is closer to the social model than the Arab perspective, again evidence of the social model's influence on practice is scarce (Hagrass, 2005). The value of ideology, belonging and family reputation is necessary to influence the parental and community actions (El-Haddad, 2003).

From the Islamic perspective, *tarbiyah* is a system of parenting which develops the child directly through behavioural, verbal, and visual means, or indirectly through being a role model for the child (Hamzah, 2019). Although the system focuses on increasing *taqwa* (God’s recognition), it also comprehensively addresses all aspects of the child’s character, including the physical, cognitive, social, moral, and spiritual components (Hamzah, 2019). In Arab culture, the parenting concept values social behaviours. The system of parenting is called *adab*, which is the expectation of social behaviours from the child to the family and society (Hammad et al., 1999). Specifically, parents are expected to teach their children to obey them and to respect older people in the extended family. Indeed, obedience and respectful behaviour continues throughout one’s life and in all matters of life (Hammad et al., 1999).

In terms of the parent’s role from an Islamic perspective, the mother’s responsibility includes providing for a child’s biological needs and educating it with the basic skills to become independent (Qarami, 2007). The father is responsible for teaching Islamic values and being a role model for the children (Qarami, 2007). In Arab culture, the role of the mother centres on household tasks, such as nurturing the child and helping it with academic studies. Meanwhile, the father is responsible for meeting the economic needs of the household and protecting his family (Dwairy, 2010). This places greater responsibility on the mother for the child’s behaviour when it does not conform to the expectations and normative behaviours of society (Dwairy, 2010). However, according to family law based on Islamic Shariah jurisprudence (theory of law), the father is the child’s legal guardian (Awadi, 2006).

Despite parents and the family being emotionally supportive, parents tend to be more authoritarian towards a child with a disability (Dwairy, 2004b, Hammad et al., 1999). Authoritarian socialisation has a different meaning in Arab society than in the West; it is seen as a social duty of parents (Dwairy et al., 2006). Hamzah’s (2019) observation might explain the previous results. He argues that Islamic teaching advocates for mediation in parenting between hardness and softness while considering the child’s right to freedom. This is because the parent is responsible for the child’s choices when they are young, as they often do not recognise right from wrong, but as the child grows, they are given more freedom. However, it seems that this differs for children with disabilities from the parents' perspective. The perspective of disability impacts parents’ rearing behaviour, so that parents continue to limit the freedom of a child with a disability (Hamzah, 2019).

### 2.2.5.3 Childhood from Arab and Islamic perspectives

The history of ADHD in Kuwait is discussed below in Section 2.3.1.6, the Individual Model in Kuwait. From the psychological perspective, ADHD is considered deviant from normal behaviour in Kuwait; however, the evaluation of deviant and normal perspectives differs in Arab culture from Western psychological theory (Timimi, 2010). Therefore, to understand the way ADHD is seen as different from the norm of Kuwaiti culture, it is important to discuss the assets of Kuwaiti culture that represent the Arabic and Islamic perspective on childhood.

The child is characterised by the Qur’an using two concepts. First, the Qur’an uses the term *heba* (gift) to describe children. Islamic teaching advocates for (and trusts) parents to appreciate and nurture this gift with Islamic principles (Hamzah, 2019). Second, the Qur’an also uses the concept of *fitra* (purity and innocence). Children are assumed to have *fitra* which leads to the awareness of God as a single entity. However, the parental and social environment impacts their actions. These two concepts emphasise the parents’ responsibility for a child’s behaviour.

Children are considered one of the main motivations for marriage (Hammad et al., 1999). Traditionally, parents have preferred to have a lot children, as they prefer sons to daughters and want at least one son in the family (Hammad et al., 1999), although Islamic teachings do not differentiate between girls and boys in their right to their parents’ love, protection and care (Kabir and az-Zubair, 2006). Sons are more valued in Arab society because they maintain the name of the family and provide social and economic insurance (Hammad et al., 1999).

As the key values are honour and shame, the behaviour of the child is often judged according to these values. Indeed, the child is expected to behave in a way that honours their family because the family’s social image and reputation depend on the child’s behaviour (Timimi, 2006). In Arab culture, children are understood to be part of one large entity and are an important link between generations within the extended family unit. Children receive an identity, discipline, and role model(s) as well as emotional, economic, and social support from the family at all stages, in return for the conformity and loyalty of the family in all aspects of life (Timimi, 2006).

While disability in Arab society is still seen as equivalent to impairment, this might deviate from the expectation of childhood in Arab society. Children with disabilities might be seen as unable to fulfil their role in supporting the family socially and economically. Therefore, according to the Arabic perspective, the inability of the child to behave according to the social norm brings shame on the family.

### 2.2.5.4 Impact of globalisation on Kuwaiti culture

In this section, I continue discussing the complexity of ADHD within Kuwaiti culture. Kuwaiti culture is not only underpinned by the Arabic and Islamic perspective, but is also impacted by globalisation. Timimi (2005) argues that differences in the understanding of childhood and disability not only appear between cultures historically, but also within a culture. Discussing globalisation is useful in order to understand historical changes to values occurring in the Kuwaiti context.

Globalisation refers to the process of increased communication and integration between countries and people without concern about borders (Wani, 2011). Cultural globalisation is one aspect of the process of removing differences between cultures and beliefs in order to create a global system of uniform culture and values. Media, the internet, technology and travel are tools that have introduced and increased globalisation (Al-Ammari and Romanowski, 2016). The main issue with cultural globalisation is that new values can challenge, threaten, and replace older traditional values (Al-Hadad, 2003). These changes impact various cultural values and sometimes colonise them (Wani, 2011).

In discussing changes associated with globalisation in Kuwait, the discovery of oil led to radical changes in Kuwait because of rapid economic development. Consequently, Kuwait joined the international capital market (Al-Haddad, 2003). Economic changes impact social, political and cultural aspects of a society to create a society with a neoliberal and capitalist character (Singer et al., 2014; Wani, 2011). These changes, seen in the economic and political system in Kuwait, led to rapid changes in individual behaviour, such as those related to lifestyle and perspectives on the family. In line with the focus of the research, I now discuss the impact of globalisation on the family, children and disability.

Globalisation has pervaded Kuwait’s social ideology, especially when it comes to the family (Al-Ammari and Romanowski, 2016). This has led to new personal interests and independence values, changing the traditional family structure and relationships (El-Haddad, 2003). The nuclear family, which includes a father, mother and their children, is now the most common family structure in Kuwaiti society, in line with the West, but the social traditions and habits of Arab culture have preserved strong connections with the extended family, such as grandparents, aunts, uncles and grandchildren (Al-Thakeb, 1985). The extended families of both parents remain in continuous contact with the nuclear family. Although the extended family may live in different houses, the nuclear family’s social interaction with them is conducted regularly, often daily. Therefore, there are strong bonds with the extended family, whose members provide economic, social and emotional support to the nuclear family and in particular help with bringing up the children (Hegazy, 2015).

Globalisation has also affected the role of the parents, and especially the mother, as women have started to take on the role of working outside the home. This has helped wives to contribute financially alongside their husbands, which has in turn transformed the relationship between the father and mother into a partnership (El-Haddad, 2003). Current Kuwait social policies and economic rights support the opportunity for women to be educated and be part of the labour force (Maktabi, 2016). However, these Kuwaiti regimes are conservative, in the sense that they equip women with certain resources and advantages, but the traditional views about her role within society are still a challenge that women encounter (Maktabi, 2016). The political changes have not changed the patriarchal family system, which favours the rights of males (especially elders) over females (Fargues, 1995). It seems that although mothers are now performing more roles within Kuwaiti society and its economic system, the assumption that a woman’s role is primarily to be a wife and mother is embedded in Arab society (Dalky, 2012). Therefore, mothers remain more responsible than fathers for rearing a child and thus are even more vulnerable to blame and shame for children who exhibit deviant social behaviours or achieve lower academic achievements (Al-Azemi, 2010; Fargues, 1995).

The impact of globalisation on the Middle East has mixed up identities, beliefs and lifestyles. This has not been done by combining Western ideas with Islamic and Arab culture, but by selectively choosing elements from Western culture that fit Arab and Islamic culture. This has led to the use of Western cultural ideas, but their meaning is different, since traditional ideas remain preserved and continue to underpin family values (Fernea, 1995: Timimi and Leo, 2009). For example, family social gatherings are important in Kuwait; however, the actions of children change as they become more orientated towards technology and the media than socialising with their parents (Jasem and Delport, 2019). The Western universal understanding of childhood increases the problem of parenting around the world, as theories of childhood and parenthood do not acknowledge differences in cultural values and expectations (Burman, 2016), which increases behavioural problems in children as well as complicating the parenting process (Timimi and Leo, 2009).

The concept of disability has also changed in Kuwait because of the impact of the global understanding of disability. As mentioned previously, in Kuwait, disability is understood as an impairment and a biological deficiency; however, from the political point of view, Kuwait signed the UN Convention on the Rights of Persons with Disabilities in 2013 (Ohchr, 2022), which was issued in 2006 following efforts from the disability movement (Oliver and Barnes, 2012). This means that the Convention forced countries to follow the social model of disability and articles in the Kuwaiti Disability Law No. 8 seem to underpin the social model (see Section 2.2.5 Disability in Kuwait); however, as discussed in the upcoming section on disability practice in Kuwait, people with disabilities still struggle to receive rights in Kuwait due to the dominance of the medical model.

## 2.2.6 Disability in Kuwait

Disability awareness in Kuwait has increased in line with the rising number of patients in neurological and psychiatric hospitals (now called mental health centres) since 1957 (Ministry of Social Affairs and Labour, 2018). Patients are usually referred to such hospitals by their families or schools, to support them with their disability (Ministry of Social Affairs and Labour, 2018).

Two disability laws have been enacted in Kuwait (in 1996 and 2010) to support the rights of people with a disability. The first disability law to be issued, in 1996, was Law No. 49 of the Kuwait National Assembly. However, this law had many problems, which were addressed by modifications in Law No. 08 in 2010, concerning the rights of individuals with a disability. The new law was published in Kuwait Today (a national newspaper; Issue 964). This section discusses the 2010 law, which is still used to support the rights and provisions of children with ADHD.

The rights of people with disability are administered by the Public Authority of Disability Affairs (PADA) in collaboration with the Ministry of Health, Education and Social Affairs (Ministry of Social Affairs and Labour, 2018). PADA facilitates support and service provision for people with disability, such as providing them with education and work. PADA is a formal government entity that represents the people with disability (Ministry of Social Affairs and Labour, 2018) and connects with public interest associations to highlight the needs of people with disabilities.

Law No. 8 defines a person with a disability as ‘one who suffers 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’ (Kuwait Constitution, p.4; see **Appendix 1:** The Law of Disability No. 08 Chapters).

صورة تحتوي على نص

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**Appendix 1:** Description of Chapters in the Law of Disability No. 08

ADHD was considered a mild disability and learning difficulty under Law No. 8, in 2010. However, since 2017, it has been counted as a learning difficulty, after an advocacy group raised the category issue in 2017, which led to changes in how children with ADHD are supported.

The rights of people with a learning difficulty are addressed in Articles 9 and 10, and include the provision of educational services and teaching aids. The Articles also mention training courses for teachers and educational professionals that aim to provide awareness to help with identifying students with a learning difficulty, as well as teaching strategies to interact with and educate them. The Articles address the creation of centres to assess and support those with a learning difficulty by providing services. Finally, they stress the need to step up the inclusion of students with a learning difficulty in mainstream schools through different teaching methods which fit the requirements and reflect the differences of each student.

According to the studies of disability literature and The Law of Disability No. 08 in Kuwait, Articles 9 and 10, inclusion in education means transferring students to a special needs school based on their disability and financial support, and providing the parents with information about the school and centre that is selected to meet the needs of the student’s different learning needs (Almumen, 2020). Inclusion also addresses teacher training in Kuwait University, colleges of education and Education and Training at the Public Authority. The two institutions provide educational programs and one model of special education training despite the transfer of the concept of inclusion and teaching strategies from Western countries, such as the UK and USA (Almumen, 2020). The meaning of “inclusion” seems to differ between Western countries and Kuwait.

According to disability studies, inclusive education means providing a place for all children to learn in a way that values them all. It advocates for an inclusive school society that allows all children to participate socially by accepting their diversity and disability, both in the school’s structure and the children’s interactions, at all levels of access and participation (Baglieri and Bacon, 2020). Inclusive education is not only about the precept of physically being present in a mainstream classroom, but also addresses engaging and participating in a school program in a way that is suitable for the individual. Special needs schools are made special through their learning strategies and special education, both of which are far from one size fits all. Thus, the way to ensure inclusive education is not only by allowing social participation, but by respecting a disabled person’s decision to study in a separate class or to join other children (Kauffman and Hornby, 2020).

However, the previous understanding of inclusion in Kuwait seems to have been from the medical perspective, where students have been segregated into special needs schools since 1950, although some students with disabilities were still educated in mainstream schools, but allowed to simply perform poorly (Bazna and Reid, 2009). The inclusion method was developed in Kuwait in order to include some students with a disability moved from a special needs school to a mainstream school. To make these inclusions work, a change in the school culture is needed in order to enable social and academic participation (Alenezi, Alqallaf, and Abbas, 2020). The current understanding of inclusion in Kuwait is in contrast to the social model principles, which emphasise that all students should study in the same school. Moreover, it does not comport with Islamic teaching which refuses the classification of human differences. Bazna and Reid (2009) argue "Islam's stress on the importance of diversity, individual differentiation, and variability" of human nature (p.151). Thus, the understanding of disability from social models in the context of Kuwait could be influenced and help, both structurally and attitudinally, to ensure the inclusion of all students (Alenezi, Alqallaf, and Abbas, 2020), yet there is still no development on the concept of inclusion.

After introducing the disability law, I now discuss the main issues arising in the Kuwaiti context concerning children with learning difficulties (ADHD) since 2010. When Law No. 8 was renewed in Kuwait in 2010, PADA had a new Director General. The main issue he faced was the significant rise in the diagnosis of people with a disability, leading to more money being spent on disability affairs (Alanba, 2010). This led him to audit the list of people with disabilities registered with PADA since 1996. He instructed medical committees to re-examine disability claims in order to find out whether anyone who was registered as disabled had made a fraudulent or incorrect claim for benefits stemming from the increased financial support stipulated by the disability law in Kuwait (Alanba, 2010). Although this audit was necessary and justifiable as a way of protecting the rights of those with real disabilities, the Director General of PADA was criticised by people with disabilities and disability activists, as the audit process led to the withdrawal of support for many people with disabilities (Alanba, 2010). Indeed, problems lay in how impairment was diagnosed and the reality behind each disability claim. A report from non-profit organisations mentioned in Al Qabas (2016) stated that the audit in 2010 gave PADA the right to determine the details of each disability claim, which made them an opponent and a judge at the same time. This caused hardship for people with learning difficulties, because of the lack of criteria for formulating a ‘diagnosis’, especially for those with ADHD.

Moreover, people with learning difficulties only receive educational support. In an interview with Al Qabas (2021), the Director of the Administration Council of KALD stated that the main issue faced by people with learning difficulties was the lack of integral educational support (including academic, social and psychological support), as well as the absence of an educational development project in Kuwait. From her statement it seems that educational support from the Disability Law would be enough, if the law was applied effectively. Since 2010, the main issue with the Disability Law has been that only the financial aspect has been applied, which puts people with learning difficulties in a deadlock.

With a lack of literature on the subject, it is difficult to identify the implications of the reform process on people with learning difficulties, especially since those with learning difficulties only receive educational support. This subject will be further explored, via the experiences of parents, in the Discussion chapter. However, here I outline the efforts of non-profit organisations in Kuwait to support people with learning difficulties.

In Kuwait, PADA is the political representative of the needs and rights of people with disability. In addition, non-profit organisations, and individuals such as KALD and the Assistant Director of Curriculum Development at the Centre for Child Evaluation and Teaching (CCET) fall under PADA. Non-profit organisations, especially those related to children with learning difficulties, were established to support children with learning difficulties and their parents, to represent them at PADA meetings and advocate for their needs.

Unlike the UK, there is no disability movement established by people with disabilities in Kuwait. Instead, the rights and needs of people with disabilities and their families are represented by the government and led by people without disabilities, although non-profit organisations advocate for the parents. Moreover, the disability movement UPIAS was established in the UK as far back as the 1970s, earlier than the oldest non-profit organisation in Kuwait, CCET, which was established in 1987. Kuwaiti non-profit organisations supporting people with learning difficulties under the auspices of the Disability Law concentrate on identifying people with learning difficulties. In 2010, concerns over changes to the disability policy of Law No. 8 (2017) were raised by KALD. A campaign under the banner ‘Give me my rights’ was later raised with the Minister of Social Affairs. The movement was opposed to placing people with learning disabilities, such as ADHD, into the category of impairment, because such people are not disabled. They demanded changes to the categories, while maintaining patients’ rights under the disability law.

The advocacy group was successful in its demand and ‘learning disability’ was changed to ‘learning difficulty’ in Article 3 of Law No. 8. Changes were also made to Articles 9 and 10, requiring improvements in educational services to meet the needs and requirements of students with learning difficulty. It also set out to help education professionals through preparing staff by sending them abroad to gain qualifications that were meant to enhance their ability to support students with learning difficulties. However, the amendments were not very effective in enhancing the lives of either children with learning difficulties or their families.

The Assistant Director of Curriculum Development at the Centre for Child Assessment and Education pointed out that from working with parents of children with learning disability, as well as with educational services, he found that there was a lack of rights for children with learning difficulty under Law No. 8, as it did not meet the needs and requirements of these children (Kuwait’s Constitution, 1962). The difficulties and challenges faced by people with a learning difficulty are not less than other impairments. Children face emotional, educational and social challenges and require support from the government.

My opinion conforms to the last argument, because addressing the needs of people with learning difficulty cannot be done simply by including such people in Law No. 8. Despite the admitted need for them to have legitimate rights, the support provided do not encompass all aspects of the lives of the children and their families. Articles 9 and 10 only focus on the educational aspect of learning difficulties. I propose more understanding of the needs of people with learning difficulty by acknowledging the disability (which here means the social barriers) they encounter in everyday life and not just focusing on the needs of their impairment. However, these demands cannot only be met by activists and non-profit organisations, they also need evidence-based research studies.

The following section discusses the achievements of studies on disability in Kuwait in demonstrating the practice of people with disability.

## 2.2.7 Disability studies in Kuwait

Most studies related to ADHD in Kuwait use quantitative methods, including prevalence studies (Salem et al., 2014), clinical studies (Alsharhan and Everatt, 2015; Alenezi, Alqallaf and Abbas, 2020), social and cultural studies (Al-Daihani and Al-Ateeqi, 2015; Al-Saeedi and Al-Harbi, 2017), psychoeducational and social issues studies (Al Qashan and Al Zubis, 2009), and risk factor and comorbidity studies (Mohammed, 2016).

Quantitative research on ADHD is important as it explores the nature and provision of ADHD ‘treatment’ in Kuwait, especially as ADHD is considered new in the Kuwaiti context (Salem et al., 2014). However, other studies have focused on children with ADHD or their families, without including the voice of the participants, while some only focus on the perspectives of teachers or medical professionals on children with ADHD. This issue was discussed using social oppression theory by Swain et al. (2003), which asserted that ignorance of studies on disability about the lives of disabled people continues to perspective constitute an understanding of disabled people of the dominant medical perspective of disability. Empowering disabled people would enable them to better convey ideas and suggestions to address their needs (Swain and France, 2000).

Some qualitative research in the disability field is in the area of social science (Khullar and Coughlan, 2018; Al Qashan and Al Zubis, 2009; Scull et al., 2014) while other research is in the educational field (Jassem and Delport, 2019; Almumen, 2020). Educational research focuses on alternative teaching and parenting interventions to treat children with ADHD. Social science research, however, focuses on the experiences of the patient and health care professional within mental health services in Kuwait (Al Qashan and Al Zubis, 2009). I noticed that social science studies incorporate qualitative methods more than educational research studies. This might be linked to the development of social science ‘treatments’ for ‘mental health disorders’ in Kuwait, while family and education based research is still in its infancy. By looking at studies published in 2019 and 2020, we notice that qualitative research is oriented towards the social and cultural aspects, which might give more in-depth and holistic understanding of the experience of individuals with ADHD (Jassem and Delport, 2019; Almumen, 2020).

A review of studies related to ADHD revealed that the language used to label ADHD varied between a mental health disorder and ‘learning difficulties’ (Khullar and Coughan, 2018; Nouf et al., 2019). For example, Khullar and Coughan (2018), investigating the experience of mental health in Kuwait, term ADHD a mental health disorder diagnosed and treated within the Kuwaiti mental health institution; whereas Alenezi, Alqallaf and Abbas (2020), focusing on preparing teachers for education services that include children with a disability in mainstream schools, consider ADHD to be a learning difficulty needing alternative learning interventions. This is not surprising, as the two studies come from a different research field in Kuwait, so the terminology used to refer to ADHD differs. However, interestingly, the two studies have a different understanding of ADHD as either a medical disease that needs ‘treatment’ or as a learning difficulty with differences that need alternative learning interventions to ensure inclusion in mainstream schools. According to the No. 8 Disability Law, ADHD is considered a learning difficulty. However, claiming that receiving disability services for children with ADHD is conditional on obtaining a certificate from a mental health institution in Kuwait (where ADHD is considered a mental health disorder) conflicts with this definition with Law no, 8 (Kuwait’s Constitution, 1962).

My argument is that the variation in language used to describe ADHD, without acknowledging that ADHD in practice is more complex than just being a ‘mental health disorder’ or a learning difficulty, might create a problem for parents of children with ADHD. This is because it reinforces confusion and ambiguity around the understanding of ADHD, as each definition used has a different cultural meaning and response attached to it, thus leaving it to the parents to negotiate past associated problems in everyday life.

To form a conclusion on the understanding of ADHD, studies of ADHD in Kuwait look at medical characteristics, as they focus on the biological and scientific aspects of ADHD, while the cultural and social environment that constrains social participation among people with disability is often ignored (Al Harbi and Al Saidi, 2017; Mohammad, 2016; Al-sharhan and Everatt, 2020; Salem et al., 2014). Moreover, most research focuses on the educational context and not on social participation outside school, which might reflect the identification of ADHD in Law No. 8 as a learning difficulty. However, it is interesting to observe that most coping strategies for ADHD are orientated towards teachers and professionals. This might indicate the awareness of teachers of their responsibility in the social context to ensure that children with ADHD can participate in mainstream schools.

Finally, the few studies that focus on culture are valuable for understanding social and cultural perspectives on ADHD and social attitudes toward them whether they be from professionals or teachers (Khullar and Coughan, 2018; Alenezi, Alqallaf and Abbas, 2020). However, it seems that these studies separate themselves from social practice, as most of them only mention the social and cultural values, while the political and economic context is rarely mentioned, which might reduce the impact of the research on policy as well as increasing the gap between academia and politics.

### 2.2.7.1 Parenting a child with ADHD in Kuwait

In this section, I limit the focus to ADHD research which concentrates on the parents’ perspective. According to the parenting literature, the main issue that families face in Kuwait is shame, which may lead to detachment from social activities and the extended family. Having a disability could minimise a person’s ability to work and marry, which is considered an important part of Kuwaiti culture. The results of Kuwait studies show a variation from the focus and findings in Western literature. In the US, studies focus on the ‘diagnosis’ and ‘treatment of ADHD, as consequences of an increase in medicalisation and use of ADHD ‘treatment’ on the life of the families of children with ADHD (Danielson et al., 2018; Bergey et al., 2018). In studies from the UK, families are shown to experience stigma as a result of an ADHD ‘diagnosis’ (Brunton et al., 2014). The findings of Kuwaiti studies on parents’ experience show many issues with ‘diagnosis’ leading to stigma, yet the main issues that parents face concern stress over societal challenges (Al-Sabah, 2015; Al-Azemi, 2010). Parents encounter many issues with health provision and educational services. These issues increase their stress by requiring them to find appropriate health and education services for their children.

Moreover, research on parents of children with ADHD indicate that they have difficulty gaining knowledge and services to support their family and endure an ambiguous and confusing experience while raising a child with ADHD (Alazemi, 2010; Al-Sabah, 2015; Al-Daihani and Al-Ateeqi, 2015). This indicates the importance of providing education and support. According to Law No. 8, education and training are only offered to teachers and education professionals (Kuwait’s Constitution, 1962). This ignores an important element in the life of children with ADHD, their parents. This increases the burden on parents, as they may be required to search for information and services that would help them better understand their child’s condition on their own.

Additionally, the focus of the research was mostly on mothers, who seem to experience more emotional burden than fathers. The mothers’ experience of having children with a disability highlight that they face both social blame and limited availability of knowledge and support resources. The pressure that mothers experience may affect their mental health, leading to depression and stress (Alazemi, 2010; Al-Sabah, 2015). Another important finding from studies on parenting highlights the kind of support that is offered to mothers. Al-Sabah (2015) showed that mothers only received financial support from their extended families. This might also apply to governmental support, as I illustrated above in the disability practice section: 2.2.5,financial support for children with disability was the only support they received, while other support such as information and social and psychological despite being issues, but they are not inactive or effective to help the families. Mothers reported having no social or wellbeing support. However, the Kuwaiti state offers free psychology and psychiatry services to support Kuwait citizens, but these are often associated with social and societal stigma, thereby preventing people from calling on them. Despite the government’s efforts and financial investment in supporting Kuwaiti citizens, including the parents of children with disabilities, it seems that there are cultural and social barriers that prevent suitable support for the families of children with ADHD or other disabilities.

Studies on parenting children with disability have mainly focused on the mother’s perspective, while little is still known about that of the father. This may be understandable, as most of the blame for children is placed on the mother, therefore mothers are more likely to face a greater physical and emotional burden due to having the responsibility of raising the children. This might also be from a cultural understanding of the absence of the father's role and responsibility towards his children (Al-Azemi, 2010). However, understanding the perspective of the father is essential, especially as he is responsible for his children’s legal affairs, including their access to support services.

Some studies explore disability from the father’s perspective (Al-Azemi, 2010). However, these studies often take a quantitative approach, for example using a questionnaire. The problem with quantitative data is that it does not allow in-depth exploration of the cultural and social values that underpin the fathers’ perspectives and attitudes toward children and disability. Moreover, an exploration of the fathers’ perspective might prevent the general assumption being made that they do not care about their children with ADHD.

Research on parents’ experiences in raising children with ADHD suggests that more opportunity should be given to caregivers of such children. This would allow them to express their experience of parenting within the Kuwaiti environment, supporting not just an exploration of their understanding of ADHD and the effect of it on their experience of raising a child with ADHD, but also exploring the cultural and Islamic values and beliefs that underpin their perspective and actions.

## 2.2.8 Summary

This section introduces the context of research in Kuwait. The main argument is that understandings and practices regarding ADHD and disability are influenced by political, economic and cultural factors. Kuwait is a small country with a low population and even lower rate of children having learning difficulties, such as ADHD. The nation’s economic prosperity and moderate socialist system afford privileges to Kuwaiti citizens in multiple aspects of life. Furthermore, the Constitution of Kuwait ensures the rights of people with disabilities, including learning difficulties, and grants them additional privileges. The Law of Disability No. 8 and the Public Authority of Disability (PADA) also guarantee rights and support for people with disabilities. However, individuals with learning difficulties have few rights, and these are only partially effective in practice. The educational rights of people with ADHD are under threat, since the Law of Disability considers ADHD to be a learning difficulty and not a disability.

The section then moves to show ADHD from a cultural perspective. As ADHD is a relatively new concept in Kuwait, the section focuses on the understanding of ADHD in Kuwaiti culture and engages mostly with the concepts of disability, childhood and parenthood. In general, the nation’s culture combines Arabic values and Islamic teaching. However, cultural understandings are also underpinned by globalisation, which impacts economic and political facets of Kuwaiti culture. The section also addresses the idea that disability and impairment are considered to be equivalent in the Kuwaiti context. While the social model idea of disability could be recognised in Islamic teaching, disability is predominantly viewed as an individual and medical issue in Arab culture.

The section concludes with a discussion of research on disability and ADHD in the Arabic and Kuwaiti contexts. These studies are mostly medically oriented and direct little attention to understanding disability in its social and cultural context while separating it from its economic and political context. There are few studies on parenting and ADHD in particular.

# 2.3 Section C: Disability Studies

Introduction

This section discusses disability studies and is divided into two sections: the individual model and the social model of disability, whilst covering the way disability (specifically ADHD) is understood within each model. I begin with an introduction to disability studies and a definition of the term ‘model’. Next, I shift to a discussion of each model.

## 2.3.1 Disability studies in the UK

Since the 1980s, disability studies in the UK have discussed and presented various ways of understanding disability (Oliver and Barnes, 2012). These studies represent a field of research that understands disability through society and critically exposes the societal mechanisms that produce disability, as well as providing an understanding of disability that challenges the dominant medical opinion (Cameron, 2014). Disability studies are based on two important principles. Firstly, disability studies focus on society as a place of exploring and a source of disability (barriers) that encounter disabled people and not on a bodily dysfunction within disabled people (Mallett and Runswick-Cole, 2014; Cameron, 2014). Second, studies related to disability are interdisciplinary and based on different disciplines (Goodley, 2016), such as medical sociology and the sociology of health and illness (Thomas, 2012).

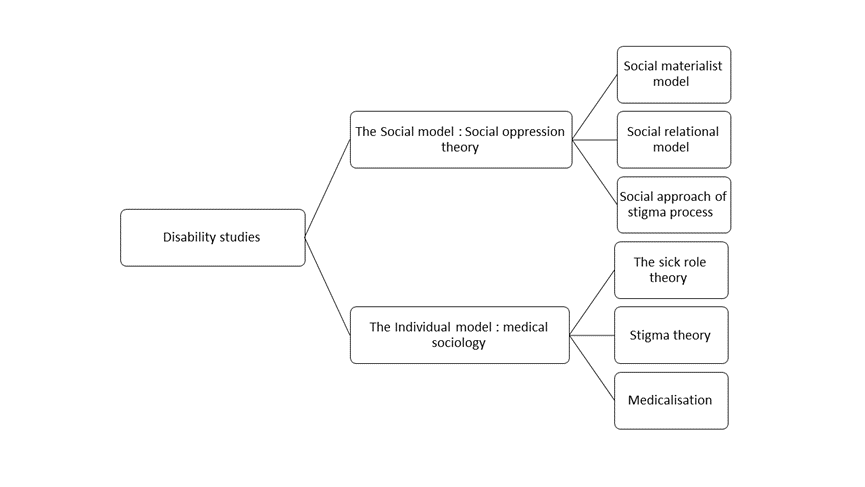
### 2.3.1.1 The term ‘model’

Variations in the understanding of disability that are discussed in the research studies are provided through models’. According to the Oxford English Dictionary, a ‘model’ is defined as a ‘description of a system used for explaining how something works’ (Oxford English Dictionary, 2021). Models have been used in disability research to illustrate the ideas surrounding disability in a social environment and make sense of its complexities (Vehmas and Watson, 2019), as disability is a complicated concept to be covered by one definition (Bickenbach, 2020). For example, we cannot use ADHD as an identity for all children with ADHD, because some might not think of their impairment as a ‘disorder’. However, the definition of ADHD is essential to prove the legitimacy of children with ADHD rights under disability social policy. Thus, models are useful for gathering information or evaluating and exploring ideas about disability, not producing facts about disability, but as a tool to organise ideas about disability (Bickenbach, 2020).

Models of disability are not firmly established or perfect for every circumstance, and no one model is better than another (Watson and Vehmas, 2019). In a sense, it is not to say that the medical/individual model is wrong, rather there are multiple ways of understanding disability. This research uses a model to offer a conceptualisation rather than a definition of disability and ADHD.

In this section, I discuss the individual and social models of disability as theoretical lenses through which to explore an understanding of ADHD from the experiences of parents of children with ADHD. I use these two models of disability not to contend that one model is better than the other, but to argue that ADHD is not as simple as may be represented by either one of the models. My intention is to explore the Kuwaiti perspective on ADHD by providing more than one way of understanding this disability in Kuwait and its impact on families of children with ADHD.

The disability studies section reviews the literature on the individual and social models of disability, which are the analytical lenses of this research (see **Figure 1**: The conceptual framework). I present the definition of each model, how each understands disability, and its strengths and limitations. Lastly, I explain the way I used each model and its relevance to the Kuwaiti context.



**Figure 1:** The conceptual framework

## 2.3.2 Individual or medical model of disability

Disability studies researchers have used the term ‘medical model’ to refer to approaches to understanding disability that take into account individual, medical, and so-called ‘tragic’ factors (Mark, 2000; Sullivan, 1991). However, for some disability researchers, the medical model falls under the individual model. This is evident in Oliver (2009), which discussed models of disability. It asserts:

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; the latter being what I preferred . . . to call the medicalisation rather than the medical model of disability (p.19).

Oliver further defines the individual model as a model that places responsibility for issues related to the disability of the individual. This model also considers that the causes of a disability are the psychological and/or functional shortcomings that result from impairment. The individual model integrates both the medical model and the tragedy model. However, unlike other research (see Haegele and Hodge, 2016), Oliver did not accept the concept of a medical model, rather he referred to this type of model as ‘medicalisation’ (Oliver, 2009, p.19), which situates the biological problem in the body and/or mind and suggests ways to cure the impairment to help the individual fit into society (Haegele and Hodge, 2016). Lastly, the individual model is, for Oliver (1996), underpinned by the ‘personal tragedy theory’, or the tragic model, which regards disability as an unfortunate event that leads to people developing disabilities. In this model, people with disabilities are regarded as dependent victims in need of help from others, which advocates for a type of pity and charity (Barnes, 1997; Amponsah-Bediako, 2013). Based on this definition, the term *individual model* is used to underpin disability studies. The appearance of the individual model is related to the demand of the Industrial Revolution to determine the value of humans by their work and productivity (Barnes, 1999). In this context, people who were unqualified for work were considered disabled and unable to be employed. These unqualified people were not able to meet the demands of discipline and production. They were seen as unproductive and as a burden on capital resources (Barnes, 1999).

In response to this problem, people who were involuntarily unable to work were categorised as ''deserving paupers'' and their needs were supported by the administration of welfare programmes by the state (Sullivan, 1991, p.256). This process of categorising was first overseen by a priest and public officials, but the orientation to a more objective means of determining who was incapable of work ultimately placed responsibility on the medical field (Sullivan, 1991). People with disabilities were placed in institutions that were constructed to separate them from their families to allow people without disabilities to be productive.

However, in the 20th century, these institutions were replaced with community-based facilities, which are still dominated by medical models that continue to legitimise the exclusion of people with disabilities from the labour market (Clapton and Fitzgerald, 2005). These changes were characterised by various methods which identify, categorise and regulate impairment. Professionals had the authority to determine the needs of and cures for people with disabilities to overcome and eradicate their impairments (Barnes, 1999). Consequently, the individual model of disability appears, which is named for the model's characteristics.

The individual model some sources used to indicate medical sociological approaches to studying disability (Oliver and Barnes, 1993). Medical sociology is a field that developed in the United States and is based on the idea that understanding human behaviour comes not only through a biological approach, but also through social processes that underpin the cultural and social environment (Cockerham, 1981; Tuckett, 2013). It considers impairment not as a disease (biological), but as an illness (behaviours that deviate from social norms) (Oliver and Barnes, 1993). In using the individual model to discuss ADHD, my intent is to illustrate how medical sociological approaches critically discuss the biomedical perspective on ADHD.

The justification for using the medical sociological approach is its importance in following the first principle of disability studies, which is to consider ‘disability’ as a social construct. By contrast, the biomedical perspective, which understands the world from a social constructionist viewpoint, and conceptualises reality according to history and context (Robson, 2011) does not fit with the current research. Instead, the perspective that is adopted by medical sociological approaches, such as medicalisation, is more suitable to the conceptual framework of the current research (Tuckett, 2013). The medical sociological approach helps us discover the social and cultural meanings of the knowledge and definition of ADHD in the Kuwaiti context, in addition to the consequences of the medicalisation process on children with ADHD and their families. However, I do not intend to ignore classic medical sociological approaches, such as those of Goffman (1963) and Parsons (1951), in which the medicalisation process is rooted, despite there being limited attention paid to ADHD from a medical sociological perspective (Rafalovich, 2001, Tuckett, 2013). Classic medical sociological approaches can help to explain ADHD from social and cultural perspectives (Prosser, 2015).

Finally, this section applies the individual model to ADHD to provide context for the argument surrounding the ability of researchers to fit biological and medical sociological paradigms into the principles of disability studies by illustrating the importance of the individual model and its main criticisms (Thomas, 2012). The next section illustrates the classic medical sociological and medicalisation approaches.

### 2.3.2.1 Sick role theory

As already mentioned, from a biomedical perspective, ADHD is predominantly understood as a biological brain dysfunction that is either biochemical or neurophysiological in nature (Engel, 2012). However, in the 1950s, medical sociology was influenced by the concept of the ‘sick role’ (Parsons, 1951, cited in Cockerham, 2013), which contributed to the discussion of the medical perspective of disability. Parsons considered disability a product of social structure and cultural values, as opposed to it being solely based on biological and scientific ‘facts’ (Tuckett, 2013). In reflecting on the topic of this research, ADHD has come to be understood as a ‘disease’ and/or ‘illness’ that causes the individual to fail to live up to the standards of ‘normal’ and ‘healthy’. Parsons’ ‘sick role’ was the first to provide a structure for theoretical discussion of illness from the medical sociological perspective, which opened the door for other theories to develop, especially related to the concepts of health and illness (Cockerham, 2013). Therefore, it is logical to begin by describing sick role' theory as the beginning of medical sociology approaches.

Sick role theory focused on conceptualisation of ‘illness’ and how it works within society (Frank, 2013). Whilst it does not deny that illness and disease are limitations in terms of physiological and psychological abilities (Barnes and Oliver, 1993), sickness-related behaviour is understood as deviant from the norms and values of ‘normal’ expectation of behaviour (Cockerham, 2013). In brief, every person has a role to play to fit in with the demands and expectations of society (Barnes and Oliver, 1993). Failing to achieve socially defined tasks and/or performance because of limitations of mind or body is seen as deviating from the ‘normal’ or ‘healthy’ (Cockerham, 2013). The term ‘sick role’ is used to describe the role that a person who deviates from social obligations and attitudes takes to be exempt from all the usual social expectations and responsibilities (Barnes and Oliver, 1993).

However, the only way to adopt this sick role is through the authority of a medical professional, who legitimises the sick role as well as explaining ambiguous and deviant behaviour (Heidarnia and Heidarnia, 2016). This occurs because sickness is seen as a threat to a healthy society and the roles that people must play in society (Heidarnia and Heidarnia, 2016). Thus, to ensure the efficient functioning of a person with sickness, the social system controls and manages the deviant behaviours of sickness by expecting people with an illness to submit to the authority of medical professionals in order to achieve a healthy state (Barnes and Oliver, 1993).

The sick role has four key components. It exempts the sick person from (1) social responsibility, and (2) responsibility for the sickness. (3) The sick person has a responsibility to pursue recovery, and (4) they have an obligation to seek help from medical professionals (Cockerham, 1981). An important concept in Parsons’ theory is the explanation of the relationship between doctor and patient (Frank, 2013). The balance of power between patients and medical professionals is unequal, as the field of medicine gives medical professionals authority over the life of the patient. However, each needs the other to complete the demands of their roles (Cockerham, 1981).

#### 2.3.2.1.1 Application of sick role theory to ADHD

ADHD fits the sick role model in that the disorder is understood as a deviation from the collective values of health, and this deviant behaviour is represented as ‘illness’. Children with ADHD present behaviours that challenge the understanding and expectations of developmental and educational psychology (Burman, 2016). In other words, these children challenge dominant understandings of childhood, educational requirements and social norms, and are considered not to comport with societal expectations of children (Armstrong, 2010). Parsons used economic productivity of people with illness and medical institutions to present the way social systems work (Heidarnia and Heidarnia, 2016); yet in the case of children, productivity is demonstrated through academic achievement. Davies (2018) asserted that the advent of compulsory education was due to the needs of capitalism, and that schools became the arena where children could be trained to become productive workers (Malacrida and Semach, 2014). At the same time, when large numbers of children congregate in schools, it leads to a decrease in the range of behaviours that look ‘normal’ (Malacrida and Semach, 2014). The gathering together of children in public institutions, such as schools, allowed professionals to observe children’s behaviour and led to the development of educational psychology and its assessment categories used to distinguish ‘abnormal’ children (Davies, 2018). In turn, this increases segregation and specialised ‘treatment’ of ‘abnormal’ children to facilitate their regulation (Malacrida, 2003).

#### 2.3.2.1.2 Critique of sick role theory

ADHD presents various challenges to sick role theory. For example, Arnold et al. (2010) suggested that ADHD can continue into adulthood, as children with ADHD might remain in a sick role for a long time if they fail to ‘recover’. This view conflicts with Parsons’ understanding of the sick role, which saw recovery as essential to achieving a normal state (Barnes and Oliver, 1993).

However, children with disabilities and their families might remain under the control of medical professionals with little autonomy over their lives and behaviours (Humpage, 2007). The ‘deviant’ behaviour continues and prevents disabled children from achieving academically (Varul, 2010). Thus, whilst the ‘sick’ child is encouraged by professionals to perform ‘normal’ roles, despite the illness (Varul, 2010), recovery actually becomes the main mission of children with ADHD and their families (Varul, 2010). This places children with disabilities in the conflicting roles of being ill and normal at the same time (Varul, 2010). In other words, children with ADHD have to continue to confirm their illness to medical professionals, with the clear understanding that having ADHD is not good, whilst at the same time, they are expected not to give up on recovering and trying as far as possible to behave normally.

This limitation of the sick role model in terms of its non-acceptance of variations in sick roles, as is the case with ADHD, is not the only challenge to Parsons’ understanding of deviant behaviour (Heidarnia and Heidarnia, 2016). Additional criticisms and debate about sick role theory are relevant to the context of the current research. For example, Barnes and Oliver (1993) suggested that Parsons’ theory fails to consider the nature of disability and related socio-economic factors when analysing the behaviour of a sick person. In addition, the theory illustrates the normative expectations of the interactive relationships between patient, medical professionals and society (Frank, 2016) that have been established in Western society.

The sick role view of disability might present a challenge to understanding illness in cultures such as Kuwait. For example, Heidarnia and Heidarnia (2016) discussed the differences in terms of understanding the concept of health in Islamic cultures. Whilst health is a vital concept in sick role theory, and achieving it is the main goal of the sick person (Frank, 2016), in Islamic cultures, sickness is considered a test from God and the achievement of health not necessarily essential (Heidarnia and Heidarnia, 2016). Muslim people might do their best to be healthy, but failure to recover from illness is an opportunity to strengthen faith in God and be patient to his will, not something to blame him for (Hammad et al., 1999).

Finally, sick role theory essentially ignores the subjective interpretation of illness (Frank, 2013), but represents people with disability through the perspective of professionals (Barnes and Oliver, 1993). In the patient and doctor relationship, a sick person is presented as dependent and passive, whilst the doctors’ perspective on the illness and the path to recovery is dominant (Cockerham, 1981). However, it is crucial to recognise that people behave differently when they are ill (Cockerham, 1981). This is an especially valid point when looking at information-seeking behaviour, because this has changed as a result of globalisation; the increased use of media such as the Internet has changed the balance of power between patients and doctors, because patients are able to find medical information independently (Heidarnia and Heidarnia, 2016). In addition, the marketing of self-sufficiency and self-care in modern capitalist society has increased patient empowerment (Varul, 2010) such that sick people are no longer seen as dependent, but as consumers of medicine (Varul, 2010).

The long experience of parents raising a child with ADHD, as well as the opportunity to explore and understand ADHD, could change the relationship with medical professionals to one that is collaborative. My argument is that, whilst Parsons’ theory might have many limitations, it is important as an introductory theory that explains, in part, the medical perspective on disability, as well as the basis for important concepts, such as health and deviant behaviour. The theory also advocated for and led to the emergence of other medical sociological theories to understand sick and deviant behaviour, such as medicalisation.

### 2.3.2.2 Labelling and stigma theories

In the 1960s and 1970s, another medical sociological direction emerged. It focused on the meanings of disability that are products of interactions between individual agency and social structures (Tuckett, 2013). From this perspective, ADHD-related behaviours are not harmful on their own, but are seen as unacceptable within the social interactions that occur in a particular culture and specific context (Posser, 2015). A label is believed to hold cultural meaning which has been used by people to define their social world, whilst being labelled a ‘deviant’ carries a social stigma (Tuckett, 2013). From this perspective, two main theories are related to ADHD: labelling and stigma theories.

Labelling theory (Becker, 1963) explains the process of labelling. According to this theory, labels are social controls that help to restrain deviants who break social rules (Algraigray and Boyle, 2017). For example, the behaviour of children with ADHD breaks the social norms of acceptable student behaviour in school or represents unwelcome social behaviour within gatherings of family or friends (Posser, 2015). Even after being diagnosed and labelled with ADHD, children with ADHD still present differently from ‘normal’ children, which provokes stigma (Posser, 2015). Moreover, ‘deviance’ in labelling theory can be ‘primary’ and ‘secondary’: primary relates to the ‘diagnosis’ and label, whilst secondary relates to society’s negative perspective on the deviant individual (Oliver and Barnes, 1993).

Similarly, Goffman’s (1963) theory of stigma captures the impact of the deviant label as well as the challenges involved with managing stigma. Goffman defines stigma as an ‘attribute that is deeply discrediting’ (1963, p.3). In other words, having a characteristic or attribute that is undesirable in a social context or that is different from the social norms leads to devaluation of the individual (Goffman, 2006). Once stigmatised, a person is transformed from a whole person to one who is devalued and unworthy (Goffman, 1963). Goffman (2006) also asserts that stigma should be considered as a relationship between the attributes of an individual and undesirable social characteristics (Link and Phelan, 2001). This perspective is based on the idea that we are all actors and present ourselves through performances that confirm social interaction norms in social contexts (Dobransky, 2011). As a result, people with disability try to avoid stigma by presenting themselves in a certain way (Dobransky, 2011).

These two theories focus on the process of ‘diagnosis’ and its implications. Dobransky (2011) suggested that the process of stigmatising, according to labelling and stigma theories, happens by identifying and labelling the differences in a child’s behaviour and his or her school or home norms. Next, social and cultural beliefs link the label with negative stereotypes, such as ‘naughty’, ‘lazy’, or ‘dangerous’. These are generalised judgments on the stigmatised attribute that are usually inaccurate and misleading (Ciftci and Corrigan, 2013). Lastly, negative stereotypes constitute the way people react to and perceive people who have been labelled (Dobransky, 2011). The social response to stigma includes discrimination (a behavioural response toward a stigmatised attribute) and prejudice (an emotional response to a stigmatised attribute) (Ciftci and Corrigan, 2013).

Goffman (1963) indicated that two kinds of people accept and might engage with a stigmatised individual: the ‘one’ and the ‘wise’. The one refers to people who share the same stigma with stigmatised individuals, because they share a similar condition (Goffman,1963). Stigmatised individuals find people characterised as the ‘one’ to be tolerant, accepting and they might build a supportive relationship with each other because they share the exact circumstances of stigma (Goffman,1963). The ‘wise’ refers to people who are not stigmatised nor do they share a condition, but they are familiar with the stigmatised individual. The close relation of the ‘wise’ to the stigmatised individual makes him/her accepted and supported. The ‘wise’ are often family or close friends; however, Markowitz and Engelman (2017) suggest that sometimes the influence of the ‘symptoms’ of the ‘disorder’ or condition might disrupt the relationship between the stigmatised person and the family, in which case, they might not be the ‘wise’.

A key concept of stigma is its impact, which can take different forms. First, public stigma involves people confirming the stereotypes of the stigmatised attribute by responding with a certain behaviour, such as discrimination (Mueller et al., 2012). At the same time, people who are stigmatised may also confirm and internalise the stigma and respond to stigmatisation based on the same stereotypes, thereby directing the stigma to themselves (Mueller et al., 2012). ‘Courtesy stigma’ refers to the stigma being transferred to the family or friends of a stigmatised person (Goffman, 1963). Family members facing courtesy stigma might be blamed for a child’s disability, which can cause low self-esteem, lowered social status, isolation or lack of support (Dalky, 2012; Corrigan et al., 2014). Finally, label avoidance involves denial of a negative label, which can lead to a refusal to accept support and services (Ciftci and Corrigan, 2013). These concepts are important to the application of stigma theory to this research, which focuses on understanding ADHD from the perspective of parents of children with ADHD.

#### 2.3.2.2.1 Application of stigma theory to ADHD

In reflecting on ADHD, I began by discussing ‘mental health disorders’ because of their similarity to ADHD in terms of both being impairments that are based on an invisible, discreditable attribute. The stigma associated with a ‘mental health disorder’ is often hidden, which might prevent immediate discrimination but leads to stress, fluctuating self-esteem, and difficulty in social interactions because of the possibility that the stigmatised attribute might be uncovered (Ciftci and Corrigan, 2013). This stigmatisation of ‘mental health disorders’ can be understood through the lens of labelling theory: ‘Even if labelling does not directly produce ‘mental disorder’, it can lead to negative outcomes’ (Link et al., 1989, p.400). A psychiatric ‘diagnosis’, by its nature, labels a person with a ‘mental health disorder’ with a stigmatised attribute (Tyler and Slater, 2018). The type of stigma related to ‘mental health disorders’ is a moral stigma and an attribute that creates a perceived blemish on the person’s character (Thoits, 2011). Goffman (1963) illustrated that people with invisible disabilities, such as ‘mental health disorders’, encounter more stigma than other disabled people.

From the stigma theory perspective, an ADHD ‘diagnosis’ constructs ADHD as a social deviance that provokes public stigmatisation which affects children with ADHD as well as their parents (Mueller et al., 2012). This occurs because although ADHD is understood from the individual model to be a neurodevelopmental deficiency, it still comes with stereotypes, such as a child with ADHD being labelled as dangerous or incompetent (Mueller et al., 2012). Moreover, public uncertainty about the validity of ADHD as a ‘diagnosis’, along with ideas about ‘treatment’ and the disclosure of a person’s ‘diagnosis’, can expose people with ADHD and their families to stigma (Mueller et al., 2012). ADHD is sometimes misunderstood as merely childish and/or socially inappropriate behaviour, which leads to rejection by others, hostility towards the behaviours and/or courtesy (Mueller et al., 2012). The impact of stigma might also reduce the desire and negatively affect the decision of people with ADHD or their parents to access social resources (Koro-lyjunberg, 2009) or create a social network (Corrigan et al., 2014). The stigma behind the ADHD label can compel parents to reject support to avoid being labelled. Moreover, the impact of stigma reaches both children with ADHD and their families, leading to isolation, exclusion and disadvantaged life circumstances (Goffman, 1963).

Courtesy stigma was evident in Blum (2007) in one mother’s experience of raising a child with ADHD. The social perception that denied the validity of an ADHD ‘diagnosis’ led to stigmatising the mother and blaming her for ‘poor’ parenting (Blum, 2007). Stigma also affects the parents’ lifestyle and living conditions and even their efforts to parent, which can eventually lead to poor health and ‘mental health disorders’ (Koro-lyjunberg, 2009). In addition, parents often internalise the stereotype of ADHD and enact social strategies, such as isolation, to avoid stigma.

#### 2.3.2.2.2 Limitations of stigma and labelling theories

Despite the value of theories for understanding how stigma and labelling work and their implications, they do have limitations. Both stigma and labelling theories have been critiqued because they depend on the perspective of the labeller and the labels themselves (Oliver and Barnes, 1993). Stigma is seen as being linked to individual attributes rather than as a relationship between society and individual interactions. This suggests that stigma is limited by the way individuals with disabilities perceive the stigma’s impact on their emotions (fear and grief), behaviours (avoidance and suicide), relationships (rejection and social exclusion), and thoughts (thoughts about themselves) (Lusli et al., 2015).

For its part, labelling theory does not permit consideration of the variations in understandings of disability that are constructed by people with a disability. For example, parents might present different ways of negotiating the meaning of ADHD when they interact within social contexts. Link and Phelan (2001) argued that the process of labelling is neither negative nor positive; it comes as a package with both advantages and disadvantages (Link and Phelan, 2001). Parents usually accept the ADHD label because it allows them to access information and services, but at the same time, they are left to deal with the negative consequences of any labels and stigmas (Ryan and Runswick-Cole, 2008).

### 2.3.2.3 Medicalisation

One recent approach used in medical sociology which underpins the social constructionist view is the medicalisation approach (Cockerham, 2013). Medicalisation refers to the process of medically identifying, evaluating and curing a non-medical condition (Conrad, 1992). Brown (2003) argued that the approach examines the social process of a widespread use of medicalisation and its influence in practice. It focuses on the process and definition of medical concepts such as ADHD and autism (Tuckett, 2013). The perspective also highlights the social factors that contribute to the dominance of medicalisation (Brown, 2003). One of the disabilities studied using the medicalisation approach is ADHD.

The social construction of ADHD from a sociological perspective was addressed by Peter Conrad’s article ‘The Discovery of Hyperkinesis’ in 1975. Conrad (1992) was keen to understand the origins and consequences of the medicalisation of ADHD by investigating the historical root of ADHD being understood as a medical condition. Timimi (2005) states that ADHD as a medical condition first appeared in the UK in the 20th century, when it was called minimal brain dysfunction (MBD) (Davies, 2018). Since then, terms have changed continuously, such as ‘hyperactivity’, dyslexia and ‘language disorder’ (Timimi, 2005). This is because ADHD has an ambiguous and complicated nature that associates with different cognitive abilities, socially unacceptable behaviours and learning difficulties.

In US psychiatry, ADHD was first referenced in DSM II (1986) as ‘hyperkinetic’. However, its name changed with each edition of the DSM. For example, in DSM III (1980), ADHD was called ‘attention deficit disorder with or without hyperactivity’; in DSM IV (1994), it was called ADHD with inattention and/or hyperactivity. In the last versions DSM V (2013), the ‘disorder’ was simply called ADHD (Timimi, 2005; APA, 2013). The historical changes in the terms used for ADHD present different causes and explanations of the condition, but at a basic level, all underpin the biomedical perspective. Conrad (2013) asserted that the continued rise of the ‘diagnosis’ of ADHD in children was a product of social control aids, such as medicine.

The medicalisation approach was used to investigate the prevalence of ADHD globally (Conrad and Bergey, 2014), the ‘treatment’ of ADHD (Timimi and Taylor, 2004), and the ‘diagnosis’ process across cultures (Edwards et al., 2012). I will present an example of the approach used to investigate the validity of the DSM-5 (2013) definition of ADHD. Timimi (2005) highlighted the influence of ideas about the psychological development of a normal child in the evaluation of deviant behaviour in children as ADHD. He also argued that the assumption of normal behaviours from psychological theory underpinned Western culture (Timimi et al., 2004), which failed to address different cultural understandings of childhood. The evaluation of children’s behaviour across cultures depends on each culture’s values and belief system, as well as the circumstances of its social environment (Timimi, 2005). Thus, James et al. (2007) suggested the generalisation of Western theories of childhood as a universal model, without considering that the cultural and environmental factors in the construction of childhood were not suitable for understanding childhood and ADHD. A review of studies criticising ADHD’s categorisation as a ‘biomedical disorder’, indicates the importance of historical and cultural factors in understanding biomedical ‘facts’ and emphasises the diversity of understanding ADHD, despite its global reach. This raises the question of how ADHD is understood in Kuwaiti culture and the role of cultural and social factors underpinning its social construction.

### 2.3.2.4 Critiques of sociological approaches in disability studies

This section presents the main medical sociology approach, which refers to disability studies using individual models (Barnes and Oliver, 1993). These models have limitations, which will be presented through the criticisms of the medical sociology approach below, followed by an illustration of using the individual model.

There are three main criticisms of medical sociology. First, both the sick role and the medicalisation approach represent people with disability as passive agents of medical power (Busfield, 2017). For example, sick role theory denies the subjective interpretation of an individual and explains the experience of impairment from the researcher’s point of view (Barnes and Oliver, 1993). It ignores people with disabilities who might resist or reject the doctor’s perspective on disability (Busfield, 2017) but assumes that people act the same way despite their social factors (Barnes and Oliver, 1993).

Second, previous sociological approaches have investigated disability from the deviance paradigm (Thomas, 2012). Although interactionist stigma theory explains that deviance is not within the person, but the way society understands stigmatised attributes (Goffman, 1963), people with a disability are presented as others or victims (Mulvany, 2000). From a medical sociology perspective, disability is discussed differently from other social groups, such as race and gender. While it is not acceptable to talk about gender as socially deviant, disability has been discussed from a normal/deviant dualism (Thomas, 2012).

Lastly, Oliver (1990) critiqued the individual model, asserting that medical sociology treats disability as an illness, ignoring the differences between these two concepts. The previous approach focused on impairment, not disability (Oliver, 1990). The issue with this understanding is that disability cannot be cured or treated, unlike an illness. Attempts to use medical knowledge to treat disability might put people with disabilities in a position where the intervention is not inappropriate or they are oppressed, because the challenges in their life come from social disadvantages and not physical disadvantages. Disability might have a biological impairment, but it is also a ‘social state’ (Oliver, 1990).

As stated above, this research falls within disability studies, which is an interdisciplinary research area. I intended to draw on medical sociological approaches to explore a biomedical/individual understanding of ADHD. The discussion thus far shows a similarity between medical sociological approaches and disability studies, as both focus on the social context to investigate disability. However, they differ in the use of language, meaning of disability, and role of people with disabilities in the investigation process. This might present a challenge because I want to follow disability studies’ principles (see Section 2.3.2.1) that contrast with individual models, but I think that approaches under individual models are valuable to the understanding of disability (in this case, ADHD). In particular, most of the research on the social construction of ADHD is based on medical sociological approaches and not disability studies. The latter focuses on the construction of disability in general (see Section 2.3.2.1). This support the analysis of the parents of children with ADHD rearing experience, as I explore the perspective of Kuwaiti parents about ADHD. Thus, in the next section, I present the way in which I used individual models in the current research.

### 2.3.2.5 Using individual models of disability

A key argument in the social theory of disability about the individual model is that its understanding of disability is associated with negative attitudes and barriers in people living with disability (Oliver and Barnes, 1993). However, this does not mean that we should ignore the medical/individual model of disability. Especially in the Kuwaiti context, critical discussions of the biomedical perspective of ADHD are rare. I agree with Thomas (2012) in using medical sociological approaches to critically discuss the biological and medical aspects of impairments. This might be similar to her argument about the social relational model of disability, which captures psychology and the psychodynamic aspect of impairment. However, the purpose is to discuss the biomedical perspective using a critical medical sociological approach, without falling into the trap of the biomedical model of individualising, victimising, and pathologising impairment. I intend to show how the individual paradigm in the Kuwaiti context differs from the Western perspective of ADHD. I want to leverage Conrad and Timimi’s (1992, 2005) ideas to explore the social aspects of varied individual perspectives on ADHD and the implications for families. Therefore, it is important to discuss the individual model in the Kuwaiti context.

### 2.3.2.6 Individual model in Kuwait

In this section, I follow the sociological approach in discussing ADHD understanding in Kuwait from an individual perspective. I began with the history of ADHD in Kuwait as well as the main social forces that contribute to the medical understanding of ADHD. I then discuss indications for the individual model understanding of disability and/or ADHD from practice in Kuwait that affect the understanding of ADHD as a ‘disorder’.

There are no sources for the date of the first appearance of ADHD in Kuwait. However, between 1966 and 2005, no research relating to ADHD was conducted in Kuwait. In 2005, Salem et al. reported the formal and government hospital’s ‘diagnosis’ of children with ADHD in Revolution Clinics at the National Bank of Kuwait Children Hospital. The centre was established in 1979 as the main hospital for the ‘diagnosis’, assessment, and ‘treatment’ of ‘mental health disorders’, one of which was ADHD. This suggests that ADHD had been known in Kuwait since then, especially after the establishment of a centre for children’s evaluation and teaching in 1984, which offered some limited attention to ADHD and learning difficulties in children.

However, ADHD was not given enough attention in Kuwait at that time. According to KALD (2017), the reason for KALD being established was that no other association took care of the students after their ‘diagnosis’. Further, in the first conference on psychological ‘treatments in Kuwait in 2011, Alanba emphasised that awareness of society with ‘mental health disorders’ in Kuwait society is scarce. He also pointed out that the impact of war and overlapping information about children contributed to the increase in ‘mental health disorders’ in children, especially ADHD (Alanba, 2011). In 2011, the first international meeting for learning difficulties and ADHD was conducted in Kuwait, organised by CCET and KALD to raise awareness of learning difficulty with educators, parents and government associations. This was important in order to try and break the false link between students with a learning difficulty being stupid or lazy (Alanba, 2015). However, the first recognition of ADHD as a disability occurred in 2015.

Knowledge about ADHD is underpinned by psychiatric and psychological discourses. However, throughout recent history, there has been a shift in naming ADHD as a ‘disorder’ and as a learning difficulty, which reflects an increase in interest in the educational discourse. Although this discourse might increase the power of doctors and teachers in labelling and treating ADHD, this might not be the case in everyday practice, as I observed that lack of awareness about ADHD in Kuwaiti society remained until recently. However, this raises the question of the kind of awareness of ADHD that non-profit ADHD organisations might share. From the background of these organisations, it seems that they follow the USA perspective on ADHD, which reflects a biomedical understanding and discourse (Khullar and Coughlan, 2018). Kuwaiti psychiatric hospitals follow the DSM-5 for ‘treatment’ and ‘diagnosis’. This indicates that Kuwaiti knowledge about ADHD is rooted in a biomedical understanding.

There is much evidence that Kuwait follows an individual/medical perspective on the understanding of ADHD. Notably, Disability Law No. 8 is underpinned by the biomedical perspective on the care and support of people with ADHD, which is usually accessed based on ‘diagnosis’ and labels. Accessing support and services requires a medical certificate of disability from PADA (Al-Daihani and Al-Ateeqi, 2015). These labels determine necessary benefits, depending on knowledge about the label from the biomedical perspective. Aspects of support for children with learning difficulties (including ADHD) focus only on academic and medical support. Families have access to the hospital to diagnose the child and for ‘treatment’, as well as educational support in special needs schools (Al-Daihani and Al-Ateeqi, 2015).

In the Kuwaiti policy section, I give the definition of disability used in Disability Law No. 8. Disability is understood to be tragic through the use of the word “suffering”. The tragic perspective on disability also appears in Article 8 of Law No. 8, in which people with disabilities are continuously referred to as being “in need of care and help”. This help is determined by the medical professional, which is termed a “competent technical committee”. The tragic perspective was criticised by disability activists, such as Swain et al. (2003), who argued that people with disabilities might need some medical help with impairment, but that does not mean they are disabled in all aspects of life neither are they unable to make their own decisions about the services they need.

Other evidence can be taken from Khullar and Coughlan (2018), which used the narrative of medical professionals to investigate mental health practice in Kuwait. They argued that Kuwait’s mental health care system is influenced by the Western medical perspective of disability. Professionals recommend pharmacotherapy as the main option for people with mental health. However, Khullar and Coughlan (2018) highlighted resistance to the medical perspective from a private sector professional, who used a more patient-centred approach to mental health that considered social and cultural influences on mental health in the intervention. As mentioned earlier, the certificate for disability is obtained from medical professionals in the government sector who advocate the medical model. The last observation was also noted by Banza (2009), who discussed the Western perspective of colonisation in the Kuwaiti context. This brought the norms and standards of what is a ‘normal human’, such as the Western concept of childhood. The adoption of the Western medical perspective in the Kuwaiti context does not consider the Arabic and Islamic nature of Kuwaiti society.

## 2.3.3 Social models of disability

### 2.3.3.1 Social oppression theory (Social Model)

This subsection discusses social oppression theory models of disability. I adopt different tools, including the social model (Oliver, 1996) and the social-relational model (Thomas,1999). I also draw on the social approach to stigma theory (Link and Phelan, 2001). First, I present an overview of social oppression theory, which is the origin of the models. Then, I illustrate the framework giving the key concepts and limitations of each model and the way they are linked to each other. Finally, I apply the models to the Kuwaiti context.

As illustrated in the previous section, in the UK before the 1990s, disability was understood in terms of ‘medicine’ and ‘psychology’, both of which were perceived as an individual’s biological and psychological pathology (Mallett and Runswick-Cole, 2014, p.4). The individual model of disability changed under the influence of an advocacy organisation for the rights of people with disability (disabled people). The Union of the Physically Impaired Against Segregation (UPIAS), founded in the 1970s, established the Fundamental Principles of Disability after Paul Hunt’s letter to the Guardian in 1972 (Shakespeare, 2006). UPIAS presented disability using the social oppression theory.

Social oppression theory understands disability not as a problem in the individual, but as an issue in the social structure and environment (Cameron, 2014). It values the personal experiences of disabled people to challenge the dominant tragic individual and medical perspectives in society (Mallett and Runswick-Cole, 2014). Disability is understood through the distinction between impairment, which is bodily dysfunction, and disability, which is the social disadvantages and restrictions that exclude disabled people from social activities (Cameron, 2014).

Social oppression theory contains many models (see Table 1: The models of disability) that are similar in unifying the purpose of empowering and improving disabled people’s lives, as well as removing social barriers that oppress them, to ensure social inclusion (Shakespeare, 2006; Oliver, 1996). However, each model differs based on where it is located and the way it discusses the problem of disability in a social context (Goodley, 2011). Social oppression theory advocates the removal of the social, cultural, attitudinal and environmental barriers that disabled people face. (Mallett and Runswick-Cole, 2014). From models of social oppression, I present the social model and the social relational model below.

صورة تحتوي على منضدة

تم إنشاء الوصف تلقائياً

**Table 1:** The models of disability

### 2.3.3.2 Materialist social model

The materialist social model is based on the resistance of activists and academic sociologists, such as Finkelstein (1980), Abberley (1987), Barnes (2008), and Oliver (1990, 1996), to the dominant understanding of disability. Their work is distinguished by its reliance on Marxist theory, which interprets disability from a materialist understanding (Abberley, 1987). They link the disadvantages that disabled people experience with the ideology of capitalist society, a view of society built on the principle of productivity (Barnes and Oliver, 2012).

A key principle of the materialist social model is the distinction it makes between impairment and disability. Impairment is understood as ‘functional limitation within the individual caused by physical, mental, or sensory impairment’, while disability is ‘the loss or the limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers’ (Barnes 1991, pp.2-3). The inability of disabled people to participate in society is not because of their impairment but because of society’s failure to provide suitable support for disabled people or to understand their needs (Anastasiou and Kauffman, 2011).

The materialist social model normalises impairment by arguing that there is nothing in the bodies or minds of disabled people that is worth discrimination and oppression (Anastasiou and Kauffman, 2011). Impairment is not tragic, and disabled people are not victims of their own impairment (Oliver, 1996). Regarding disability, the model focuses on economic, political, and social forces and aspects of the context that affect social policy and create disadvantages for disabled people, who are characterised as dependent and disabled (Barnes and Oliver, 2012).

The notion of dependency is crucial to the materialist social model of disability (Oliver and Barnes, 2012). In general, we all depend on each other, but disabled people are portrayed as dependent because they rely on the state for all material aspects of life (Swain et al., 2003). This negative interpretation of dependency is a product of society’s structures (Sullivan, 1991). The exclusion of disabled people from work has made them dependent on the state for support (Sullivan, 1991). Furthermore, the dominant use of the medical model to explain the problems and needs of disabled people promoted the notion of care and legislated the idea of dependency (Swain et al., 2003). With power and control remaining in the hands of professionals who underpin the medical and biological perspectives, disabled people are given little information or choice about possible help (Swain et al., 2003).

The materialist social model advocates balancing the power between disabled people and professionals as a way which helps achieve independence for disabled people (Oliver and Barnes, 2012). It defines independence as the ability of disabled people to be able to control the decision done over their lives, even when they need help, and how they receive that help (Oliver and Barnes, 2012). However, this notion is easily misinterpreted. Overly criticising professional authorities, without giving a clear explanation of dependency and challenging others’ interpretations of it, might cut off medical services and welfare and make the lives of disabled people even worse (Oliver and Barnes, 2012). Although the materialist social model succeeds in claiming some of the rights of disabled people, it still faces many criticisms.

#### 2.3.3.2.1 Criticisms of the materialist social model

The materialist social model was critiqued for not considering the variety of experience of disabled people. The social model discusses disability from a physically disabled, white male, middle-class perspective (Morris, 1992). This perspective fails to recognise that some disabled people’s experience differs as a result of their colour, race and/or gender (Morris, 1992). Moreover, it would be more comprehensive to address other cultures that might have a different understanding of disability (Cameron, 2014). The previous two criticisms were reflected in Ghai (2002), which presents a study of disabled women in India. This highlighted the double experience of disability in society from the perspectives of gender and disability. The low number of women in comparison with men in Indian culture adds more oppression and marginalisation to the experience of disabled women, in addition to what they had already endured because of their impairment (Ghai, 2002). These issues are often ignored by the materialist social model of disability discussion.

Moreover, despite the assumption that materialist social model is used to address all disabled people, including those with sensory and cognitive disabilities (Lester and Tritter, 2005), there is still an argument on the limitation of the materialist social model to include people with learning difficulties (Goodley, 2001) and with a mental health disorder (Beresford, 2002). Beresford suggested that the lack of discussion of ‘mental health disorder’ in the materialist social model might be linked to the invisibility of the condition. Goodley (2001) added that ignoring impairments such as learning difficulties (this also applies to mental health) discriminates against people with learning difficulty from the materialist social model (Goodley, 2001). Both scholars gave a similar argument about the importance of discussing impairment to address all disabled people.

Lastly, the materialist social model has been criticised because it creates a distinction between disability and impairment and focuses on disability. In a simple way, criticism based on the idea of removing material barriers cannot ensure the inclusion of disabled people in society (Swain and French, 2000). For example, access to work and public places does not prevent disabled people from being stigmatised or from experiencing the discriminatory attitudes of other people (Swain and French, 2000). However, Oliver (1996) responded to such critiques by suggesting that the social material model did not deny issues with impairment or the possibility of impairment restriction, but focused on social barriers (Oliver, 1996). Addressing issues around ignoring the discussion of impairment from disability studies led to the appearance of relational models, which discuss the personal and social aspects of impairment (Tøssebro, 2004; Shakespeare, 2006; Thomas, 2007). The relational model understands disability as a product of the social environment as well as impairment (Reindal, 2008). However, the way impairment is conceptualised differs between relational models.

One direction came from scholars such as Shakespeare and Watson (2002), who suggested a combination of biological (impairment) and social (disability) aspects in discussions of disability. While the social material model focuses on disability as a way to unify the claims of disabled people and advocate for changes (Oliver, 2013), disabled people differ in the barriers they face because they are linked to different social factors, one of which is impairment (Shakespeare, 2013). In response, Oliver (2013) was cautious about discussing impairment, because it would depoliticise materialist social model and its value in improving and defending the lives of disabled people. Barnes and Oliver (2012) supported their argument by discussing the way the biological aspect of impairment had been used in government policy to reduce benefits and services based on the type of impairment. Certain benefits were provided to disabled people with critical needs, while other disabled people were ignored (Oliver and Barnes, 2012). Another direction is the Nordic relation model, which understands disability to be “a mismatch between the person’s capabilities and the functional demands of the environment” (Tøssebro, 2004, p.4). It does not ignore individual limitations but indicates that these limitations are related to certain circumstances (Gustavsson, 2004). The relational model highlights the social and environmental aspects that affect disabled people uniquely and negatively because of their impairment (Gustavsson, 2004). A key point in the model that is relevant to current research is the definition of disability. In the Nordic model, there are no differences between disability and impairment, which is similar to the Kuwaiti context.

I intended to use the materialist social model to discuss the understanding of ADHD, and the main reasons for discussing its criticisms are to demonstrate its scope, as well as to address its limitations in a variety of disabilities, including ADHD. The Nordic model illustrates a very different understanding compared to the social material view of disability. Therefore, while the debate above illustrates that a discussion of impairment is important in understanding the variety of disabled people’s experiences of disability, I situate the understanding of impairment in the social relation model (Thomas, 1999; Reeve, 2014). However, as I am using one of the feminist models, the social relational model, to discuss impairment, addressing the feminist disability studies and acknowledging its position within the current research is essential.

### 2.3.3.3 Feminist disability studies

Feminist disability studies focuses on issues from the experience of disabled women that are often ignored by disability studies and feminist theory (Thomas, 1999; Be, 2012). Be (2012) argued that a key idea of feminist disability studies is that disabled people are not a unified group, as the disadvantages faced by disabled women differ from those faced by disabled men. Scholars working within feminist disability studies address a combination of different ideas, such as *rethinking of impairment* (Thomas, 1999), *the personal is political* (Morris,1992), *interdisciplinarity* (Wendell 1996) and *cultural diversity* (Garland-Thomson, 2002) contributing to disability studies. In this section, I consider my attempt to use feminist disability theory to discuss gender (Morris, 1992; Garland-Thomson, 2002) in the current research on parenting a child with ADHD.

Ideas from feminist disability studies are crucial in the current research, which focuses on the perspective of mothers and fathers and on ADHD. For example, Morris (1992) was a good lesson on how to evaluate taken for granted ideas about disabled women (or in the case of the current research mothers of disabled children) in non-disabled society by listening to the different perspectives of women who had often been silent. The social model focuses on independent living, which means that disabled people are in control of how and who provide services of care for them. Feminist scholars such as Morris (1992) provided a different perspective on care in the life of disabled women that often falls outside feminist and disability studies. Using the personal stories of disabled women, Morris argues that disabled woman who were often seen as dependent and in need of care could themselves have been a carer for their family. She critiqued the perception of dependency and extended the understanding of care.

To contextualise the discussion of gender and disability in parenting studies, Blum (2007) used a combination of feminist and disability studies to highlight issues and explain the inequalities faced by mothers of disabled children, such as mother blaming. Malacrida (2009) showed that inequality and blaming are often linked to an ideology of so-called normal motherhood and fatherhood, which provides a limited perception of the role of each individual in the process of parenting. This ideology sees the role of parenting a child and caring for a husband as the responsibility of the mother, which leads to various and different family roles being either unrecognised or presented as other (Malacrida, 2009). As a consequence, mothers are usually blamed if they fail to play this role, while fathers’ parenting efforts are often unrecognised in the literature on parenthood.

This unrecognised grouping of care and parenting is absent because disability studies needs what Wendell (1996) called an interdisciplinary analysis of the experience of disability. In her discussion of the relationship between age and disability, she illustrated the way society is built from certain paradigms that emphasize being young, non-disabled and male. This makes any individual that does not fit the criteria disabled. Thus, everybody is temporarily non-disabled until they become old. Despite her discussion being around who identified as disabled or non-disabled, interdisciplinary analysis could open up the discussion on the link between disability and other social groups such as gender or class. This is important for the current research on parenting, which often addresses issues of care from the mother’s perspective, ignoring the father’s perspective. Moreover, as recommended by Rayan and Runswick-Cole (2008), it could be used to focus on the complexity and diversity of the parents of disabled children’s experience and perception, which often differs because of the disability experience combined with other social categories.

However, the combination of feminist orientation and disability studies to discuss inequality and gender is even trickier with the parents of disabled children (Robertson, 2014). The social construction of parenting disabled children is linked with negative perceptions and incompetence, which puts the parents of disabled children under constant observation and stigmatises their role, while there is a lack of access to support and information (Rayan and Runswick-Cole, 2008). Ideologies of parenthood and social structures, in combination with social perceptions of disability, make it even harder for parents of disabled children to fit the expectation of parenting.

To complicate this topic, the current research focuses on non-disabled parents’ experiences of raising disabled children. The position of parents with disabled children is complex within feminist and disability studies. This is because disability scholars question the status of non-disabled parents and the legitimacy of them representing their children (Ryan and Runswick-Cole 2008). This leaves the parents’ experiences to be represented by medical research models that focus on the negative impact of impairment from a personal and psychological point of view, while ignoring other parts of their experience. The issue with medically oriented studies is that they ignore the complex social context and medical practices that play roles in the negative experiences of the parents (Blum, 2007; Malacrida, 2009). Thus, a feminist approach could offer an interactionist perspective that captures the complexity of the parents’ experiences (Ryan and Runswick-Cole, 2008). However, in the current study, it is important to contextualize feminist theory within the Arab and Kuwaiti contexts.

Since the first half of the 20th century, the patriarchal nature of Arab societies has challenged women (Al-Serhan, 2016). Like their Western counterparts, Arab feminists have endeavoured to understand the nature of gender inequality (Al-Serhan, 2016). In Kuwait, there are two feminist orientations: Islamic women who are part of the Islamic movement and liberal, activist women. An important achievement of the alliance between two movements led to reform in the role of women in some aspects of Kuwaiti politics and economics (Al-Mughni, 2010). For example, as the constitution of Kuwait is based on Islamic principles, the alliance between the two movements presents arguments based on religion, the Kuwaiti constitution and international human rights to achieve rights such as the involvement of women in parliament and claiming payment for housework and bringing up children (Al-Mughni, 2010).

The alliance of activist and Islamic movement feminists has led to advocating for women’s rights using the understanding of Islamic women scholars to challenge men’s interpretation of Islamic teaching. This could be useful when addressing the issue of motherhood from the religious and cultural perspectives, because Islamic women are able to challenge the traditional Islamic interpretation of the role of women, depending on their knowledge of Islamic studies, without being criticised for colonising Islamic society with Western ideas that do not fit Islamic and social values (Al-Mughni, 2010).

However, this alliance is similar to Arab feminist movements in Egypt and Jordan, which were limited to the areas of politics, education and economics, following the Western perspective (Al-Serhan, 2016). This could be problematic because it might ignore important cultural and social issues, such as males authority over females, the destructive effects of patriarchy and negative stereotypes of women being less capable and intellectual than men (Al-Serhan, 2016).

Moreover, like the mistakes made by Western disability studies in the Arab world, it seems that feminist achievements present a collective presentation of women’s issues relating to equality and gendered understandings that fail to address minorities. This includes the cultural aspect of the perception of parenting and blaming mothers for their children’s behaviour and disability. Therefore, feminists advocate for an interdisciplinary approach to address the complexity of women’s rights when mixed with social types, such as gender and class. For example, Boukhari (1997) explained that the association between motherhood and the birth of a disabled child could lead to the stigmatisation of the mother because mothers are seen as being mainly responsible for the birth of a disabled child. This issue sometimes extends to the mothers themselves if they internalise the stigma and blame themselves when they hold such a belief. However, this issue does not receive the attention that the political, educational and economic inequality of women in Arab societies has (Al-Serhan, 2016).

To conclude, it is tempting to use interdisciplinary ideas from feminist theory when discussing the experiences of parents raising children with ADHD, especially when exploring gender differences in the roles of mothers and fathers in parenting a child with ADHD. This because feminist interdisciplinary analysis tools could help to understand the powerful social norms that acknowledge certain parenting practices while devaluing others (Wendell, 1996). Moreover, examples such as Ghai’s (2002) analysis of the impact of postcolonial on the social perspective of disabled women could help to understanding the influence of globalisation on the parents' ideas about parenting a child with ADHD.

However, I chose not to use feminist disability theory as the main theory to discuss gender in the current research, because feminist theory encourages exploring the link between disability and the social and cultural contexts (Garland-Thomson, 2002). As I mention above, most Arabic and Kuwaiti feminist studies is economically and politically oriented while the cultural aspect remains undeveloped. Thus, it is difficult to articulate a cultural and Islamic feminist interpretation of the complexity of parenting a disabled child. Moreover, the current research does not focus on gender, despite it being a factor in the differences in the parenting experience. However, it is important to acknowledge the influence of feminist disability theory on my gender analysis and understanding of the experience of parenting a child with ADHD. While I was only able to use some feminist disability theory ideas of gender, I used other feminist scholar’s ideas to discuss impairment, which I will explain below.

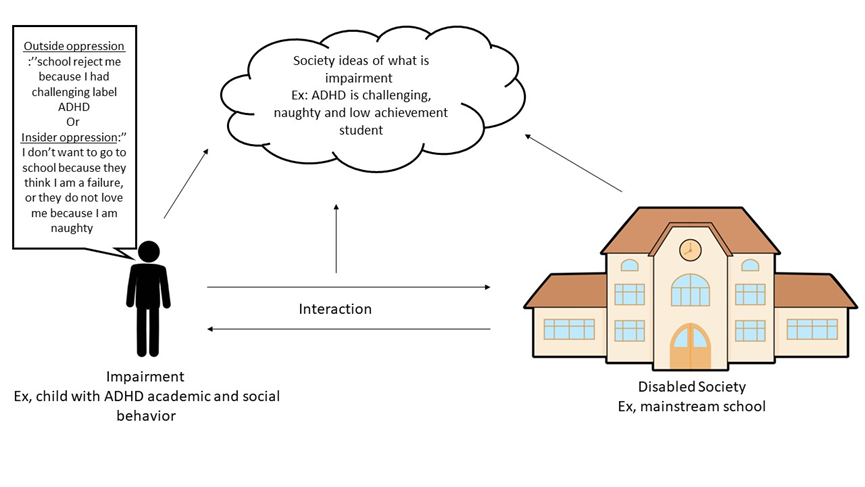
### 2.3.3.4 Social relational model

In this section, I continued the discussion on how to address the limitations of the materialist social model by discussing the work of Thomas (2004) and Reeve (2014), who advocated refining the model into a social relational model. The social relational model added to the meaning of disability, extending the materialist social model and answering its critics. Unlike the materialist social model, which used the term disablement to refer to the impact of the material social barrier on disabled people, Thomas (2004, p.11) argued that social barriers leads to disablism (see Figure 2: The social relational model - disablism). Disablism is:

The social imposition of avoidable restriction of the life activities, aspiration and psycho-emotional well-being of people categorised as 'impaired' by those deemed 'normal'

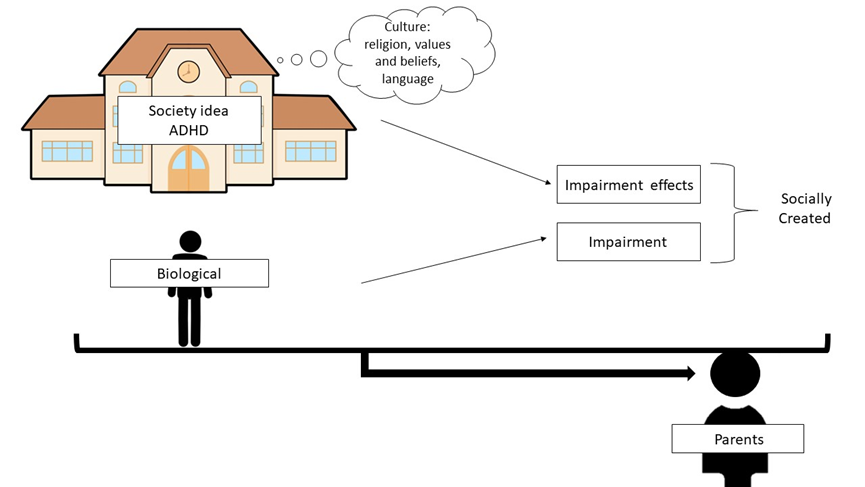
Thomas (1999) maintained the main principles of the social materialist, with one being that disadvantages are based on social reasons, and not because of an impairment. Another is the distinction between disability and impairment, but with clarification of the meaning of disability (Reeve, 2014). Disability is defined as social oppression; it restricts disabled people from social inclusion and affects their emotions and wellbeing (Thomas, 2004). Thus, it includes structural and psycho-emotional dimensions (Reeve, 2014). From the social relational model, social oppression negatively affects how disabled people see themselves, such as feelings of worthlessness (Reeve, 2014). While the materialist social model focuses on social structures and environmental barriers that restrict what disabled people can do, the relational model argues that the psycho-emotional barriers from social oppression could affect the way disabled people could ‘be’ (Thomas, 2007). This barrier to ‘being’ is perceived as how disabled people are seen or how they see themselves (Reeve, 2014). The psycho-emotional aspect of the experience of disabled people has been discussed in terms of individual psychopathology, yet the social relational model illustrates how these experiences are linked to social oppression (Reeve, 2014).

A key point of the social relational model is that social oppression is based on an unbalanced relationship between people with an impairment and people without an impairment (Reeve, 2014). Specifically, people with an impairment do not recognise the disadvantages imposed on them because of the social structures and common cultural practices that place disabled people in inferior situations (Thomas, 1999). Moreover, the medical language used in conversations devalues and disempowers disabled people (Thomas, 1999).



**Figure 2**: The social relational model - disablism

Further, the materialist social model was criticised for ignoring impairments and focusing on social aspects of disability, which left the discussion of impairment in the realms of biological realism (Thomas, 1999). The social relational model brings back impairment, on the basis that both disability and impairment are socially created and create barriers (Thomas, 1999). However, Thomas explained impairment using the term ‘impairment effect’ to show that social oppression could happen because of an impairment (Thomas, 2004; See **Figure 3**: The impairment and the impairment effects - the social relational model). The negative effect of impairment on society’s understanding of impairment is separate from biological impairment (Thomas, 1999). Social oppression is caused by the impairment effect and disablism. The former is part biological and part social, while the latter is wholly social (Thomas, 1999).



**Figure 3:** The impairment and the impairment effects - the social relational model

Applying the previous point to ‘mental health disorders’ (such as ADHD), many barriers faced by people with ‘mental health disorders’ are non-material, such as hatred and harassment, rather than material barriers (Goodley, 2001). Reeve (2012) argued that psycho-emotional disablism was more relevant to the experiences of people identified with ‘mental health disorders’. The explanation of non-material barriers from disablism theory situated intervention and changes in the social context, not in the individual (Reeve, 2012).

#### 2.3.3.4.1 Criticism of social relational model

As with the social materialist, the social relational model also faced criticism. The social relational model does not focus on impairment, but on the impairment effect, ignoring the biological aspects of the impairment (Shakespeare, 2013). It is true that impairment might create a barrier for disabled people. Ferrie and Watson (2015) illustrated this in their study of people with motor neurone disease (MND). People with MND experience a fear of impairment ‘symptoms’, such as choking. This affected the participants’ understanding of what they could do (Ferrie and Watson, 2014). Thomas (2012) addressed this criticism, showing that the model focuses only on social psycho-emotional impairment, because extending the discussion could return the impairment to the medical model, which might oppress disabled people further (Thomas, 2012). Moreover, another criticism of the social relational model is that it only sheds light on two aspect (the medical and the social aspects) of the experience (Watson, 2012). This leads to the assumption that their experience has a dual source, instead of acknowledging that it is a very complex experience (Watson, 2012). It is true that other models of disability have addressed other perspectives (Watson, 2012). One example is the effort of critical disability studies to deconstruct the impact of cultural discourse on understanding disability (Meekosha and Shuttleworth, 2009). However, in the context where there is a lack of studies of disability from a social perspective, such as Kuwait, it would be better to begin with two of the simpler models of disability as a good and encouraging start, and then advocate for future research to explore disabilities in more depth.

### 2.3.3.5 Affirmative model of disability

Both the social material model and the social relational model focus on highlighting the way disabled people are disadvantaged and oppressed in their social environments (Shakespeare and Waston, 2010; Reindal, 2008). The affirmative model was developed to address the limitations of the social material model in failing to account for the personal experience of impairment. It also shares features with the social relational model by addressing disability and impairment as relational between the context and people with disability. This subsection will continue to discuss the ways in which the research addresses the limitations of the materialist social model in studies on ADHD by using a model that addresses the positive aspects and the differences in the personal experiences of disabled people with impairment through French and Swain (2000) and Cameron’s (2014) affirmative model.

The affirmative model was designed as a critique of the tragedy model and the development of the social model. In this research, it is used to address the limitations of the social relational model, which often focuses on the negative experiences of disabled people. The affirmative model was developed by Swain and French (2000), who set up their ideas and features as clearly defined by Cameron (2014):

Impairment: Physical, sensory, emotional, and cognitive differences, divergent from culturally valued norms of embodiment, must be expected and respected on their own terms in a diverse society.

Disability: A personal and social role that simultaneously invalidates the subject position of people with impairments and validates the position of those considered ‘normal’ (p.6).

The affirmative model is about challenging the normality of being and living from the perspective of disabled people (Swain and French, 2000). Moreover, it celebrates the differences between disabled people, without assuming that all disabled people might celebrate their impairment (Swain and French, 2000). It does not claim that the experience is all positive, nor does it ignore the hardships that disabled people encounter (Swain and French, 2000). It highlights the way societies can be oppressive based on disabled people’s experiences in everyday life (Cameron, 2014). While impairment might be difficult, but not inherently a problem, for people with disabilities, oppression from society can make it problematic. It causes negativity in the social response to disabled people’s impairments (Cameron, 2014).

The affirmative model has been used to highlight the positivity of employing people with learning difficulties (Inglis, 2013). Inglis (2013) indicated that people with learning difficulties are competent, loyal and enthusiastic, adding a positive element to their work and motivating their fellow employees. The model is not only about diversity, but also respecting the views of disabled people, even if they are children (Flynn and McGregor, 2017). Flynn and McGregor (2017) discussed social work for children’s protection in an Irish context. They used the affirmative model (French and Swain, 2008) to advocate for the importance of listening to children’s voices to better protect disabled children. They argued that children should be considered experts and active participants based on respecting their values and dignity to critically evaluate the interventions used to protect disabled children (Flynn and McGregor, 2017). Being respectful of the way disabled children think and present their experience could also apply to the non-disabled parents of disabled children, who are the participants of the current research. In line with their argument, this could also apply to parents whose voices are often ignored by support services for children with ADHD. This would help to meet the requirements of families and their disabled children in a way that addresses their individual needs by listening and being open to them. Standardisation in services and support might not always be the way to care about disabled people because it limits the flexibility of attending to the varying circumstances of different families (Flynn and McGregor, 2017).

#### 2.3.3.5.1 Challenges of the affirmative model

The ideas of the affirmative model could fall to the same feminist critique of the materialist social model , which fails to acknowledge the personal experiences of disabled people, which can be painful and difficult (Morris, 1992). However, the criticism here is not because the affirmative model ignores impairment, unlike the materialist social model , but instead because of focusing on positive cues, giving the assumption that disabled people might not need support and services. Although this might not be a valid criticism, because the affirmative model does not focus on positivity alone, it is also about how the experience of ADHD is different from the social perspective of the parents' experience with ADHD. However, Morris’s warning could be a wake-up call not to exaggerate when illustrating the positivity of the lives of disabled people, which presents a challenge for using the affirmative model (Flynn and McGregor, 2017).

This starts with the challenge of using positive terms to talk about people’s learning difficulties, which could potentially lead to more exclusion (Flynn and McGregor, 2017). For example, in the Kuwaiti context, especially in media advertising to share awareness about learning difficulties, people with disabilities are sometimes called ‘people of determination,’ in Arabic, ‘As-hab Alhemam’. The term might be superficially positive, but in looking at the meaning, it further excludes people with disabilities, as the term portrays impairment as a problem that people with the impairment must be patient with and are determined to overcome. This reveals the socially tragic view of people with disabilities. Despite using positive terms to describe people with disabilities, they are still seen from a negative perspective. While the model focuses on positivity from the disabled people's personal experience with their impairment, it might be better to look at the way disabled people talk about themselves.

Another challenge to positive talk about people with disabilities comes from Inglis (2013). He argued that talking positively about caring for people with disability might lead to the assumption of patronisation from the caregiver. The concern is that such comments, if made without thought, portray the caregiver as gaining power and self-congratulation by talking positively about caring for people with disability, especially if it was previously uncommon for them to talk about caring for disabled people in a positive way (Inglis, 2013). Goodley and Armstrong (2001) recommend stories of love that can assert positivity without being confused with being patronising.

Finally, talking positively about people with a disability might imply that they do not need services or support because they are independent and able to control their lives. In normative society, as mentioned in Parson’s theory (see Section 3.1.1), the patient must play the role of victim and dependant in order to get support and help (Heidarnia and Heidarnia, 2016). Thus, using the affirmative model might be misunderstood as an invitation to cut off services and financial support for people with disabilities. The problem with talking about positivity is that it is seen from the view that impairment is either good or bad; while the affirmative model advocates listening to the ways people with disabilities might challenge this dichotomy by using their own terms to define their impairment, and talk about their lives and the societal perspectives on their impairment (Inglis, 2013). As with any other individuals, people with disability might have good experiences, but this does not mean that they never encounter difficulties. Inglis (2013) suggested a balance between talking about people with disabilities’ positive experiences, without ignoring their needs, because listening to people with disabilities directly could provide a better understanding of their needs which is not solely focused on the impairment (Inglis, 2013).

#### 2.3.3.5.2 Neurodiversity vs. affirmative model in ADHD

As illustrated in the previous section, the affirmative model focuses on disabled people’s modes of discussing their impairment in a way that is different from social expectations. This idea was similar to the neurodiversity approach, which is often used in research on people with ADHD rather than the affirmative model (Taylor et al., 2020; Sedgwick et al., 2018). Both approaches also challenge the negative social expectations of ADHD in a more positive way than it being abnormal or deviant behaviour. However, there are also differences between the two approaches. This subsection outlines the specifics of the neurodiversity approach before advocating for the use of the affirmative model.

The neurodiversity approach started as a social movement for autistic people and was used to explore the experiences of people with other neurodivergent conditions, such as ADHD and dyslexia (Armstrong, 2010). The reason for choosing to talk about neurodiversity as one of the approaches underpinning the social oppression model is that it has some influence from the social oppression model, as it focuses on the ways in which social and cultural practises and perceptions of neurodivergent conditions, such as autism and ADHD, create disadvantages for people with such conditions (Shakespeare, 2013). This approach targets the social environment for changes, instead of situating the problem in neurodivergent individuals who need to change to fit normal standards (Graby, 2015; Runswick-Cole, 2014). This is based on the idea that the neurological causes of neurodivergent conditions are natural differences that should be appreciated and valued instead of being cured and normalised (Graby, 2015; Runswick-Cole, 2014). However, this approach has been used in various ways.

According to the literature (Ortega, 2009; Graby, 2015; Runswick-Cole, 2014), there are several main principles in the neurodiversity approach. First, neurodivergent conditions, such as ADHD and autism, are natural and positive. Neurological differences only consider mental ‘disorders’ to be negative because of the standard tools used for the ‘diagnosis’, such as DSM-5, instead of situating the brain condition between normal and abnormal dichotomies (Armstrong, 2010). Second, the neurodivergent approach is based on the assumption that there are differing mental states and that each is unique but not abnormal (Rothstein, 2012). The question is not a matter of differing terms, between disorder or neurodiversity, but about the support that we provide, depending on whether it is a curative or inclusive environment. The argument is effectively whether to normalise neurodivergent children or to work to enhance their diversity (Rothstein, 2012). Third, the brain causes neurodivergent conditions. Armstrong (2010, p.11) argued that ''there is no mental capacity, no normal brain, to which all other brains are compared; neurodiversity simply means being wired in a different way rather than wrongly.'' Finally, people with neurodivergent conditions are experts in their experiences. This approach is used to explore the views of people with neurodivergent conditions to challenge such conditions being viewed as ‘deficits’, ‘disorders’, or stigmas (Ortega, 2009; Graby, 2015; Runswick-Cole, 2014).

According to a systematic review examining research using the neurodiversity approach to explore the experiences of students with learning difficulties, the intervention often suggested from such studies shares the principle of rejecting the labelling and segregation of neurodiverse students (Clouder et al., 2020). However, the authors warned that rejecting labels without supporting their cultures and environments might not be in the best interests of neurodivergent people (Clouder et al., 2020). The current research is in line with their argument, because in a society where the medical model dominates, as in Kuwait, this might prevent neurodivergent people from accessing the needed support. This does not mean that we cannot choose a less stigmatising label for neurodivergent people by being open to the experts in social interaction, particularly parents, as highlighted in the implications of this research (see Chapter 8).

Moreover, the neurodiversity model has been accused of ignoring the difficulties that neurodivergent people and their parents face, as well as the psychological and medical support needed by neurodivergent people (McWade, Milton and Beresford, 2015). The purpose of this approach is to provide an alternative to the untold side of the experience and not to diminish the difficulties neurodivergent people face (Armstrong, 2010). This helps to understand the strengths of students with ADHD and to create a positive environment that enhances their abilities. This is also an orientation that parents’ stories adopt in many episodes. People’s societal expectations often impact their behaviour. If ADHD is always represented as negative, it may not only affect children’s behaviours, but also compromise the attitude of educators and people around them (Armstrong, 2010).

It must then be asked: which approach (affirmative model or neurodiversity approach) is better suited to the current research? As mentioned above, the social model leaves the understanding of an impairment to the medical model, which sees it as ‘disorder’ or ‘disease’; this ignores a number of people with mental health and neurodevelopmental issues who might not think of their conditions as impaired (Beresford, 2010). Neurodiversity addresses this limitation by considering impairment to be part of the diversity of human existence and not a medical problem. This makes neurodiversity an option to address the impairment limitation of using the social model to explore ADHD underpinning the disability perspective, which focuses on society as a source of impairment and disability, not the individual (McWade et al., 2015).

The current research is influenced by neurodiversity, but it ultimately rests on an affirmative model. This relies on the assumption that neurodiversity may help to understand the strengths of students with ADHD in order to create a positive environment that enhances their abilities (Armstrong, 2010). It may also improve social attitudes towards ADHD and decrease its stigma (Armstrong, 2010). However, this research does not contribute to the validation of the neurological claim that the brain is simply different in ADHD (Rothstein, 2012). Rather, the aim of this study is to explore the social construction of ADHD, not the ‘reality’ behind it. Thus, it focuses on the difference itself, for example, as manifested in various lifestyles or circumstances (Cameron, 2014).

### 2.3.3.6 Disability studies on ADHD

Significant research has been conducted to explore the experiences of children with ADHD and to illustrate the social barriers they face (Peters and Jackson, 2008; Blum, 2011; Nurullah, 2013). However, these studies are not specific to the materialist social model approach. A few researchers have used the social relational model. James (2020) studied the physical course of inclusion in postsecondary school for students diagnosed with ADHD. Interviews with students with ADHD showed that understanding the ‘diagnosis’ of ADHD and its characteristics played a role in empowering them in the response and attitudes of teachers in practice and strategies of students in physical courses. However, by focusing on the social understanding of ADHD (disablism), James argued that the instructors’ inability to conceptualise ADHD created barriers and challenges, such as time constraints, on the students’ strategies. The social relational model extended the discussion of the experience of social barriers to ADHD by illustrating the social perceptions underpinning such barriers.

The current research also focuses on understanding the parents’ experience. Little is known about the experiences of parents of children identified with ADHD from the perspective of the materialist social model (Jarret and Llewellyn, 2014). The challenges that children with disabilities present to the norms and common assumptions about childhood, especially the behaviour of children with ADHD, are often linked to questions about the efforts of the parents to fulfil their responsibilities according to the dominant understanding of parenthood (Blum, 2011; Ghosh et al., 2016). This leads to disadvantages and barriers that parents must face through their experiences of parenting (Blum, 2011). Thus, there are links between disability and parents’ social barriers. However, it is important to understand how social perceptions of ADHD can affect the experience of parenting a child with a disability.

The experience of mothers of children with disabilities illustrates that mothers also encounter disablism (Ryan and Runswick-cole, 2008). The lack of knowledge and information about impairment by mothers of disabled children and about parenting a disabled child leads them to face a fear of social assessment that doubts their role as a mother (Ryan and Runswick-Cole, 2008). This was also the experience of thirty mothers of children with learning difficulties from Wales, in a study that showed how mothers faced barriers in negotiating their views about their children’s impairment and their ways of parenting differently compared to professionals (Todd and Jonas, 2003). Mothers faced disablism from the professionals due to their medical perspectives on the children’s disabilities, which created barriers to the mothers obtaining suitable support for their children (Todd and Jonas, 2003).

Despite the usefulness of the social relational model in understanding the experience of parenting a child with ADHD, it has yet to address the previous criticisms, especially those related to the investigation of cultural values. Thus, in the next section, I expand the discussion using the social approach perspective of Goffman’s theory.

### 2.3.3.7 Social approaches to stigma theory

Stigma theory has been used to explore the individual, social and structural aspects of disability stigma (Link and Phelan, 2013). There are many models of Goffman’s stigma theory (Yang et al., 2014). For illustration purposes and to trace back the development of stigma theory from individual to social, I discuss three of these models using Rohwerder’s (2018) terms of classification: intrapersonal, interpersonal and structural using a comparison of the model’s perception of disability and the main components of stigma they focus on. I then show how the components of the model are used to expand a discussion on the social approach to disability.

The intrapersonal terms link the stigma to the individual character (Corrigan et al., 2014). This orientation focuses on the familial context to highlight the type of stigma and its effects on people with disabilities, which contributes to developing personal coping strategies (Dalky, 2012). Interpersonal terms locate the stigma in the interaction between the person and their society (Thornicroft et al., 2016). This model is used to understand the way stigma happens, without any negative experiences with people with disabilities (Corrigan et al., 2004). Thoughts, feelings, and behavioural responses to stigma are affected by the stereotype and meaning of disability within society (Corrigan et al., 2004). The structural model locates the stigma within the social, political and economic power of society (Link and Phelan, 2001). As with previous models, the structural stigma process starts with stereotyping, labelling and separation, which identify attitudes towards people with disabilities but add status loss and discrimination (Link and Phelan, 2001). Stigma is believed to be a product of the disadvantage and disempowering of social structures that advocate stigmatised attitudes towards people with disabilities (Link and Phelan, 2014).

The models of stigma theory are useful in expanding social oppression models of disability. In the social relational model, both stigma and the model share similarities in understanding the perceptions of people with disability. Stigma theory focuses on internalising stigma, that is, people with disabilities believe and apply the cultural and social values of negative perceptions of disability to themselves (Thornicroft et al., 2016). This perception might prevent people with disabilities from certain social activities or affect the way they think about themselves, which Reeve (2004) called psycho-emotional disablism. The exploration of internalised stigma can expand the discussion of structural and psycho-emotional social barriers from the social relational model by illustrating the impact of stigma on people with disabilities and the cultural perspective of disability.

Moreover, and especially for the materialist social model , the use of the structural model of stigma illustrates the variation in the material social barriers of people with ADHD. As I mentioned earlier, ADHD presents a challenge for the materialist social model because of limitations to the impairment discussion, as well as the different material social barriers it presents (see Section 2.3.3.2). While environmental access and a lack of support tools present a material social barrier for people with physical and sensory disabilities, the label and its social perception lead to discrimination and oppression for people with ADHD (Grue, 2016). The social approach to stigma theory is based on the idea that labels not only reflect the impairment limitation, but also the social structure that advocate marginalisation in return for services and support (Grue, 2016), which may expand the discussion of material social barriers.

However, as the research is located in Kuwait, below I negotiate and tailor the comprehensive stigma model (Link and Phelan, 2001) to fit global research on the stigma process.

#### 2.3.3.7.1 Cultural studies of stigma

The stigma of disability is considered a universal problem (Ciftci and Corrigan, 2013), yet the process of different aspects of stigma and the implications for the parents of children with ADHD differ between cultures. Modified labelling theory (Link et al., 1989) has been used to understand the cultural conception of disability (Phelan et al., 2013). This is because social perception, such as the beliefs and devaluation of stigmatised attributes, as well as the expected discrimination against them, is learned and internalised by individuals during socialisation (Link et al., 1989). The relevance of the modified theory to culture studies is shown in the observation that social beliefs about ‘mental health disorders’ are not always “strongly negative” but changeable based on culture (Link et al., 1989, p.404). However, I will expand the exploration of cultural beliefs and ideas to not only illustrate how stigma differs in certain contexts (Araujo et al., 2017; Dalky, 2012), but also to investigate cultural social aspects, that is, the way culture impacts social structures and practises in the experiences of disability (Link and Phelan, 2001).

Based on a review of global studies on the stigma process (Griffiths, 2006; Yang et al., 2007; Yang et al., 2013; Dalky, 2013; Kayama and Haight, 2014; Rohwerder, 2018; Gayapersad et al., 2020), most research often discuss the culture and structural differences in the stigma process. One important issue in applying Link and Phelan’s (2013) conceptualisation of stigma is that it is difficult to distinguish between the influence of culture on social perception and structure. This is because social structure and institutions impact the way people understand disability, but they are also affected by cultural values. For example, Gayapersad et al. (2020) showed how street children in Kenya were stigmatised because of the label ‘chokoraa’, which is a negative socially constructed label for street children. In their analysis of the label and stigma, it seems that the power of cultural values, such as kinship structures and expectations about childhood, as well as poverty, failure of social policies of care, and media, were all factors that legitimised negative social responses to the ‘chokoraa’ label and street children (Gayapersad et al., 2020). The cultural values and structural stigma were interconnected and both were linked to public stigma, which makes it hard to determine whether stigma’s negative impact was the result of the structure or cultural values.

Another important issue that arises from cross-cultural research is the link between social institution policies and practice, and social attitudes (Griffiths et al., 2005). Policies might influence public attitudes, but in return, public opinion might influence the range of the application and the presence of certain policies (Kayama and Haight, 2014). An example from a Japanese study on the experience of parents of children with learning disabilities in decreasing stigma through intervention may support and illustrate the argument. As indicated by Barnes and Oliver (2012), the UN convention on the rights of persons with disabilities in 2006, especially towards the inclusion of people with disabilities, was adopted universally to ensure the rights of people with disabilities. Kayama and Haight (2014) had a critical discussion on the implications of the global convention on disability social rights such as children's right to special education in Japan, especially regarding stigma. Japanese cultural values present a different response to people with disabilities and in the implications of universal strategies and interventions to decrease stigma. Despite interventions and support provided to children with disabilities in Japan, parents were sensitive to their children’s “differences” and “other people’s eye“ in a culture that valued conforming to society (Kayama and Haight, 2014). A lesson learned from the example of Japan is that a discussion of structural stigma is more complex than simply illustrating the economic, political, and institutional differences between countries; there is complexity in the understanding of disability in practice, such as people’s beliefs and traditions (Griffiths et al., 2005; Link and Phelan, 2001).

Moreover, across cultural studies, understanding stigma focuses on culturally specific mechanisms that impact stigma (Link and Phelan, 2001). Researchers have argued that social interaction is affected by what matters most, which determines a person’s social state in a certain culture. ''Culture affects stigma by threatening an actor’s capacity to participate in the activities that determine what matters most within the cultural context “(Yang, 2013, p.73). The threat from culture specifically adds more negative responses than universal threats, such as being dangerous or dependent (Yang et al., 2014). For example, in the Chilean context, men and women with mental health problems face different stigmas depending on their role and social status in the social situation and the way it affects what matters most (Yang et al., 2013). The ‘mental health disorder’ might be processed differently, depending on how it affects the social roles and the ability to fulfil such roles (Yang et al., 2013). This might provoke varied stigmas towards men and women with mental health issues (Yang et al., 2013).

Based on the discussion of individual and social models of disability in this section, I conclude that the concepts and ideas of the chosen analytical approaches are not inevitable, because their relevance comes from the social and cultural context. Therefore, I will illustrate how the social materialist, the social relational model, and stigma theory may fit in the Kuwaiti context.

### 2.3.3.8 Social oppression theory approaches - Kuwaiti context

Studies on disability in Kuwait are scarce and have a different orientation from disability studies in the UK which use the social oppression model. In the previous section, I gave a general understanding of the Kuwaiti context and an overview of the sociological approach and social models that have been used in Western disability studies. This is important to help in understanding the development of my perspective on the best way of using previous models and approaches as analytical tools to investigate the experience of parents bringing up a child with ADHD within the Kuwaiti context. In this section, I start with a justification for using each model and approach. I then discuss how this approach and the models address the differences and challenges that the Kuwaiti context presents and how each approach was useful in the Kuwaiti context.

#### 2.3.3.8.1 Materialist social model - Kuwaiti context

The materialist social model focuses on the political, economic and social aspects of the UK, which is different from the Kuwaiti context. My argument follows some southern hemisphere scholars, who have argued that the materialist social model analysis of the social context of disabled people failed to address the issues and challenges that disabled people face in southern hemisphere countries (Hari, 2016; Berghs, 2017). For example, Hari (2016) noted that Western scholars criticised the individual model and the model of social barriers it presented for disabled people. Nevertheless, the individual model seems very important for countries like Nepal, which are still fighting to meet the needs of disabled people to survive. This statement is very important, because despite the claim by Oliver and Barnes (2012) that the analysis might not fit other contexts, the materialist social model has affected social policies around the world. In an analysis of the post-materialist social model period, Oliver and Barnes (2012) stressed that the UN had applied the ideas behind materialist social model in their policy in 2006, and they had been adopted by many countries around the world. This demonstrates the importance of understanding the differences between the UK context, where the materialist social model emerged, and the Kuwaiti context, where I applied the model.

In the UK context, the materialist social model critiqued the capitalist system that prevented disabled people from claiming their rights and getting support (Oliver and Barnes, 2012) (see Section 2.3.3.2). As noted earlier, the Kuwaiti economic system is a combination of capitalism and a collectivist system, while the economic system relies on oil (see Section 2.2.2). This is reflected in a welfare system that covers health, education and social care. It could be argued that the welfare system for disabled people is able to support all aspects of their lives. This means that issues with services in the UK are not relevant to the Kuwaiti context.

However, the materialist social model not only focused on achieving the rights of disabled people. It also investigated the process of applying those rights and providing them to disabled people (Oliver and Barnes, 2012). For example, Oliver and Barnes (2012) showed how the claims of the materialist social model to achieve independence for disabled people were wrongly applied in practice. As a result, disabled people were left without financial support, on the basis that the government had programmes to help disabled people get jobs. This did not improve the lives of disabled people; it made them worse (Oliver and Barnes, 2012). This analysis is important for the aim of this research. Despite a good welfare system for disabled people in Kuwait, in practice services and support are assigned depending only on a medical ‘assessment’ and ‘diagnosis’. Especially as I mentioned before, the diagnosis for children with ADHD is still a struggle within Western literature. At the same time, ADHD is considered new in Kuwait, so children could fail to gain the diagnosis and assessment to achieve the support needed. This is because medical assessment ignores the voices and needs of disabled people. The key idea behind the materialist social model is that asserting the rights of disabled people might apply in Kuwaiti social policies through an investigation of how social policies are implemented in the life of families of children with ADHD.

In addition, the materialist social model in the UK was underpinned by a social movement that criticised social policies and the way they conceptualised disability. For example, Goodley and Ruswick-Cole (2012) explored social policy in England and its understanding of disability, childhood and parenting, illustrating the way social policy was not meeting the minimum requirements and needs of families of children with disability. While this idea might be very important, the Kuwaiti context has not had a social movement to promote changes in social policy. This is dependent on suggestions from members of the Assembly being presented to the state. Applying the analysis of the materialist social model to political practice may require an analysis of the decisions of the assembly in Kuwait and the way those decisions affect the lives of the families of children with ADHD.

On the other hand, the materialist social model could help to empower and give more agency to disabled people in Kuwait, because such issues are still not fully addressed in the Kuwaiti context. Using the materialist social model is important, not only in illustrating the material barriers that disadvantage children with ADHD and their parents, but also to challenge the environment and promote changes that meet the needs of the families of children with ADHD. In the case of ADHD, the impairment is still not clearly stated in Kuwaiti social policy on disability (see Section 2.2.5). By giving such power to parents, we might promote efforts by members of the Assembly and advocacy groups to gain ideas for improvement. Although the materialist social model addresses disability is general; it cannot address impairment (see Section 2.3.3.2). This does not decrease the importance of investigating the material aspects of disabled people. I will address such limitations by putting more focus on people with learning difficulties to underpin the social relational argument in relation to ADHD as an impairment will be acknowledged through the social relational model that fits the Kuwaiti context.

#### 2.3.3.8.2 Social relational model – Kuwaiti context

In this section, I discuss the usefulness of using the social relational model to focus on ADHD in Kuwait. The justification for using the social relational model is discussed by again bringing in the way impairment is conceptualised in Kuwait. The social relational model investigates the understanding of impairment through focusing on culture. The current research focuses on the Kuwaiti context and its Arab culture, beliefs and values. Hadidi and Al-Kateeb (2015) showed that people with disability in Arab countries still believe that impairment is a burden on families and society, and so they encounter social stigma from society. Because of the shame they bring, people with disability should be hidden away. Such behaviours could be explained by investigating the link between the Arab understanding of culture and the concept of family. Hammad et al. (1999) described the Arab view of family structure, noting that a person’s relationship with his family in Arab culture is very important and his duty to his family is a social obligation. Actions and decisions not only affect the person, they also affect the whole extended family (Hammad et al., 1999). While impairment is seen negatively in Kuwaiti society, as a deficit and a burden, this perspective often extends to the shame of the whole family. Impairment could be seen as a hereditary defect in the family, which would lead to social avoidance, a decline in social status, or the rejection of marriage to anyone in the wider family (Hammad et al., 1999). Therefore, most families choose to hide it. The negative cultural and social perceptions of impairment might create psycho-emotional barriers that reflect the principles of the social-relational model.

In addition, as mentioned earlier in Section 2.2.5, applying for disability welfare and support requires a disability certificate and the disabled person admitting to having an impairment. This puts disabled people in a difficult situation. They might be torn between getting support and services, which requires them to admit their impairment, and protecting their family’s social reputation and living with their difficulty. For example, Saad and Borowska-Beszta (2019) studied the caring attitudes of parents of children with disabilities. They found that the social attitude to impairment might affect the parents’ decisions on educating their children and getting the support they need.

This discussion underscores the importance of adopting the social relational model to explore the impact of cultural and social norms on impairment and acts of disablism. However, important aspects of Kuwaiti culture must also be acknowledged.

#### 2.3.3.8.3 Sociological approach to stigma – Kuwaiti context

This section addresses the justification for using the sociological perspective of stigma in the current research. I also demonstrate the best way of using such an approach to fit the Kuwaiti context. Before getting into that, I want to highlight the issue of stigma in Kuwait.

Stigma in families of children with ADHD cannot be investigated by exploring only the perception of parents about the stigma and explaining it from Arab and Islamic cultures. Stigma studies in Arab countries have investigated the stigma placed on Arab parents of children with disabilities or ‘mental health disorders’ (Dalky, 2012; Almazeedi and Alsuwaidan, 2014; Hadidi and Alkateeb, 2015; Ibrahim and Ismail, 2018). Such studies often focus on individual perspectives, on the parents’ attributes and on psychological consequences like stress. Moreover, focusing on the negative consequences from a cultural perspective might be the main aspect related to stigma. In addition, stigma is addressed by providing interventions that only support the mental health of parents or children with this stigma (Mohammadzadeh et al., 2020). However, it is important to explore other aspects such as living conditions and social structures (Mohammadzadeh et al., 2020). The social, economic and political aspects of the context also must be considered. Considering the lack of research on stigma from a sociological perspective in Kuwait, I will try to draw a connection between what is already known about the Kuwaiti context and the sociological perspective of stigma. However, I first give the justification for adopting the sociological perspective on the stigma approach.

I am adopting the approach used by Link and Phelan (2001) (see Section 2.3.3.6) to understand the experiences of parents of children with ADHD. Their idea about the degree of stigma is relevant for families of children with ADHD, who face different levels of stigma. They are stigmatised because of the label of disability, which is a requirement for accessing welfare. Finally, the impairment in the case of ADHD is invisible and with the lack of understanding about the ‘symptoms’ of ADHD, it is often seen as ‘bad’ behaviour (Mueller et al., 2012). These issues show different levels of stigma being applied to families of children with ADHD, but the stigma seems to be mostly in the social and political contexts.

However, the Kuwaiti context might differ in the mechanisms of stigmatising, as the condition of disabled people in this context differs from that seen in Western research. For example, Link et al. (2018) noted that one structural arrangement in the stigmatising process is where people live and economic disadvantages for disabled people. The problem of where people live might appear in different ways because of cultural norms. The extended family is still common in the Kuwaiti context. Living with extended family might provide social and emotional support, but it might also facilitate stigma. As can be seen, where a person with disability lives is the main mechanism that increases them being stigmatised, but it is seen differently because of cultural differences. My argument here is that I consider the mechanisms of stigma in general. However, my findings provided alternative examples of the ways that social, economic and cultural circumstances function in the Kuwaiti context.

## 2.3.3.9 Models of disability

This section discussed models of disability in disability studies in the UK. It starts by explaining the main principles of disability studies and focuses on the social construction of disability, which varies by discipline. Disability can be understood in a variety of ways by using models, which are systems that offer a particular explanation of reality. Different models are applied not for comparison but to reveal the complexity of understanding ADHD. The section on disability studies reviews literature that is relevant to individual and social models of disability, which provide the analytical lenses of this study (see **Figure 1**). This part outlines each model, including its definition of disability and its strengths and limitations, and details the use of each model in this study as well as its relevance to the Kuwaiti context.

# 2.4 Conclusion

The literature review discusses a suitable framework for investigating the experiences of parenting a child with ADHD. The first section presents an overview of the Kuwaiti context and representations of disability and ADHD. The next section situates the current research within the existing literature and establishes the background to the research topic. The rest of the chapter discusses how disability has been conceptualised in Western research and applied in the Kuwaiti context. Therefore, the second section addresses the individual model of disability, while the third section reviews the social model of disability. These two perspectives form the main lens for exploring experiences of parenting children with ADHD. The last subsection specifies how to use the two perspectives to consider the differences in Kuwaiti culture and the context of conceptualisations of disability. This chapter gives the background to the research and also identifies the gap in the literature. From this, the next chapter gives the design of the research to address the gap.

# 

# **Chapter 3**

# **Methodology**

Introduction

The chapter describes the research design, the selection of which primarily depended on the aim and questions I sought to answer through my investigation into the parents’ experiences of raising a child with ADHD (Attention Deficit Hyperactivity Disorder). The aim and questions were developed from my exploration of the literature related to ADHD and disability studies. As mentioned in Chapter 2, despite the domination of the biomedical perspective which understands ADHD as a ‘disorder’, the literature on ADHD and disability studies shows wide variation in understanding ADHD as a disability, an illness, or ‘behaviour’ which ‘deviates’ from social norms. Another essential idea from the literature is that the experiences and thoughts of people with disabilities or their parents might be as valuable as medical professionals' ideas about ADHD. These two conclusions from the literature directed the research question towards the ideas that parents constructed about ADHD from their experiences and the influence of social context on constructing their ideas about ADHD.

Moreover, as the research is situated in the Kuwaiti context, I provided a review of disability studies, illustrating that ADHD research in Kuwait fails to explore the implications of the social context on how ADHD is understood, as most research is medical in nature (Salem et al., 2014). This drove my interest in exploring the experiences of Kuwaiti parents of a child with ADHD. More specifically, the aim of the current research was to explore ADHD in the Kuwaiti context through the parents’ experiences. However, I was also interested in the principles of disability studies, which focus on the social construction of disability and/or impairment and not just the biological aspects of the condition. As I was inspired by the idea of interdisciplinarity, the current theoretical framework combines both medical sociology and disability studies models of disability. Therefore, in constructing the questions below, I developed an open and general question style that complied with the principles of disability studies, while also addressing the gap in disability research in Kuwait (see Section 1.4).

In the previous chapter, I discussed how the conceptual frameworks of the current research are individual (from medical sociology and critical psychology) and social models (from disability studies). This allows for an exploration of the various understandings of ADHD. I argued that despite different ways of understanding ADHD, both models share a similar focus on society as a place of investigation. This exploration led me to realise that there was a need for an approach that would help me understand differences in social construction, as well as the impact of the cultural and social context on different ways of understanding ADHD. The most suitable philosophical stance from which to address the different perspectives on ADHD that emerge within the social and individual models of disability is social constructionism, which will be discussed in detail below. First, I will introduce the structure of the chapter.

This chapter discusses the philosophical values and beliefs that guided the research methodology design. The qualitative paradigm and social constructionist stance are initially discussed to illustrate the ontological and epistemological orientation of the research. The chapter then provides a discussion of different qualitative methodologies and justifies the use of narrative as the research methodology. I argue that the narrative methodology is beneficial in illustrating the unheard stories and perceptions of parents in Kuwait. While the narrative approach underpinning social constructionist theory might be beneficial, it also presents some limitations that will be discussed in the ethical considerations section. The last section discusses the quality of the research and methods of evaluating the current research methodology design.

## 3.1 Qualitative and quantitative paradigms

The design of the research starts by distinguishing between the established paradigms of quantitative or qualitative research. In general, quantitative research refers to empirical research that is used to explain social phenomena, test a theory, and/or explain the causal relationship between variables (Mills and Birks, 2014; Robson, 2011). It seeks to discover the objective truth of a single reality (Castellan, 2010) and advocates free-value research by limiting the variables and separating the researcher from the participants and/or the object being researched (Robson, 2011). The aim is to collect facts that are reliable, valid, and generalisable to the wider population to explain and predict theories about social phenomena (Robson, 2011; Castellan, 2010).

Qualitative research focuses on individual accounts of a phenomenon and the assumed meaning is related to the context and individual perspective (Mills and Birks, 2014). It seeks the subjective truth of multiple realities that are continuously interpreted and constructed (Castellan, 2010). It encourages researchers to admit to and reflect on their values and assumptions about the research and the participants (Denzin and Lincoln, 2000). Qualitative research is characterised by interpretive practice (Castellan, 2010), and the aim is to better understand the phenomena, describe the meaning and investigate the process of constructing meaning about certain phenomena (Mills and Birks, 2014; Castellan, 2010).

The current research is situated in the qualitative paradigm because the aim is to explore how ADHD is understood in the Kuwaiti context by drawing on the perspectives of parents and the literature. Qualitative research is suitable for determining meaning, ideas, beliefs and attitudes (Creswell, 2013); thus, it is appropriate for investigating the parents' process of constructing ideas about ADHD. Moreover, this research used a narrative research methodology, as the data collected from the parents included stories giving unique, subjective reflections on disability, childhood and parenting within a specific cultural and social context. Finally, the focus on a small sample of eight parents’ stories provides space for an in-depth investigation to illustrate not just the participants’ ideas about ADHD, but the process through which these ideas are constructed and the reason behind this construction. The characteristics of qualitative research are thus reflected in the current research.

The qualitative paradigm encompasses many methodologies whose analyses depend on certain ontological and epistemological stances (Mills and Birks, 2014). The following section presents a brief introduction to the terminology and an example of the extreme positions on the ontological and epistemological continuum before detailing my own stance.

## 3.2 Philosophical stance: ontology and epistemology

A philosophical stance encompasses the ideas and beliefs that guide the research process and designates the way in which the research questions have been answered (Mills and Birks, 2014). A review of the philosophical stance usually starts with a discussion of ontology and epistemology. Ontology refers to assumptions and opinions about the nature of reality (Gray, 2014). Epistemology refers to the beliefs and assumptions regarding how knowledge is produced and what kind of knowledge is considered valid and sufficient (Gray, 2014). In general, qualitative research is consistent with the idea of a multi-reality, which means that qualitative researchers might use different evidence to represent the knowledge that different individuals have about reality (Creswell, 2013). Nevertheless, qualitative approaches differ slightly in their certainty about reality and the degree of subjectivity of knowledge (Moon and Blackman, 2014).

In general, the ontological position falls on a continuum between the contrasting positions of realism and relativism, which differ in whether there is a single reality or a multi-reality viewpoint. The realist ontological position used in qualitative research holds that reality exists independently of an individual's interpretation, despite the way individuals understand or experience it (Moon and Blackman, 2014). This means that we cannot fully know what the independent universe is like, but we can access a glimpse of reality (Moon and Blackman, 2014). In relativist ontology, the belief is that we can only access a subjective experience of reality which does not exist separately from an individual’s perspective (Denzin and Lincoln, 2005). This view is based on the belief that we understand reality through individual experiences, which might vary. As a result, relativists believe in a multi-reality (Thorne, 2016).

Epistemological positions also vary in terms of objective and subjective knowledge (Crotty, 1998). Crotty discussed this aspect of epistemology by illustrating the relationship between object and subject. On the extreme of the continuum, objectivist research builds on the belief that our knowledge of phenomena should be objective and descriptive of glimpses of reality (Thorne, 2016). This kind of research is interested in discovering objective truths (Moon and Blackman, 2014). In terms of research that depends on subjective knowledge, belief in knowledge depends on the way individuals perceive reality. As individuals depend on different social values and meanings, there are thought to be various truths about reality (Thorne, 2016). This kind of research is interested in producing contextual knowledge, as it focuses on the way individuals interpret or construct their understanding of reality (Moon and Blackman, 2014). Having provided this introduction to ontology and epistemology, I will now situate my research position.

The orientation of social research focuses on the human experience and society. The subjectivity of human life requires different methods from those of natural science research (Mclaughlin, 2012). This is because society is a product of human construction, and human thoughts are variable and subjective. Thus, they require different scientific methods to explain them (Mclaughlin, 2012). Therefore, an interpretive and humanistic approach is more suitable for understanding and interpreting individual lives. One such interpretivist orientation is social constructionism (Berger and Luckman, 1966), which is the chosen approach for the current research. Below, I first define social constructionism and then provide a justification for using this approach.

## 3.3 What is social constructionism?

Social constructionism is a theory that explores, and challenges taken for granted concepts such as normality by illustrating the social process of the idea become to be taken for granted or ''knowledge'' (Irwin, 2011). Social constructionism does not try to explain, predict or produce a fixed meaning, because knowledge is believed to be continuously changing with time, context or culture (Gergen, 1985). Thus, this perspective investigates taken-for-granted knowledge about the world, whether it be scientific knowledge or general understanding of social norms (Gergen, 1985). It presents a common form of understanding as it is used now or through history (Gergen, 1985). Focusing on ways of understanding the world is important, because it has implications for people’s practice.

A key idea of the social constructionist view is that the relationship between the inquirer and knowledge is based on assumptions concerning the ways in which knowledge is constructed (Willig, 2013). A social constructionist approach considers participants as active agents in constructing their world and its meaning, but also admits the influence of the power of culture and social context (Burr, 2003). When individuals articulate their understanding of social reality in relation to a specific topic, they draw on cultural resources that are familiar and common to themselves and to their listener (Esin et al., 2013). Equally, in thinking about the current research as socially constructed, the researcher’s beliefs and ideas might impact the ways in which knowledge is constructed. Social constructionism highlights the impact of researcher subjectivity and values, and advocates the clear communication of researcher positionality (Willig, 2013).

## 3.4 Philosophical assumptions of social constructionists

Social constructionism takes an opposite position to that of realism, because it understands reality as socially constructed, while the latter believes in only one reality that can be investigated through observation (Burr, 2003). In other words, for social constructionists, reality is not something natural or given. This approach explores the processes of constructing social reality and meaning through social interaction and does not explore reality itself (Burr, 2003).

My research focuses on the accounts provided by parents of children with ADHD and takes an in-depth look at the ways in which they make sense of the world around them. I am interested in focusing on the interaction between the person and the ‘reality’ of their experiences to identify the knowledge and discourses that have determined their experience, and to consider the impact of this understanding on their lives. In this study, ADHD is understood as a social construction or creation. The ontological position of the research is that there are different realities for those labelled as having ADHD, and each has consequences for the parents’ experiences of raising a child with ADHD in everyday practice. Thus, a social constructionist approach offers a means by which academic awareness of the importance of parental experience can be raised, and another possible way of looking at these experiences from a marginalised perspective.

In terms of the epistemological stance, knowledge is not discovered or observed, but is instead a product of individual interactions between people and their environments (Taylor, 2018). Knowledge and an individual's social activity work together (Taylor, 2018). Knowledge is produced from social activities in which individuals participate and negotiate ideas about their life. Knowledge is not something we process in our heads, but something we create together through language, which is a shared activity (Gergen, 1985).

Social constructionist theory investigates knowledge through language use. Focusing on the language is important, as it contains and produces meaning through social exchanges (see Schwandt, 1994; Burr, 2003; Van Nes et al., 2010). In other words, language is a tool for describing our own meaning of reality and preserving that meaning in a certain social context (Burr, 2003). Since language produces and mediates knowledge, one cannot experience a certain social reality outside of its cultural and ideological categories (Burr, 2003; Schwandt, 1994) (see Section 1.6). As we shall see, social constructionism takes two main approaches to investigating language.

Schwandt (2000) noted that there are two main types of social constructionism. These types adhere to the same relativist stance, but differ in what they consider to be socially constructed. A ‘strong’ social constructionist approach suggests that individuals use discursive resources in a certain context to achieve a specific purpose. Thus, this approach focuses on understanding how and why certain discursive resources are used in particular contexts (Willig, 2013). Studies that take this approach are concerned with the purpose that these constructions achieve in certain contexts. In terms of moderated social constructionist approaches, they are interested in the interaction and the relationship between the ways in which participants use particular discursive resources and the broader social and cultural contexts of the participants (Willig, 2013). In this context, social reality has power and boundaries that determine the ways in which individuals construct knowledge (Schwandt, 2000). Unlike strong constructionism, which rejects any reality outside the construction of the participants, the moderate social constructionist approach pays attention to this reality in the form of dominant discourses and tracks its impact on the way individuals communicate about their experiences and meanings (Willig, 2013).

By aligning my research with a moderate constructionist approach, I aim to explore the ways in which parents construct their understanding of ADHD within a broader social and cultural understanding of disability and mental health. However, the strong and weak types of social construction are not separate ways of thinking (Irwin,2011). They are linked together in ''a continuum regarding the extent to which what is constructed has been regularised'' (Irwin,2011; p.100). This means that even though I want to focus on the economic, political and social aspects of Kuwait's context influence on the parents' idea of ADHD, I might address some issues about the powerful role in constructing the parents' ideas and experience with ADHD.

Moreover, an important idea in social construction is the notion of facts as power. Using Berger and Luckmann’s (1966) way of understanding the nature of knowledge, we can see that there are two types of facts: objective, such as knowledge about natural science, and subjective, which refers to knowledge about ideas, behaviours or even experiences. The latter type is considered subjective because it is influenced by society and people, as well as by what is considered meaningful for the individual. Social constructionists have been doubtful about the factual nature of scientific knowledge, especially facts that are constructed from social contexts (Berger and Luckmann, 1966). However, agreement on some ways of understanding the world could be called facts (Berger and Luckmann, 1966). Here I mean that not all facts are objective, but some facts could be based on agreements shared by society. Another possibility is that facts often dominate because they are advocated by a person or system that holds power; therefore, they may appear to be true and real (Burr, 2003). These facts influence the way people behave and think to gain social acceptance.

In reflecting on the current research, the people who created knowledge and facts, and made decisions about people with disabilities in the past were medical professionals (Barnes, 1999). This group had the authority of scientific and objective knowledge about disability, which enabled them to control the kind of knowledge shared by people in society about disability (Sullivan, 1991). Despite the appearance of the social model, which advocates an orientation towards accepting disabled people’s understanding of disability. The authority to construct knowledge about disability is still in the hands of medical and psychology professionals in a society. This is because the acceptance of results coming from empirical research, such as the medical view of disability, gives them power over other perspectives (Burr, 2003). Nevertheless, in practice, ideas that construct knowledge are changeable because ideas are continuously constructed in interactions between people. Therefore, social constructionists advocate for the opportunity to demonstrate alternatives to a dominant and taken-for-granted understanding of knowledge about ADHD or disability by focusing on social constructions, whereby people with disabilities can construct knowledge (Gergen, 1985).

In using social constructionist theory, I am not concerned with ‘the truth’ behind these constructions (Willig, 2013), nor do I argue that the parents’ perspectives provided here represent ‘the truth’ of all parental experiences of ADHD. Social constructionism offers a range of individually positioned conceptualisations of ADHD (Raskin, 2002). The parent’s perspective is considered no less important to our understanding of this issue than the medical understanding of ADHD. Additionally, by acknowledging the perspectives of parents, we may be able to reinvestigate and re-evaluate those medical practices.

## 3.5 Benefits and limitations of social constructionism

Social constructionism states that a new shared meaning will eventually be constructed (Van der Haar and Hosking, 2004). This might not be a limitation of the current research, as the focus is on presenting alternative ways of looking at ADHD. For this purpose, I argue for the importance of exploring taken-for-granted knowledge, such as the idea that ADHD is a ‘disorder’. I also emphasise the importance of considering and understanding the parents’ perspectives, as they are directly experiencing ADHD as they raise their children. Even if the ‘facts’ about ADHD change, the principle of being open to different interpretations, as well as the importance of listening to disabled people, remains essential.

Moreover, social constructionism has been criticised for being unreal, as it accepts anything constructed about reality, so everything is considered acceptable within the relativism stance (Raskin and Debany, 2018). This is because social constructionists refuse to evaluate the construction as true or false (Raskin and Debany, 2018). It is true that constructionism takes a relativist stance on knowledge, as it is construed as a construction based on people interacting within a particular context, but this does not mean that anything goes. Instead, the investigation depends on knowledge systems in communities of shared intelligibility (Willing, 2013). We live in a social world that underpins a system of meaning, ideas, and discourses that influence what we consider makes sense in certain contexts. However, at the same time, social constructionism invites researchers to view these rules as historically and culturally situated (Gergen, 1985). In other words, these rules are objects to use for discussion but are also subject to investigation and transformation (Gergen, 1985).

Finally, the relativist position of social constructionism presents another limitation when used to investigate disability. For example, both medical sociology and the social models consider disability to be a social construction from the social environment. This presents an issue because medical sociological theories such as Conrad (1992) focus on contextual knowledge, without having a position on the reality behind the phenomena. The discussion of ADHD as a social construction does not go far enough to include the biological aspect of ADHD. While the social models, the discussion of disability through the social aspects of its construction to advocate political changes to the rights of disabled people (Oliver, 2013). However, the social model goes too far to ignore the reality behind disability with regard to the social context. This led to models that underpin social construction being criticised for ignoring impairment (Shakespeare, 2006: Bury, 1986). Thus, the biological part of impairment is left to be discussed in biomedical studies. Denying the biological part of impairment might have negative consequences for the lives of disabled people, such as the loss of support and services (Swain et al., 2003). Therefore, investigating and discussing ADHD as socially constructed is as important as biological impairment, because it affects people’s lives as much as biological impairment.

Therefore, it depends on the researcher's view on social construction. This research claims that the impairment might be real, but it can only be known through social construction. The importance of taking the social constructionist stance is that discussion of impairment as a social construction can lead to different interpretations of the child’s behaviour and its cultural perception based on culture and history. The section below discusses the benefits of the social constructionist stance in this research.

## 3.6 Social constructionism in disability studies

In the literature of social constructionism (Raskin, 2002; Galbin, 2014; Anastasiou and Kauffman, 2011; Burr, 1995), it is clear that there are different views about social constructionism as something that developed rather than having appeared or been discovered at different times in different disciplines (Galbin, 2014). To link this history to the fields that are relevant to the research, which are psychology and medical sociology, the development of social constructionism is often said to be influenced by Berger and Luckmann (1966) and Gergen (1985). In sociology, the theory was used to understand how individuals construct and sustain social phenomena in practice, but at the same time, they experience social phenomena as something pre-given (Galbin, 2014). Despite the differences between the various uses of social construction, there are themes shared by these applications. Medical sociology and disability studies have similarities in looking at disability as a social construction, but they differ in what they consider the social aspects of disability to be (Taylor, 2006). The difference lies in situating a disability as the location of the study and in using it as a means of investigating the social practices and social representations surrounding people with a disability (Titchkosky, 2000).

In general, many medical sociology and disability studies have been influenced by social constructionism (Anastasiou and Kauffman, 2011). On one hand, from the medical sociology point of view, psychological claims that ADHD is a ‘disorder’ have been criticised for their primary focus on the individual and a comparative lack of attention to contextual and historical factors (Conrad, 1992). Social constructionism has also underpinned studies on childhood and ADHD. Using a social constructionist approach, James and Prout (2001) offered an alternative understanding of childhood by considering the relationship between childhood, Western history and culture. In the same vein, Timimi (2005) extended this discussion to consider childhood with ADHD and highlighted the influence of culturally different understandings of acceptable child behaviour as a means of identifying ADHD-related behaviour. Both studies present childhood as a socially constructed concept that is impacted by social and cultural contexts.

On the other hand, the social constructionist approach is used in disability studies, as it forms the basis for a social model of disability (Anastasiou and Kauffman, 2011). The influence of social constructionism is evident in the interest in how the socioeconomic origins of disability underpin the history of social interest in mobility in a capitalist system (Abberley, 1987). The social model denies essential knowledge about how to be normal and human because scholars such as Oliver and Barnes (2012) have argued that agreement on what is considered normal depends on the cultural norm, and not on the biological aspect of the impairment. Studies undertaken within this framework focus on the social context of disabled people, arguing that disability is not within the person, but within the social context (Oliver, 1996). Social constructionism is thus used as a theoretical framework through which to form a social understanding of disability and reconsider the impact of medical labels on people with disabilities (Anastasio and Kauffman, 2011). The theory also provides a basis for doubting medical authority in social ideas about disability.

By challenging the dominant assumptions regarding lived experience, social constructionism has offered a range of benefits for disability studies. It helps us to investigate the ways in which disabled people have constructed their social reality, evaluate public policies (e.g., Goodley and Runswick-Cole, 2011), investigate special education inclusion practises (e.g., Anastasio and Kauffman, 2011), examine social representation (e.g., Malacrida, 2004), and provoke social action and changes in the practises that affect people with disabilities (Brett, 2002; Lynn et al., 2012).

The social constructionist approach is a useful framework for my research as I explore the ways in which parental experience is constructed within social contexts, such as through engagement with medical professionals, teachers and friends, and in relation to disability policies and Kuwaiti culture. This research also considers how parents communicate their understanding of their experiences of raising children with ADHD, and the implications of such understanding on their everyday lives. A focus on social practice will also be helpful, in combination with the medical sociology approach within disability studies, which rather than viewing disability as only socially constructed considers the experiences of people with disabilities in relation to both their social and medical realities (Thomas, 2012). This is important because despite the impact of the social model of disability on policies relating to welfare and services, mental health is still understood from a predominantly biomedical viewpoint (Beresford, 2002). A social constructionist approach therefore allowed me to explore how dominant psychological conceptualisations of ADHD and childhood have constructed detrimental concepts of normality and abnormality and the implications of these concepts on the everyday lives of families.

## 3.7 Methodology

In researching a suitable methodology that would fit my social constructionist philosophical assumptions, I will briefly introduce the narrative approach and then justify its choice as the methodology used in this research. However, the process of using the narrative approach and the main challenges faced will be discussed in Chapter 4.

### 3.7.1 Narrative

The terms narrative and stories are often used interchangeably to indicate a personal account (Polkinghorne, 1995; Sarbin, 2004), while others consider a story to be a type of speech used in a narrative (Riessman, 2008; Brown, 2017). From my experience with narrative research, I agree with the latter and believe that there are differences between narratives and stories. An attempt to identify the story in a transcript showed me other forms of speech that participants use, including reflection, additional information and arguments. Furthermore, a story is a part of narrative presenting problems to solve, conflict, interpersonal relationships, an experience and the temporality of existence (Ryan, 2007; Floersch et al., 2010).

Thus, in this research, the term story is a series of events that serve to construct meaning and information (Mishler, 1991). Telling stories is a self-representation skill of combining actions, feelings, thoughts and events to communicate a person’s understanding of a subject. While the term narrative is used as a way to interpret and make sense of our currently ''understood past, experienced present and anticipated future'' (Mishler, 1991, p.68) in a story form, in a logical manner within a plot. Storytelling is presenting events while connecting them in a sequence to specific related actions to produce a meaning for the listener (Riessman, 2008). Therefore, although I believe there are differences between the terms narrative and story, in the upcoming section, I use the terms interchangeably to fit the terminology of studies on narrative inquiry.

#### 3.7.1.1 Narrative Inquiry

Narrative inquiry is an investigation of a particular point of view of an experience (Connelly and Clandinin, 1990). The way narrative enquiry is used varies based on the discipline. In psychology and sociology, the main purpose of paying attention to the narrative is not merely the construction of the stories, but to unravel the way the individual’s mind works (Polkinghorne, 1995). Narrative is seen as the human ability to connect units of linguistic expression in temporal order to transfer experience and social meaning from one to the other (Labov, 1997). Stories recount past events within a temporal juncture to present an interpretation of those past events (Labov, 1997).

My research adopts a narrative approach from constructionist epistemological assumptions, considering stories as social events that are a product of a person’s interaction with a specific interpersonal, social and/or cultural context. Therefore, a narrative is co-constructed (Esin et al., 2013). Language within stories is both a means to construct an understanding of the world and a source that constrains and shapes the stories because it is linked to culture (Lambie and Milsom, 2010).

Narrative inquiry is used for different purposes. A narrative helps to understand an individual and others through the meaning they shape into a story. In storytelling, we select experiences and organise them, thus giving meaning to them. These meanings are not just about ourselves, but also about others (Elliot, 2005). A narrative also contains information about social and cultural life, because in creating our narrative we show our interaction with the world in which we live. We also draw on social and cultural values as we live these experiences and interact with others (Murray and Sools, 2014). Furthermore, narratives have been used to represent the constructed identity of the individual and to advocate action, because the construction of a narrative facilitates the presentation of embodied moral meaning and self-perception, which allows the reader to feel the experience of the narrator and to feel inspired to resolve their moral issues (Sarbin, 2004). In the current research, narrative enquiry is used to understand the perspective of parents on ADHD while considering the impact of social and cultural elements on the way they construct their understanding of this experience.

The narrative method has been widely applied in disability research, for example, childhood studies (Lyons and Roulstone, 2018; Muthukrishna and Ebrahim, 2014), disability studies (Smith and Sparkes, 2008; Lambert et al., 2019; Olsvold et al., 2019) and parenthood, especially maternal, studies (Green et al., 2011; Muthukrishna and Ebrahim, 2014). The emergence of a social model of disability inspired researchers to evaluate how people with disabilities understand themselves in relation to society (Oliver, 1996). Disability studies used a narrative methodology to show that the experiences of an individual with a disability extended beyond a biomedical representation and understanding of the impairment (Goodley and Tregaskis, 2006).

Furthermore, Lalvani (2015) used narratives to explore the differences between the perspectives of 32 parents and 30 teachers of children with disabilities in the US and the influence of the social context on these perspectives. While the teachers’ perspectives on disability were biological and medical, which follows the universal understanding of disability as a physiological limitation, the parents’ understanding was constructed from the social meaning of having a disability, which was linked to stigma and marginalisation (Lalvani, 2015). The researcher looked in depth at the implications of these perspectives on the opinion of education support staff using stories. Lalvani (2015) showed that narrative is a tool the individual uses to construct meaning about disability, and this construct is embedded in the social context. The way the study used narrative could help in understanding the impact of the social context which parents include in their stories, such as school, health services, disability policies, as these could influence the life of the families and their actions in parenting.

Narrative inquiry has also been used within cross-cultural research to understand the parenting experience in different cultures outside Western society. For example, Barlindhaug et al. (2016) explored the influence of cultural and structural form on the everyday experiences of two families of disabled individuals in Malawi. One of the many findings that focuses on the influence of culture on the experience of parenting is the mother's narrative about stigma that was not linked to the disability itself, as is often depicted in Western culture, but to the way the families and mother were able to cope with differences in the child and their life. Mutual respect is a moral value in Malawi culture that families work hard to achieve (Barlindhaug et al., 2016). Caring for a child with a disability and participating in society illustrates the differences between families in a good way that gains the respect of others, as well as preventing stigma (Barlindhaug et al., 2016). The narrative used in this research is important for my research on Kuwaiti culture and the way it influences the meaning and the activities of parents in their experience bringing up children with ADHD.

A lot of researchers conducting disability studies used narrative to study the experiences of parents bringing up a child with a disability (Koro-Ljungberg and Bussing, 2009; Singh, 2003; Lalvani, 2015; Fisher and Goodley, 2007; Green et al., 2011). The literature review below highlights how the narrative methodology is used in disability research, as well as its usefulness for this research.

The narrative method was used in the current research, which explores the experiences of parents of children with ADHD to shed light on resistance to the medical negative and tragic view of disability. For example, narrative enquiry was used in disability research adopting the affirmative model that seeks to highlight challenges and resistance among people with disabilities beyond the 'tragedy perspective' on impairment (Swain and French, 2000). Considering how parents’ narratives can challenge the dominant negative narrative of the experience might lead to a deeper understanding of ADHD and parenthood.

The narrative approach fits the aims of the research, as the storytelling process allowed the parents to reflect on their experiences and to construct their understanding of ADHD. The attention to language in the narrative approach allows the language to be seen as more than a vehicle to communicate, but also a reflection of society’s meaning and values (Lambie and Milsom, 2010). The language that parents use might also add a cultural and social aspect to their perspective on ADHD, and the subjectivity and uniqueness of each narrative is suitable for highlighting alternative ways of viewing ADHD that challenge the social norm perspective. The length and depth of the participants’ stories extended the discussion of the experiences beyond understanding ADHD as disorder. Finally, the narrative approach was used primarily to lift the voices of those who are absent or silent from studies on disability (Smith and Sparkes, 2008). This idea was adopted in this research because most studies in Kuwait with a focus on the perspectives of parents are dominated by the voice of the researcher and their understanding of disabilities.

#### 3.7.1.2 Narrative research in Kuwait

There is a lack of disability research in Kuwait that has invested in the narrative methodology. This observation is supported by Alshammari (2018) suggesting the importance of the narrative for Kuwaiti studies of disability from the perspective of people with disability. She stated that:

There has been little scholarly attention focusing on Eastern perceptions and understandings of disability. There is hardly any work discussing specific and qualitative and/or ethnographic experiences of Arab women with disability (p.37).

The gap due to not using narrative research in disability research demonstrated by Alshammari means that studies on disability in the medical and scientific fields are limited (Alshammari, 2019). This an issue because the findings from medical research may be too ambiguous for the disability experience, with no space for variation within the sample to ensure generalisability of the results due to limiting the bias between the participants. My argument concurs with her observation that a narrative better acknowledges the complexity of the participants’ experience, which qualitative Kuwaiti studies focusing on the patterns within participants’ stories fail to address. A narrative constructs what it means to have a disability by exploring the self, the other, agency, and emotion; it is a tool that illustrates the experience with all its complexity and inconsistency. This can be better understood by looking at the narrative method used in other disciplines.

For example, Husain (2017) explored environmental policies in Kuwait. The narrative illustrates more than just a perspective on the environment; it helped explore the social narrative about Kuwaiti societal values towards the environment. He used social narrative to convey an understanding of the way economic and religious institutions impact people’s perspective on the environment (Husain, 2017). The narrative was essential for an understanding of the socio-cultural context of Kuwait, which shaped the participants’ perspectives.

Similar to Husain, Al-Issa (2013) used a narrative methodology in understanding and evaluating the experience of undergraduate students. However, Al-Issa focused on student’s understanding of information literacy and the social and cultural elements that impacted that understanding. For her, the narrative investigates the process of constructing the student’s understanding of information literacy. In her analysis, Al-Issa focuses on both the personal and the social aspects of the stories to understand the perspective of the student. In addition, Al-Haroun (2015) used the narrative method to understand the reason behind the emergence of apartments in Kuwaiti houses. Narratives were used to explain the Kuwaiti participants’ actions in their houses. Narratives and the participants’ behaviours and feelings about houses were established and analysed within the complex dynamics of the political, economic, cultural and social elements impacting Kuwaiti participants. Al-Suwaihel (2010) explored the perspective of female leaders on leadership, and the influence of the leader’s personal and professional character and the impact of notions rooted in the social and cultural context of Kuwait regarding women and leadership. Using feminist theories, Al-Suwaihel (2010) highlighted an understanding of the Kuwaiti female that challenged current understanding of leadership as well as the difficulties the female leaders faced with respect to Kuwaiti cultural values. The narrative method was used to explore an unfamiliar side of the leadership experience, which is mostly dominated by males.

There are more studies that could be mentioned on the use of the narrative method in the Kuwaiti context. However, the reason for mentioning these studies is to illustrate the importance of using narratives and the possibilities that stories can bring to the subject of disability. There are a lot of studies on disability that focus on the perspective of the parents and children with a disability, or the social aspect of the family (e.g., Al-Sabah, 2017). However, narratives could yield deeper insights by facilitating an understanding of both the personal and the social aspects of the parents’ experience, as well as the interaction between these aspects within the social and cultural context of Kuwait.

#### 3.8 The limitation of the narrative approach

The use of the narrative approach is not without challenges and limitations that need to be acknowledged. The narrative approach has attracted the same criticisms as any other qualitative research method in relation to validity, generalisation and reliability, as discussed later in this chapter, in the quality section 3.8. However, in this section I discuss some limitations and challenges related to the nature of narrative research.

##### 3.8.1 Truth

The main criticism of narrative inquiry relates to the discussion of the truth of the personal narrative (Freeman, 2007). The concept of the truth which is used to evaluate the quality of the scientific quantitative approach cannot be used in narrative research. Under scientific criteria, narrative data offer weak proof because stories are biassed (Freeman, 2007). Hence, stories are not the ‘truth’ but an individual perspective on reality (Freeman, 2007). A story consists of subjective data, as the individual discusses a version of reality, selectively using words and discourse; moreover, stories are influenced by interaction with the social context (Denzin, 2016). Questioning whether the participants are saying what really happened is controversial, because even if the person might be telling the ‘truth’, memories and interpretation of events also play a role in the process of retelling the past (Freeman, 2007). The concept of the truth in a narrative is understood as relativist: that is, what might be true for one person might not be for another (Freeman, 2007). This relativism allows us to see ideas about and perspectives on phenomena in various and complex ways (Fincher, 2012). Therefore, the ‘truth’ in narrative research is not evaluated on the basis of ‘true’ or ‘false’ but is seen as the point of view of the participant, based on an authentic experience and ‘likeness to real life’ (Muylaert et al., 2014; Foxall et al., 2021; Lyons and Roulstone, 2018; Greenhalgh, 2016; p.03).

##### 3.8.2 Memories

Stories are made from memories (Sikes and Goodson, 2016). The ability to remember a memory changes over time, because an individual develops personally, and their experience shapes the way they remember memories and tell stories (Sikes and Goodson, 2016). Kitzinger (2004) argued that individuals are selective in choosing memories to tell stories about, and that changes them over time. Thus, the way an individual tells stories might be different to what actually happened, because they tell their memories as they grow to understand them (Kitzinger, 2004).

It is important to discuss this limitation of narrative, because the current research includes mothers who talked about their experience of parenting a child when they were of junior school age, but the child is now 18 years old. Parents’ accounts might contain some basic events that do not change, such as registering in the disability support system. However, the way the events happened and their interpretation of and reflection on them reflect different interests and perspectives to those they had years ago (Sikes and Goodson, 2016). This might be a limitation that we cannot avoid, but their actual experience of revisiting the memories enables them to discuss their perspective on ADHD now, after years of raising a child with the ‘disorder’.

##### 3.8.3 Time

Furthermore, it is important to acknowledge the issue of time in a narrative approach, because it enables us to understand the story and ideas of the participants (Andrews et al., 2013). The temporal nature of a narrative does not refer to the sequence of time but to the sequences of causality (Denzin, 2016). Some events might be repeated in the same story, or events might be organised in sequences in a way that does not make sense to the researcher, because such organisation serves a purpose or helps the idea of the participant as they tell the stories. For example, one of the participants, Rawan twice recalled an event where the teachers told her that her daughter, Mona was a failure. She first mentioned it happening at the beginning of her story, when Mona was in a mainstream school. The next time she mentioned it was when she discussed Mona doing well at a special needs school. Her story was nonlinear in order to present the wrong idea that the teacher had about her daughter's academic ability. This repetition was indicating that ADHD is often misunderstood by society around the family. The causal nature of a sequence of events makes a narrative helpful in presenting complex ideas about a phenomenon (Greenhalgh, 2016; Andrews et al., 2013).

##### 3.8.4 Language

Another challenge concerns collecting narrative data, which requires a participant to have the vocabulary and ability to express themselves and present their perspective on an experience. However, not all participants are able to talk fluently about personal experiences. Some participants, especially mothers, were more fluent and wide-ranging in talking about their experience than others, especially fathers, regarding complicity and tension, as well as in expressing ideas about ADHD (see Appendices 3 and 9). Sikes and Goodson (2016) discuss how the quality of a story depends on how articulate participants are and their language abilities, but these skills are acquired from social position and people’s experience of social context and the dominant discourse. Their arguments might explain the fathers’ lack of ability to talk about parenting, which is often the topic of the mother (Sikes and Goodson, 2016). Although this limitation decreases the amount of data generated, I think it is important to understand the perspective of all the participants and encourage them to talk about and express their ideas.

#### 3.8.5 Interpretive nature of narratives

Additionally, narrative is critiqued for being subjective, which means it does not lead to definitive knowledge (Plummer, 2017). ‘Different stories will be told in different times and places to different audiences with different motivations and impacts’, which might be interpreted differently by different audiences, so it is difficult to draw on a single conclusion (Plummer, 2017; p.281). Even for the same reader, meanings and ideas differ every time they read a story. This characteristic of narrative might be a limitation in terms of providing a final conclusion and knowledge, but it opens up different possibilities about meaning and the way we understand phenomena (Sikes and Goodson, 2016). This characteristic fits the purpose of the current research, that is, to expand and provide alternatives to the understanding of ADHD, as more than just a ‘disorder’. While this characteristic is inevitable, writing in detail and reflecting on the process of interpretation when discussing the results might help the reader to understand how the research reached its interpretation.

#### 3.8.6 Narrative presents many ethical challenges

Lastly, adopting a narrative approach means asking participants to talk about something in their personal and private lives (Savin-Baden and Van Niekerk, 2007). This might expose participants to various dangers (including the ethical issues concerning anonymity, which are addressed below, in the ethics section 3.9). For example, participants might discuss very embarrassing moments in their life, while others want to mention characters by name. These kinds of issues related to the narrative might endanger both the participants and the research; for example, the identity of the participants might be revealed, or they might regret talking about something after the interview. In addition, information about other characters in the story or institutions might expose the researcher to legal liability. Therefore, I had to keep discussing with the parents the implications of exposing some events or names within the current research to ensure protection for both parties. For example, after reading her stories, Sara removed some of them (see Appendix 7). The deleted sections were not parts of her story but concerned her knowledge of the topic. This step was necessary to understand her story better and avoid any misunderstanding (Savin-Baden and Van Niekerk, 2007).

## 3.9 Quality in qualitative research

In general, the quality of research is assessed by an evaluation of its validity, reliability and generalisation. The dominant understanding of these concepts comes from a positivist stance that understands the world as an objective reality that can be investigated through observation and measurement (Kvale, 1995; Golafshani, 2003). However, social constructionism develops different ontological and epistemological assumptions, which make the previous understanding of the criteria irrelevant for assessing the present research (Kvale, 1995). Below, I begin by discussing the dominant understanding of the former criteria. I then present an alternative understanding of them that fits the current research in a social constructionist narrative.

First, reliability is understood as the ability to exactly replicate the method’s processes and results (Spencer et al, 2004). Applying this understanding to assess the consistency of a narrative finding is not possible because of the methodological and theoretical differences within social constructionist narrative research (Spencer et al, 2004). From a methodological perspective, unlike the experimental and control variable nature of quantitative research, narrative research admits the researcher's influence on the process of the research, especially that interviews primarily depend on the researcher (Spencer et al, 2004). For example, the position of the researcher, the context of conducting the interviews and the nature of the information collected (Esin et al, 2013) all make the replication of the process and its results difficult.

From a theoretical perspective, social constructionism assumes a reality that is socially constructed based on a person’s understanding and interpretation of the world, an engagement which produces multiple realities. Knowledge is seen as a linguistic and socially constructed reality that can be understood through negotiation and interpretation (Kvale, 1995). Obtaining knowledge changes the focus from observation to reality, and dialogues are fundamental to understanding the obtained knowledge (Kvale, 1995). Thus, the focus of evaluating the research should change from evaluating the research’s production to evaluating its process (Kvale, 1995).

The above does not mean that social constructionist narrative research is unreliable but rather that the way it understands reality is different. Reliability is claimed to be the ability of methods to present consistent or solid results (Spencer et al, 2004). It changes from finding the same results to the ability of other researchers or readers to generate the same construction of the narrative in a similar setting. This can be achieved by ‘dependability’, which rests on the technique the researcher uses to ensure that the research is “logical, traceable and clearly documented”, so that the reader can investigate the process and evaluate the research (Nowell et al., 2010, p.3). Basically, the reliability of narrative research is increased by being descriptive and reflective and by the justification of the research’s process.

Second, validity is the concern with the truth of the research results (Golafshani, 2003). There are two types of validity: (a) internal validity, which is the ability to control variables in the current research, and (b) external validity, which is the researcher's ability to measure what it intends to measure (Kivunja and Kuyini, 2017). This definition stems from empirical conceptions such as universal law, evidence and facts.

In considering such an understanding, the construction of the narrative may not be valid because the researcher may have wrongly interpreted the results (Spector-Mersel, 2010). Moreover, the complex nature of a research of individuals’ lives is subject to many variables, not just participants’ differing circumstances and the different ways they describe their experiences, but also the influence of the researcher’s values, beliefs and background (Riessman, 2008). In a narrative methodology, the production of knowledge is a co-construction process between the researcher’s interpretation and the participants’ experience and understanding (Spector-Mersel, 2010). Because this form of research does not aim to find the truth, assessing its quality by examining whether the knowledge provided is true or not is irrelevant; the participants’ understanding of the world is complex and different.

Polkinghorne (2007) asserted that validity is a way of convincing the reader of knowledge claims which depend on agreement within a community on what is considered valid. Evaluating the legitimacy of evidence and reasoning depends on the background and assumptions of different communities (Polkinghorne, 2007). Thus, validation in the social constructionist narrative approach is not a different concept, but a different understanding of how to justify a claim’s validity.

Narrative methodology focuses on social and personal constructions which require evidence and arguments beyond the limitation of traditional scientific validation methods for justifying knowledge (Polkinghorne, 2007). This is especially true because narrative methodology questions the reality of knowledge and believes that an individual’s personal construction of reality provides evidence concerning neglected aspects of the human world.

Validity in narrative research is oriented to the ability of the reader to follow and evaluate not the wrong or the right of the claims but the possibilities of the researcher’s claims for and interpretations of the narrative based on the presented evidence and argument(s) (Polkinghorne, 2007). In practice, researchers often increase the validity of qualitative research by providing a discussion and argument of how the researcher’s claims and interpretation(s) fit the selected quotation and give reasons for such claims. This can be achieved by predicting and answering questions that the reader might have in regard to the research’s claims (Polkinghorne, 2007). Moreover, it helps to determine the kind of evidence and argument that the research process might provide to reach interpretations and claims about the narrative (Polkinghorne, 2007). The evidence needed for proving certain interpretations of the stories comes mostly from the research processes, such as collecting and analysing data. Therefore, a discussion concerning the validity of the interpreted evidence and its collection is necessary.

I analysed the narrative using a narrative thematic analysis based on the social constructionist assumptions of knowledge (see Chapter 4: Research Procedure). In qualitative research, enhancing the quality of interpretation can be achieved by triangulation (Patton, 2001), a strategy used to enhance trustworthiness by employing two or more methods, data sources or methods of analysis (Golafshani, 2003). In this research, I only used narrative data because I believe that narratives are themselves very complex constructions. I embrace the complexity of the narratives by highlighting their subjective features and how they could be read in different ways, some of which are almost opposite to each other. I used both the medical and social models, inspired by how feminist theory (Morris, 1992; Lloyd, 1992) interprets themes illustrated by a narrative. The purpose of using this strategy is not to prove that a participant’s account is true, but to provide more complexity and richness to the participant’s account (Denzin and Lincoln, 2011; Polkinghorne, 2007).

Silverman (2015) discussed strategies used to ensure validity and trustworthiness within the data and interpretation using member checking, which is the process of giving a report of the interpretation and analysis to the participants for them to check that the researcher has derived the right meaning from their account. I was considering this strategy before I did the interviews; thus, the participants were informed of this process for acquiring their feedback about the report. Additionally, as I discussed this step with the participants, I thought of this approach’s usefulness for protecting the participants’ information, that giving them the report would allow them to check its confidentiality and anonymity. The participants’ feedback indicates any gaps that I missed in the report that might lead to their disclosure. Finally, the participants’ feedback correct or challenge the researcher’s interpretation (Willig, 2013).

Concerning the validity of evidence collection, the current research builds on the assumption that the narrative is not just the creation of the participant but rather is a co-constructed product of an interview that is based on the research’s aims (Jovchelovitch and Bauer, 2000). Enhancing validity within the research depends on the narratives, as evidence needs to acknowledge and address the limitations and threats in the process of constructing the narrative. Polkinghorne (2007, p.480) stated that: ''Narrative evidence is gathered not to determine if events actually happened, but about the meaning experienced by people, whether or not the events are accurately described''. In other words, the threat in narrative research is not the accuracy of the narrative, but is instead how well the narrative allows the researcher to interpret its meaning.

Despite the impact of language on the way we experience the world, the actual experience is more complicated. Language itself sometimes fails to express the complex and layered meanings of experience, and thus a language-imposed structure presents boundaries to participants’ descriptions of their experiences. Polkinghorne (2007) suggested encouraging the participant to use metaphorical and analogical descriptions in talking about an experience to better illustrate its meaning than would a literal expression. In practice, most participants used metaphorical descriptions without my interference, but I did find encouraging metaphors useful with a minority of participants that needed support in being more descriptive in their narratives.

Collecting stories can expose a private and sensitive aspect that gives a lot of detail to an experience; however, a participant might exclude them from an interview. Therefore, building a trusting relationship can lead the participant to speak more freely (Polkinghorne, 2007). Gubrium and Holstein (2001) recommend interviewing each participant three times to build this trust.

In my research, I conducted two interviews with each participant, before which I spoke to them on the phone after they responded to my advertisement. The pre-interview was aimed at introducing myself and the research and to test the participants’ intent to take part in the research, as well as to find a starting point for the first interview.

Gubrium and Holstein (2001) highlight the importance of listening carefully to participants without interrupting the flow of their stories. This encouraged me to ask more questions about the participants’ intended meaning; however, for the sake of the story flow, I left the question to the end. This technique is important for allowing participants to explore the meanings they construct and to recall more experiences that impact their understanding (Polkinghorne, 2007).

Following the recommendation in Gubrium and Holstein (2001) while collecting the stories was difficult, because so many questions come to mind. My solution was to write down any questions as I was listening, which allowed me to pay more attention to the stories. The technique was also useful to prompt those participants who were not talkative. Ahmad and Laila finished their whole story in approximately 10 minutes and then asked me what more they could say. I then asked the questions I had written down. Writing down my questions allowed them to think and talk more about their experiences without interruption, enabling them to give details that better illustrated those experiences.

Lastly, generalisation is understood as the ability of the research sample to represent and be applied to a broader group of people (Ali and Yusof, 2011). This is problematic with the current research, which illustrates an understanding of the world from a small sample of individuals and does not appear representative enough to imply broader inferences about parents of children with disability (Patton, 2003). At first glance, this might present a limitation of qualitative research, yet in understanding the assumptions that undermine such an assessment, I argue that the focus on statistical sampling procedures in generalisation is irrelevant. The social constructionist approach, which is an in-depth investigation of the complexity of the individual experience, is less impacted by sample size. Patton (2003, p.245) argues that the meaningfulness and insights generated from qualitative inquiries have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher than with the sample size. Hence, Lincoln and Guba (1985) proposed ‘transferability’ as an alternative to previous understandings of generalisation applying not to the results, but to the process of the research, by being descriptive in detail to future researchers who want to apply the research to their own context (Nowell et al., 2017; see Chapter 4 for the procedural process in detail).

Moreover, Smith (2018) illustrated other ways that qualitative research, such as the narrative approach, could be generalised. He represented two types of generalisations. The first is naturalistic, which is the ability of the narrative understanding to allow the reader to identify differences and similarities with their own experiences (Smith, 2018). Such analyses of narratives can offer the reader in-depth detail about the lives of the participants and the context(s) in which they live, while the lens used for the narrative might highlight different layers of understanding of participants’ narratives. These features can help different readers, including those from families having children with and without disabilities, teachers or professionals, to connect with an interpretation of the narrative that increases generalisation in different ways.

## 3.10 Ethical considerations

Edwards and Mauthner (2002) illustrate three models that the social science researcher draws from to think about the issues of ethics in the research process. Firstly, the “duty ethics of principle”, which describes a universal principle that advocates honesty, justice and respect. Secondly, the “utilitarian ethics of consequences” model, which focuses on the outcome by evaluating the action of the researcher and their impact on the consequences. Finally, the “virtue ethics of skills or ethics of care” model, which focuses on how the researcher negotiates the ethical issues of a specific context with participants. While the first and second are a universal system of ethics that all research shares, the third is not ethics on its own, but more like ideas that challenge and customise the universal ethics in relation to the research details. Ethics of care is not a checklist that researchers follow to confirm that the research is ethical, but an ongoing discussion throughout the research process (Edwards and Mauthner, 2002).

Feminist scholars such as Morris (2001) represent the ethics of care, which looks at conventional ethics as universal and impartial in taking care of human rights, because they only focus on concepts such as individuality, autonomy and independence, forgetting that we are human beings that link to each other through relationships and interactions (Mckenzie and Macleod, 2012). The feminist model argues that the concept of care within the conventional model of care is universal and does not fit all people; we are not totally independent, but we need each other, which the feminist theory refers to as interdependence (Mckenzie and Macleod, 2012). The theory advocates challenging the notions of ethics (Morris, 2001).

Mckenzie and Macleod (2012, p. 26) argued that “reciprocity within relationships might be difficult to discern when viewed from a binary perspective on carer/dependent that values only certain kinds of services”. In reflecting on the research, Mckenzie and Macleod (2012) advocated that the researcher’s relationship with participants should not be objective through just observing the data and interpreting the findings from the researcher’s point of view, but the relationship should be looked at from a subjective and emotional attachment that is constructed of both the participants' and the researcher's perspectives in investigating the focus of the research. The relationship between the research members creates a type of dependency, as the participant is engaged in the research and tells a story that the researcher then tries to interpret and represent in the research. It depends on how much the researcher cares about the participant’s needs to achieve better ethics, especially if the participants were individuals with disabilities, or their parents, which presents a different and more sensitive kind of dependency, because of their vulnerable position. For example, the researcher could easily present them in a way that takes away their right to present themselves in the way that they want or even in a way that hurt them. Therefore, the theory advocates negotiation with the participants, not just about what the research wants to explore, but also the needs of the participants from the research presentation.

However, Denzin (2017) argued that the modernist model, which emphasises a rational universal solution to the issues of ethics, ignores the fact that the interactive nature of humans should be replaced with the ethics of care model. Sevenhuijsen (1998) asserted that the ethics of care do not provide a principle to apply to the research, but are more like questions or ideas which cause the researcher to pay attention to the issues of ethics and think about them through their interactions with those participating in the research. Therefore, I used the feminist idea throughout the research process and illustrate this argument through a reflective journal, which is discussed below in Section 3.9.

The research had ethical approval from the University of Sheffield ethical application system. I added a justification to all aspects of the ethics about the research process, sampling and collection; however, I do not think acknowledging systematic and universal ethics from ethical approval is enough (see Appendix 8). The nature of narrative interviews demands informed consent beyond the participants’ rights to withdraw from the research and an illustration of the research interview and analysis process (Smythe, 2005). Narrative is an exploring methodology that makes predictions about the type of the data the interview will produce, and how the researcher uses this data is difficult. The interview data is the personal and private story of the participants and giving consent to use this type of data might raise ethical issues for the participants in relation to privacy and anonymity (Smythe, 2005). Therefore, consent in narrative research is an ongoing process involving negotiating with participants throughout the research process.

Moreover, narrative research is a co-construction process between the researcher and the participants. Many researchers advocate friendly relationships with the participants. I agree with the feminist argument that creating a relationship with participants may cause problems for both parties, such as a physical load on the researcher or an emotional load on participants after the research has ended (Ellis, 2016). I do not intend to deceive the participants by creating relationships for the benefit of the research. With respect to all the participants, I think friendships are more than just conversations between people. Thus, I just worked and collaborated with participants in a compassionate way during the research (see Section 1.2), as the researcher-participant relationship in narrative research is about understanding, feeling and connecting with each other (Richards, 2011).

Lastly, it is important to discuss the issue of ownership of the narrative in narrative research (Bolen and Adams, 2016). Some researchers claim that the owners of the narratives are not the participants, because the narrative is not about the illustration of the participants’ perspective, but the meaning of their experience. However, the researcher must make participants part of the analysis to ensure accurate interpretation and presentation (Bolen and Adams, 2016). Following social constructionist assumptions (Schwandt, 2000) about the role of the researcher, it is clear that the nature of ownership is co-constructed, where both the researcher and the participant engage in producing the narrative interview, as well as the way the stories are interpreted. I think that the participants’ role is a form of negotiation between the two parts of the research, because it is unfair that I am allowed to discuss their stories with them while they are not allowed to question the way I experience their stories. The way I understand the stories might be affected by my own understanding of the topic, which could be impacted by my own subjectivity and background. It will make the understanding more accurate with misrepresentations removed.

## **3.11 Conclusion**

This chapter discussed the ontological, epistemological and methodological stance of this research. It began with a reflection on the aims and questions in the research as the first step in guiding the research design choices. The research used the narrative methodology, underpinned by a social constructionist philosophical stance, which allowed the exploration of various parents’ perspectives. The narrative methodology was selected, as it allows the exploration of unpopular voices, such as parents, about disability and ADHD, as well as of the cultural and social influences on parents’ perspectives (see Section 1.2). Moreover, I offer a justification for my choice using a comparison with the phenomenology and ethnography approaches, as well as a discussion of the criticisms and challenges I encountered in using such a methodological stance. The chapter ended with a discussion of research quality and ethical considerations, in line with the theoretical assumptions of the research.

While this chapter illustrated the beliefs and assumptions underpinning the research, the next chapter will demonstrate the application of the philosophical assumptions in the procedural steps of the research.

# **Chapter 4**

# **Research Procedures**

Introduction

This chapter discusses the research procedures, including how I used the philosophical assumptions from social constructionist theory and narrative inquiry in the current research. The first section outlines the methods I used to recruit participants and to collect and analyse the data. It also presents reasons for combining criterion and snowball sampling to recruit participants. The second section provides an overview of the participants’ demographic data and the interview questions and process. Moreover, it discusses the benefits and challenges of using the narrative interview style. The third section addresses the steps in the analytical approach used to investigate and explore the data. As the current research was focused on Kuwaiti participants, the last section discusses the translation and its influence on the analysis. Thematic narrative analysis is a complex process involving many challenges that will be discussed below.

## 4.1 Recruitment

This subsection starts with the clarification and justification of my choice of sampling method. I then introduce the participants and their characteristics and the places they were recruited. Lastly, I discuss the recruitment process and the issues involved in the process.

### 4.1.1 Sampling method

The recruitment process included a combination of two approaches to sampling: criterion sampling and snowball sampling. Criterion sampling, defined as a ‘review and study [of] all cases that meet some predetermined criterion of importance’ (Patton, 1990, p.176), was used to identify participants who fitted the focus of the study: being Kuwaiti or living in Kuwait and having a child aged between 6 and 12 years old with ADHD. This age criterion was chosen because children are generally diagnosed at around six years old (KALD, 2010). However, during the study, I changed the age criterion because my research eventually included children up to 18 years of age, which I will explain below. Setting the sampling criteria meant that the number of appropriate places for finding participants was minimised; however, I faced a further recruiting challenge of finding families willing to participate in the research and share their experiences. The research investigated a sensitive topic, so a lot of families were hesitant to talk about it or felt that the research threatened to marginalise them.

Therefore, I also used a snowball sampling approach, which is a non-probability sampling method in which existing participants identify other possible participants from their family, friends and acquaintances (Sharma, 2017, p.752). Using this approach provides access to participants using a gatekeeper – a family with children who have ADHD – that acts as an intermediary between the researcher and new participants for the research (Cohen and Arieli, 2011; Woodley and Lockard, 2016).

The snowball method allowed me access to the ADHD community. The participants saw my research advertisement in a WhatsApp group that functioned as a community of women who had experience parenting a child with ADHD. It gave both professional and social support to help other parents meet the challenges they might experience rearing a child with ADHD. It was the most suitable place to find participants, and I was able to find most of my participants in this way. Moreover, the snowball approach builds comfort and trust in participants without them feeling that the interviews would further marginalise them (Woodley and Lockard, 2016). Being introduced by a trusted person from the group increased trust and collaboration when collecting the data, especially as the first participants had already experienced the interviews and believed in both the importance of the research and my good intentions in using their stories.

However, the snowball method has been criticised for selection bias and a lack of diversity when selecting participants (Sharma, 2017). This criticism could be relevant if the sampling results were to be used as generalisations about the topic and used to represent a broader context. However, this is not the intention in my research, which takes a social constructionist approach to seek naturalistic and analytical generalisations to generalise concepts and theories and highlight differences in the participants’ experiences (Smith, 2018) (see Section 3.9). Hunter (2010) noted that the narrative research approach is valued not for its ability to generalise results, but for its ability to provide a rich and reflective experience that would allow other researchers to learn from and apply the narrative approach. This kind of generalisation needs great depth and richness, which is difficult to achieve with a large number of participants.

The rich and purposeful sample generated by the snowball sampling method increased generalisation in this research, especially when generalisation is understood as the ability of the participants’ stories and the researcher’s representation to offer enough detail and practical evidence from the stories to help the reader reflect on the stories, make a connection or even use the stories in their lives (Smith, 2018). Moreover, in narrative research, the generalisations go beyond an argument that the researcher wants to make about a topic, with which the reader may agree or disagree based on the evidence. Rather, the generalisations are more subjective, meaning that the reader gets to evaluate the shared evidence to support the probability of the interpretation of the narrative.

### 4.1.2 Sample size

Patton (2001) argued that sample size in qualitative research depends on the research purpose, the time available and the level of credibility given to the research. I wanted to focus on the parents’ experiences by using narrative interviews to collect their stories. This method generates an enormous amount of data (Jovchelovitch and Bauer, 2000); therefore, the sample only included eight parents.

### 4.1.3 Participant characteristics

Table 1 illustrates some of the parents’ details, such as gender, education and the child’s age. I used pseudonyms to refer to the children and the parents to hide their real names, as stated in the participants' Consent Form (Appendix 4). I have not included any other descriptions of the parents, such as occupation, because of the sensitivity of this information, especially as Kuwait is a small country, and exposing more information might put the parents at risk of being identified by others.

I did not want to include the parents of children aged less than five years old because I wanted to focus on school-aged children to explore the parents experience of society’s (e.g. teacher, administration and professional) reactions to the children’s differences; however, the child was already in nursery school and I could explore the child and mother experience in school setting.

صورة تحتوي على منضدة

تم إنشاء الوصف تلقائياً

**Table 2:** The participants’ characteristics

### 4.1.4 Place of recruitment

I attempted to recruit participants by contacting the administrators of the parent support organisation and talking to friends who work in public sector institutions. I eventually recruited participants from different parent support institutions. My choice of recruiting institutions was built on my experience as a volunteer and my research on disability policies in Kuwait. I posted advertisements in these places after receiving administrative permission from each institution starting with the University of Sheffield Ethics procedures committee (See Appendix 8).

To advertise the research, I made the Information Sheet and the Consent Form (see Appendix 4 and Appendix 5) available to the institutions. I presented the information in these documents in Arabic and English, as some parents may not have been able to read English. Using Arabic made it easier for them to read the documents; however, the documents of parents who responded in Arabic were translated into English by a professional translator to enhance the credibility of the parents’ data consent.

### 4.1.5 Recruitment process

This section recounts the journey and the challenges I faced when recruiting the eight parents. I recruited four participants. While preparing for my confirmation review, I was introduced to Kuwaiti disability policies. I found that there were multi-governmental organisations concerned with children with ADHD. This allowed me to expand the number of places I could search for participants.

I started with the state-run special needs school because I wanted participants that fitted my criteria. It also gave me the opportunity to observe the impact of disability policies in state-run special needs schools on families child with ADHD. However, it was difficult to get permission to display my advertisement in schools and organisations because I was undertaking narrative research, which is a new method for conducting research on families of children with disability, and getting permission for such research increased the risk of exposing the families’ personal information. After facing challenges to justify my research methods and get approval from the Ministry of Education, I finally obtained permission to approach schools, but it was too late because some schools were closing for the summer holiday. In the end, I was left with one government school option. After sending the advertisement there, I recruited 2 fathers of 10 years old children with ADHD.

I then went to the non-governmental association. They were very welcoming and sent my advertisement to a WhatsApp group of parents of children with ADHD. I received a call from a mother in this group who was excited about participating; however, her child was over 18 years old. Although she did not fit the research criteria, her excitement about the research and the method used to explore parents’ experiences led me to ignore this and interview her. I decided to focus on her child’s early years. At the end of the interview, I asked her to introduce me to other parents whom she felt might be comfortable talking about their experiences, and she introduced me to three mothers of children with ADHD. Most of these children were also over 18 years old, but one of the three mothers, who had several children with ADHD, had a 12-year-old child.

I was challenged by the age of the children of the parents I was trying to recruit. Most of the interviews with parents with children aged between 6 and 12 years old were very short because they did not have much to say about the experience. I remember one parent telling me that he would like to help, but he was still struggling to understand and solve the issues that come with children with ADHD. This situation justified my recruitment of parents of children over 18 years old, and there were many mothers of children aged over 18 years old available. This led me to change the sampled age criterion; I considered that parents of children aged over 18 years old might have more to say about their experiences. Their experiences would also help me understand and evaluate the historical experiences of parents in the Kuwaiti context and the impact of changes to disability policies on the families of children with ADHD in Kuwait.

Reflecting on the participants’ experiences, I approached Al-Sabah Hospital, where parents must pass through an important stage for getting their children into a special school. After receiving permission from the Ministry of Health, I placed an advertisement for participants in the hospital. A participating mother called me to see if I was still looking for participants because one of her friends might be interested, but the friend wanted to first talk to me about the study. After a discussion about the study and the nature of the interview, she agreed to participate. Her interview was rich in detail and one of the longest interviews I conducted, but, again, her children were over 18 years old.

## 4.2 Data collection

The second subsection of the research procedures describes the data collection process. I start by explaining my reasons for choosing narrative interviewing as the data collection method. I discuss the questions used in the narrative interviews, then demonstrate the process of interviewing the participants and the strategies used.

### 4.2.1 Interviews

The most commonly used tool in narrative research is the interview (Muylaert et al., 2014). Narrative research is conducted using different type of interviews, such as structured, semi-structured, in-depth and narrative. My research aims to explore the experience of parenting, and the assumptions that I stand on do not deny the impact of researcher value, but try to minimise it. I had two options: in-depth interviews and narrative interviews.

In-depth interviews: ‘commonly involve one-on-one, face-to-face interaction between an interviewer and an informant, and seek to build the kind of intimacy that is common for mutual self-disclosure’ (Johnson, 2001, p.2). Denzin (1989, p.55) defines the narrative interview as ‘merging the objective feature of subjective life with the subjective meaning attached to life experience’. It is a method that prepares an unstructured, inviting setting that stimulates stories from the participants’ life experiences within their social context (Jovchelovitch and Bauer, 2000). Both narrative and in-depth interviews bring more details and rich data about the focus of the study from the experience of the participants. However, the difference between narrative and in-depth interviews is that the latter is much more structured than the former, as the interview will be directed by the researcher. Also, the in-depth interview is used to find in-depth information about specific questions that interest the researcher (Johnson, 2001).

Narrative research involves communicative open-ended questions. It begins with generalised broad questions based on the research topic, although they are specific to the time and issue that is of interest to the researcher, and give guidance to the participants to describe their lives (Flick, 2018). As my research follows an epistemology that focuses on the role of language, using these kinds of questions allowed the stories to be constructed through the participants’ spontaneous language, showing how they use language to construct their understanding of the phenomenon. Another reason for using narrative interviews is that they are considered a collaborative process, constructed from the conversation between researcher and participant. They give some power within the interviews through limiting the influence of the researcher’s ideas on the stories. They are designed to avoid hard and fast themes, and instead depend on what the participant presents from their experience, inviting further questions about those events (Jovchelovitch and Bauer, 2000). This is suitable for narrative thematic analysis of the research, which starts with the themes produced in the stories (Riessman, 2008). Therefore, I chose narrative interviews over in-depth interviews for this research.

Narrative interviews have been criticised for the lack of validity of their data. The stories produced from narrative interviews are constructed in a specific form by the influence of the research aims and the participants’ interpretation of the interview situation (Denzin, 1989). Muylaert et al. (2014) stated that narrative interview data might seem selective and unreal because of the limitations of the memory process that lead to changing or forgetting what really happened; however, the memory process does not minimise the importance or validity of these experiences. The narrative interview has a basis in constructionist theory, which considers it to be an interpretive process instead of an illustration or description of the world (Denzin, 1989). The validation of the data is subject to the usefulness of the stories and not what is right or wrong (Lincoln and Guba, 2000). The participants are only expressing their own views and interpretations of the topic at a certain time, in a specific cultural and historical context.

The interview process was done in three stages: pre-interview, main interview, and post-interview, following Gubrium and Holstein’s (1995) suggestions for building trust between the interviewer and the participants. The pre-interview was conducted over the phone to introduce the nature of the interviews and research to the participants, and allow them to ask any questions about the research, process or data. I then scheduled the first interviews over the phone and determined a time and place based on the participants’ preferences. Half of the interviews were done in the participants’ workplaces, two were done in the non-profit organisation, and one was done via video call. All interviews lasted for over an hour. I conducted the interviews over one month, in Kuwait. The post-interview was done in the analysis stages to clarify some parts of the stories. It was also used as a checking method, allowing the participants to check the interpretations and the way their experience was presented.

### 4.2.2 Interview questions

Mishler (1986) advocates the empowerment of the participant and encourages them to find their voice. He recommends giving encouragement with open-ended questions, which comes from the idea of shifting the power between interviewers and participants. To achieve that, the interview question must be simple and straightforward, but still related to the research topic (Hollway and Jefferson, 2000). The question should invite the participants to talk about a specific time and situation in their lives and not their whole life histories (Hollway and Jefferson, 2000). After discussing this idea with my supervisor, we came up with a simple question related to the aim and research questions, which was, ‘Can you tell me about your child?’

In addition, I developed an interview schedule to help remember the research questions and aims; however, I waited until participants had finished telling their stories and answering any questions I had about them before asking them the set questions that were not covered in the stories (see Appendix 2: Interview Guide).

Before I did the interviews, I thought about my position and initial ideas, and this was useful during the interview process. It was a reminder not to assume that I knew the participants’ intended meanings just because I shared some culture and language, but to ask questions about what they were trying to show with their stories and metaphors. For example, my initial understanding of the fathers came from previous studies and talking to the mothers I worked with in the education centre, who presented the fathers as unsupportive in the parenting process. However, through the participants’ stories, I saw this as different and more complex, with some participants explaining how the father could be supportive in some aspects of parenting, but not in others.

### 4.2.3 Conducting the interviews

Interviewing the parent of a child with a disability is a very emotional and sensitive process for the parent. Morris (2001) explains that talking about impairment might be dangerous because it might evoke some negative feelings about their experience. They might not want to talk freely, and may not want to present a negative image of themselves to the interviewer. I addressed this issue by conducting a pre-meeting. I wanted to make the parents feel comfortable by discussing the research, answering their questions about the research and how their stories would be used, and their active role in presenting these stories.

Following Hollway and Jefferson’s (2012) suggestion on the interview process, I began the interview by giving the participants the Information Sheet and the Consent Form (see Appendix 4 and 5) to read, and asking if they had any questions about it. I also introduced the interview process, explaining their rights and responsibilities within the research.

Reliving the experience of disability in society had the possibility of evoking sad emotions for the participants. Acknowledging such issues, I provided information about options for further support should they need it. I was very clear about the intention of the interview before I proceeded, told the participants that the interviews could potentially raise some emotional and sensitive topics, and reminded them of their right to withdraw if they did not wish to continue (Hollway and Jefferson, 2011). None of the participants showed a need for support on this issue.

I began with the prompt ‘Tell me about your child’ to stimulate stories about their experiences. Narrative interviews often employ open questions to offer participants more control and the chance to construct their own stories. The questions are used to allow the participant to speak and tell their stories without interruption (Glover, 2003). Moreover, the reason for choosing one open question is the interest in the dynamic of power between me as researcher and the parents(Mishler, 1986). Giving some of the power in research to the participant is considered important in disability studies, which advocates empowering disabled people and their carers, as experts in understanding disability and impairment (Goodley, 2011). The interview is seen as a learning process, where the participant takes control by choosing the experience they want to discuss, and the researcher is a collaborator who helps to explore the selected aspect of the participant’s experience (Mishler, 1986). Some participants needed encouragement as they were discussing their child, because the narrative interview style was new to them. Some participants were expecting a more standard interview, where there were questions and they simply had to answer them. It was hard for me to develop questions from what they were telling me, as it seemed they were interrupting the flow of their responses to wait for questions. However, as I was conducting the interviews, I began to tell participants from the beginning that there would be no set questions, as the interview aimed to explore their stories. I think managing the participants’ expectations of the interview questions allowed them to speak more freely about their child and ADHD in Kuwait. Moreover, Glover’s (2003) recommendation to use the active interview style was highly helpful. Active interviews were conducted through follow-up questions to help the participants tell their stories, as well as to ensure the researcher understood the participants’ meaning. Mishler (1986) recommends using the participants’ language in asking for more information about the stories and any unclear meanings. I considered this as I was asking the participants questions using the information they gave me, and I tried not to influence the flow of the stories.

The stories explored the children and their relationship with their parents, siblings, teachers and extended families. We then talked about the ADHD diagnosis process, the policies and school selection. They also mentioned the support they got from policies, professionals and their families. Moreover, they mentioned their relationship with the community and their partners, and the impact of their experience with ADHD on them. When talking about policies and school, participants mentioned changes they wanted to happen that would help their lives. We talked about parenting and their role as a parent in the experience, and finally, about the way they understood ADHD and how they coped with it. At the end of the interviews when I stopped the recorder, I asked the parents what they thought of the interviews, how they felt, and if they had any questions for me.

**Appendix 2:** Interview Guideصورة تحتوي على نص

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## 4.3 Analysis method

My choice of analysis method follows the narrative methodology and social constructionist assumptions to explore the way people make sense of the world through narratives as central to investigation. I chose to analyse stories through narrative inquiry, which focuses on what people present, such as things and events, as well as examining the way they present them and the way they experience them. I had the option of choosing analysis of narrative, which identifies the common themes across the stories (Polkinghorne, 1995). However, this method focuses on what the stories are about, breaking down the stories into abstract themes written within a theoretical frame (Smith, 2016). Analysis of narrative fits my philosophical assumptions, which focus on the relation between the context and an individual understanding of social reality. Part of my purpose in the analysis was to understand topics related to the parents' experience of bringing up a child with ADHD (Polkinghorne, 1995), but it was important for me to keep the story intact to investigate the process of storytelling. This allowed me to examine what kind of meaning the parents might communicate, instead of treating the story as data to be broken down into parts and then interpreted to keep their organisation and communication of the past, present and possible future as well as the meaning of the story (Smith, 2016).

This means that I categorise the stories into themes, but when analysing the stories I return back to the place of the story within the whole narrative to understand it in relation to the whole narrative. However, in presenting the results, I return back to breaking down the stories. In constructing stories about the way they understand the present social reality, the individual retells the events of the past in different ways, and they interpret them differently to understand the present and illustrate the influence they might have on the future (Smith, 2016). Frank (2012) discussed the consequences of breaking down the story into data, and how it can remove the spirit of the participant. He encourages being attentive to the participants behind the stories. This method of working with data as a whole had a lot of positive consequences for the current research.

Moreover, narrative inquiry does not primarily focus on what kind of knowledge is found in the data. It highlights alternative ways in which the data could be understood to invite the reader to think with the stories and the implications for people’s lives (Bochner and Riggs, 2014). The focus on the process of narrative, such as the character, the setting and how they work together, helps the reader to evaluate and reflect on the meaning and the actions in the stories (Polkinghorne, 1995).

Lastly, narrative inquiry reconstructed the narrative in collaboration between myself and the participants, instead of claiming objectivity and rigour in the analytical method (Bochner and Riggs, 2014). In other words, the narrative is my interpretation of the participants’ stories, but it also includes a discussion of the way I arrived at such interpretations by highlighting the story construction and giving some excerpts. Narrative inquiry illustrates the process in which participants make meaning, which does not erase the existence of the participants and their subjectivity (Mckenzie and Macleod, 2012). These are my justifications for choosing narrative inquiry (narrative analysis), and this method has been used in various ways to focus on different aspects of the narrative.

### 4.3.1 Thematic narrative analysis

Narrative analysis covers a group of methods that investigate the narrative and its elements from different standpoints and is used for certain purposes (Bochner and Riggs, 2014). For the sake of comparison, I will mention Riessman’s (2008) typology of narrative analysis, which includes thematic, structural, performance and interactional analysis. There is one important idea to mention before doing the comparison, which is that all types work together in constructing narrative, and the boundaries between them are not very sharp (Smith, 2016). In using one of them, I am not rejecting the others, but simply giving them less attention. In doing the analysis, the other types are helpful in understanding the meaning in the narratives.

Riessman (2008) demonstrated that thematic analysis focuses on the story content, where the ‘told’ is the focus rather than the ‘telling’, paying attention to the themes in the story to interpret the meaning. Structural analysis focuses on the way of telling; in other words, the way an individual uses narrative devices to convince the listener or reader (Riessman, 2008). Structural analysis gives attention to the elements of the story that constrain the meaning of experience. Performative analysis focuses on the way participants use language and gestures to convince their audience. It is concerned not only with the telling, but also the doing (Riessman, 2008). Finally, interactional analysis focuses on the dialogue between the teller and the listener within a particular setting (Riessman, 2008). It understands stories as a co-construction process that help to understand the relationship between the listener and the storyteller in different settings. All the above methods work together, so it is very difficult to separate them during the analysis of the way participants construct stories and the meaning behind their stories, but in the discussion, I represent only one type of analysis to fit the research purpose.

My research questions were oriented to explore the topics and the language that parents used in communicating and constructing their experience of raising a child with ADHD. My interest in the narrative differed from that of structural analysis because I understand narrative as a resource, not a topic of investigation. Moreover, I was interested in language and discourse more than the gestures, body language and emotions that participants used to communicate stories, so I paid minimal attention to performative analysis. This left me with thematic analysis.

Thematic narrative analysis is an inductive analysis method that depends on the data to construct the themes (Smith, 2016). Demonstrating and theorising the themes from the cases can sometimes be confused with grounded theory (Braun and Clarke, 2006). In analysing the data, grounded theories fracture the stories into categories inductively to theorise the themes across the data, while thematic narrative analysis focuses on each case. I intended to explore the themes within each story separately to keep the stories complete. This decision follows Riessman’s (2008) argument about the usefulness of long sequences in keeping the detail of the meaning presented in the stories.

Thematic narrative analysis uses theory and previous research to guide the analysis through the data (Riessman, 2008). However, that does not mean the analysis is theory-laden, because I used an inductive approach, which aims to identify the themes from the data and not from prepared theories (Braun and Clarke, 2006). The themes were constructed from the stories while the prior theory was only used to guide the analysis and help explain the themes to answer the research questions (Riessman, 2008).

After defining thematic narrative analysis and its main features, I explain my process. However, before that, I want to illustrate the degree of attention to context in analysing the narrative.

### 4.3.2 Consideration of context

Thematic narrative analysis does not usually focus on the researcher’s role in narrative construction, nor on the broader context, such as social structure and power in society (Reissman, 2008). These features are not relevant to social constructionist epistemological assumptions. Knowledge, according to social constructionism, is not an internal cognitive process, but an interactive process between the individual and the context surrounding them, whether situational (with the researcher), historical, cultural or social (Burr, 1998). By drawing on social constructionist assumptions, the narrative is considered a co-constructed and social process (Esin et al., 2014). Thus, a discussion of the context of the research and the position of the researcher in the analysis of the narrative is important to understand the complexity of the meanings of the participants’ responses to the interview questions. Moreover, the position of the researcher influences the way participants tell a narrative and the way the data is interpreted. Therefore, it is important to understand the personal, social and cultural position and the theoretical and methodological assumptions.

I have already discussed my position with regard to research interests and methodological stance (see Section 1.2); here I discuss the impact of my position on narrative construction and interpretation. In understanding my relation to the participant and stories, I consider myself an insider and outsider. This stand impacts the way stories are told and the way I interpret them. I am an insider because I share a similar language, culture and context with most of the parents, while I am also an outsider because I do not experience disability or parenthood. The influence of my position was clear in the way the participants presented the stories and the language they used.

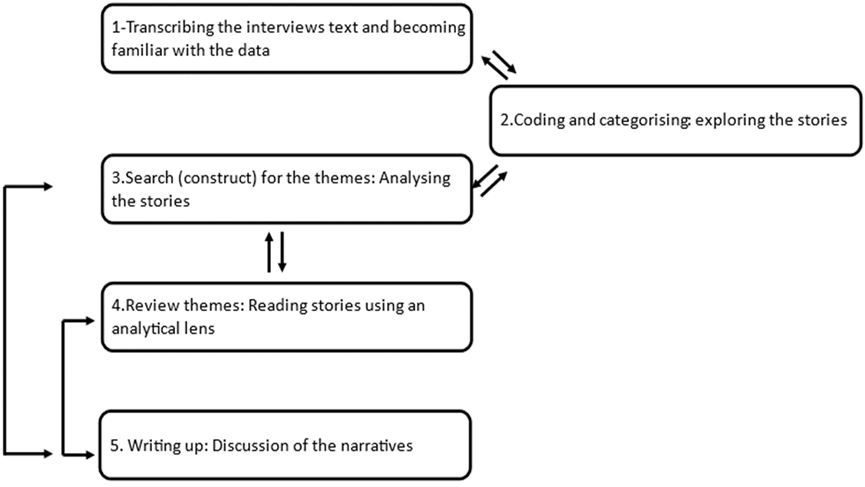
One example can be seen in Marleen’s stories. In positioning myself in her story, we share a context, but not the experience of disability or parenthood. While telling the stories, I noticed that Marleen talked a lot about parenting, using many stories to help me understand the parent's role. However, when she explained Kuwait’s reaction to disability, she assumed a collaborative understanding from the Kuwait context, stating: ‘You know how it is in Kuwait’, and then continued talking about the lack of family support in a very short story. She assumed that I would understand the negative reaction from Kuwaiti society and the shame of talking about disability that affects the whole family, not just the parents, and affected her decision to be silent about her children’s disability and take on all the responsibility for caring. Marleen’s assumptions affected the details of the story, which would likely include more examples of her life if it were for a listener from a different context.

Regarding the context, reflecting on the position of the research in the analysis process was effective in considering the ethical issues in interpretation and publishing the participants’ narratives. I established in the Methodology chapter that anonymity and confidentiality of participants’ information was one of the essential areas of ethical considerations. Thinking about ethics in narrative research is a continual process in all parts of the research. Information or stories that are considered vulnerable, sensitive or personal are difficult to determine, but must be considered. Esin et al. (2014) recommended addressing these issues in relation to the context and particular circumstances of the research.

Concerning the context of the current research, which focuses on personal stories of everyday life, the participants’ stories did not just include accounts about themselves, but included other people from Kuwaiti society, such as professionals, teachers and school principals. The participants were careful about hiding their names and their children’s names as a way of protecting their children from being identified in the stories; however, they did mention the name of the school and other people who had helped them in their experience of parenting a child with ADHD. They varied in their reasons for giving details, from helping other parents, to hoping that the research might bring justice to these mothers. I understood their reasons, but considering that I did not get consent from the other people, this could expose both myself and the parents to legal liability. Thus, I had to remove the names of other people and schools because in ethical considerations, narrative research is not just concerned with participants but also the other characters in the narratives.

### 4.3.3 Thematic narrative analysis procedure

This section discusses the analysis steps taken to explore and investigate the parents’ stories using thematic narrative analysis (Reissman, 2008). To organise my presentation of the analysis steps, I draw from Braun and Clarke’s (2006) five-phase thematic analysis, as it offers a structured framework to the current research. The thematic narrative analysis process was a disorganised and complex journey which is difficult to describe. Thus, I used thematic analysis, but the process differed according to my analysis tool.



**Figure 4:** The analysis steps

#### 4.3.3.1. Transcribing the interviews text and becoming familiar with the data

Transcription in qualitative research means transforming interview data from audio into written form. In narrative research, transcription is a form of interpretation. Reissman (2008, p.28) asserted that transcribing is not just representing ‘what was said’, but preparation of narratives for analysis. The choice of transcription methods underpinned the theoretical perspective and methodological orientation of the research (Reissman, 2008).

Thematic narrative analysis focuses on the content of the speech to parse the narrative into themes or meaningful units (Riessman, 2008). Therefore, I first did a verbatim transcription of every word in the audio recording. I then removed all disfluencies and non-verbal language (see example in Appendix 3). Later, in preparing the interviews for analysis, I represented the stories as they were produced from the participants themselves, removing my voice from the transcript to represent the voice of the participant only.

All transcriptions were done by me which helped me to become familiar with the data, because the interviews were in Kuwaiti Arabic, and I needed a person with a background in the way it is used. I still sometimes had to confirm my understanding with the parents. I also replaced all personal information about participants and other characters and places in the narrative with pseudonyms to prevent them being identified. My research takes a thematic narrative approach with a focus on the stories of Kuwaiti parents of children with ADHD. The meanings and ideas of the parent’s stories are dictated through the language they are told in, which forms the basis of understanding the subjectivity of parents' experiences (Van Nes et al., 2010). Thus, a discussion about the translation is important because most of the stories were told in Kuwaiti Arabic and translated into English.

Translation

Translation has gained a lot of interest in qualitative research due to research interest across languages and the nature of data, which is composed mainly of words (Squires, 2008; Van Nes et al., 2010; Regmi et al., 2010). Regmi et al. (2010, p.18) defined translation as ‘a process of converting ideas expressed from one language into another, [which] is embedded in the sociocultural language of a particular context.’ The individual stories someone shares with a researcher must be understood within the context of all the stories they have told and the culture that these stories come from (Esin et al., 2013). This is because language does not just help an individual express meaning, but it also plays a role in the source of meaning for that individual (Nes et al., 2010).

Two main types of Arabic are used in speaking and writing: Modern standard Arabic is primarily a written language, while colloquial Arabic is used in everyday conversation (Al-Amer et al., 2016). Modern standard Arabic is considered a formal language in all countries where Arabic is the primary language (Al-Amer et al., 2016). Colloquial Arabic differs from one country to another based on the culture. The two forms of language present different challenges in translating to English, which I will explain through a reflection of qualitative and narrative literature as well as my own experience in this research. The analysis was conducted in the original Kuwaiti Arabic. I only translated the excerpts used in the results and discussion chapters to English.

The first challenge of translation is concerned with finding equivalent words (Squires, 2008). This could be reflected in modern standard Arabic, which presents challenges due to its distinct phonological, morphological, lexical and syntactic features, and its sentence structure that differs from English (Al-Amer et al., 2016). For instance, some words in Arabic are gendered (Al-Amer et al., 2016); the word ‘teacher’ is not gendered in English, but in Arabic, it could be translated as ‘muealam’ (a male teacher) or muealama (a female teacher). Although these challenges could be addressed by working with a language translation expert, the large quantity of words is a difficult problem to overcome, as this requires a great deal of time and effort, and can become a financial burden for someone thinking about hiring translation services (Van Nes et al., 2010). In addition, despite an effort to find the 'proper' equivalent words, some of the meaning will be lost in translation because some words might not have the same meaning in English (Van Nes et al., 2010).

To solve the first challenge, the translations in my research were done primarily by me, because Kuwaiti Arabic is my first language. However, I did at times enlist the services of my friend, who specialises in Arabic language studies. Concerning the second challenge, I used the Arabic interviews in the earlier analysis stages. I only translated the excerpts that I used in writing the narrative, ensuring the translated versions remained as true as possible to the original versions in Kuwaiti Arabic. This is because interpretation and understanding meaning are the primary aims of narrative research, where stories are the medium that transfers meaning. Moreover, conducting the analysis and writing in English could have led to thinking in English, which could have influenced how I would understand the stories and how meaning was linked to the stories (Van Nes et al., 2010). Therefore, I left the parents’ stories in Arabic until writing up. This allowed me to minimise loss of meaning which occurs when data is translated and then analysed. As I wrote up the results and the discussion, I translated the script from the parents' Arabic stories into English.

The second challenge of translation was looking at the language as meaning in itself, which is important to my epistemological and methodological stance. I am conducting constructionist narrative research, which is underpinned by the belief that a narrative is a construct of our interpretation of the world and is influenced by the culture and the context surrounding us (Eisn et al, 2014). The translation process depends not only on our knowledge of the two languages, but also on our understanding of the context and culture behind the language used (Esin et al., 2014). This is relevant not only from the Arabic perspective, but also from the perspective of the Kuwaiti dialect. Although Arabic is the formal language of 22 countries, each country has a distinct dialect influenced by differences in Arab cultural beliefs, values and rules (Al-Amer et al., 2016).

Some participants expressed the meaning of their stories using phrases or proverbs that are popular in Kuwaiti culture. Some phrases in the Kuwaiti language have their own stories that are shared amongst the people of the culture. For example, Reem (a participant and parent of a child with ADHD), as she was sharing her experiences with health services to get her son, Zyad, a diagnosis of ADHD, said: ‘There are some places for free, but they have to open a file in the health centre. This is very hard’. A reader from a different culture might not understand why it is hard for Reem to open a file at the health centre, but the negative stigma about the place and people getting ‘treatment’ is a cultural and social idea shared by Kuwaiti people. Thus, as a Kuwaiti researcher, I can transfer meaning better than using a translator. Nonetheless, some words were difficult for me to translate. Thus, I first went back to the participants to determine their meaning. Then, I spoke with a Kuwaiti linguistic professional to determine the best way to present a translation of the words.

Identifying narratives

The second step in the transcribing process is identifying the stories within the transcripts. This process involves drawing the ‘boundaries of the narrative’ (Riessman, 2008, p.41) from a conceptual lens. A narrative of individual experience often has no clear beginning or end, and no easy-to-follow plotline, but is usually a complex account with multiple stories.

I followed Smith’s (2016) suggestion of searching for beginnings in the interviews, which are highlighted by a shift in the story’s content. I began to examine where the lines started and ended, and I then followed the line to construct a story (Smith, 2016). However, this was an imperfect method to use, as the transcript did not feel like one whole story and some parts of the transcript were more similar to reflection than a story.

I returned to Reissman’s (2008) process of drawing ‘the boundaries of narrative’. The stories constructed from the transcript had multiple plotlines, so I had to specify the topic around which I wanted the stories to be constructed. I used my conceptual lens in selecting storylines that helped me to explore my interests. The stories of parenting, childhood and ADHD were the focus of the analysis, while the other stories were used as context. This means only stories about the focus of the research were analysed, though other stories were not ignored because they could still help in understanding the focus stories. At the end of this stage, I was left with only the stories relevant to the research interest, and I created separate documents that only contained the participants’ stories.

#### 4.3.3.2 Coding and categorising: exploring the stories

Categorising is a means of classifying excerpts of text into codes (Lieblich et al., 1998). Codes represent the main sentences of the stories and are used to facilitate their organisation (Lieblich et al.,1998). I followed Lieblich et al.’s (1998) suggestion to look for the main sentences in the stories. I used inductive analysis because it was important to explore the topics that the parents presented using their experiences. I wanted the parents’ story topics to shape the theoretical framework. Lieblich et al (1998) suggested that coding and categories also help to minimise long, complex stories for analysis by organising them into codes and categories.

However, coding narrative data was different, because unlike with a grand theory, the stories were not broken into abstract parts (Reissman, 2008). As a consequence, as Smith (2016) stated, stories could produce a lot of codes, because each story or part of a story could be coded more than once and so the stories could be categorised under two or more categories at the same time, because they have more than one theme (See Figure 5: Codes of Eight narratives).

From my experience of following Lieblich et al. (1998), a lot of the codes and categories were much clearer to analyse than complex stories. This is because by creating categories, the process of identifying the similarities and differences in the stories is easier to develop some ideas about the stories. Moreover, it allows a broad and clear idea of the content of all the data.

Based on the categories and ideas developed from the stories, I developed and expanded the model and theories I used as the conceptual framework for the current research (see Section 2.3 for details). For example, I noticed that parents’ stories were dominated by biomedical ideas of ADHD, which view the condition as a disorder. However, my research follows the principles of disability studies, where the focus is on the social aspects of disability. Therefore, I added and amended the individual model (medical sociology) to critically analyse the way that biomedical models such as ‘diagnosis’ and ‘treatment’ of ADHD are used by the parents (see Section 2.3.1). The coding and organisation step of the analysis ended by expanding the conceptual framework to fit the interview topics.

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Table 3: Example of coding

In the coding and categorising stage, the categorisation was determined by looking for topics within the stories, but this was not enough to construct final themes, because the categories only describe the surface of the stories. Constructing themes that would help to answer my research question required an in-depth look at how the stories were constructed to convey ideas and meanings (Reissman, 2008), and the parents did not usually illustrate them explicitly. A deep investigation of the implicit aspects of the stories is needed to enhance understanding and to help create themes for the following stages (see **Figure 5:** Codes of Eight narratives).



**Figure 5:** Codes of Eight narratives **Key instruction for the coding map:** The bold lines writing are the categories The fine lines are sub-categories. The number refers to the stories: 1. Farah 2. Noor 3. Reem 4. Rawan 5. Marleen 6. Ahmad and Laila 7. Sara 8. Yousef

#### 4.3.3.3 Constructing themes: Analysing stories

To construct themes from the categories, I used different types of narrative analysis, such as structural (McCallum et al., 2019), thematic and dialogue (Smith, 2016), to understand the flows in the stories, characters, settings and sources the participants were using in the stories. Although my aim from the analysis was to understand the ideas and meaning the parents aimed to convey, I analysed the structure and dialogue features of the stories to help open up the stories and understand the content and unspoken ideas of the parents. For example, the structural narrative analysis of the tensions was helpful to identify implicit meanings in the stories that participants might have felt embarrassed to discuss or might have assumed were already shared with me. I made notes on the stories about characters, settings and sources the participants used in the stories in short sentences to distinguish repeated ideas.

صورة تحتوي على نص

تم إنشاء الوصف تلقائياً

**Table 4:** Example of narrative analysis (1)

I tried to search for meaning and ideas in the stories by understanding them as a whole. Smith (2016) presented questions that help to open up stories, enabling the exploration of things that may go unnoticed (Table 5: Example of narrative analysis (2)). The previous question about the resources helped me understand what kind of dominant narrative the parents were expressing and how it impacted their understanding of the topic.

صورة تحتوي على منضدة

تم إنشاء الوصف تلقائياً

**Table 5:** Example of narrative analysis (2)

However, Smith (2016) also advocated asking questions about the listeners of stories. For him, there are various ways of constructing a story, depending on the audience, so I started asking myself: To whom is the story being told? What source is the story drawn upon? How do stories enable us or constrain the way we understand the stories? (Smith, 2016, p.218) I considered that the story was initially told to me, but some stories were constructed in a dialogue between the parents and others. I was able to see how the parents presented themselves and their children in different ways to different people. In addition, the type of language used to explain the child or parent’s behaviour with others was different from that used in explanations to me.

صورة تحتوي على نص, منضدة

تم إنشاء الوصف تلقائياً

Table 6: Example of narrative analysis (3)

It is important to note that when I approached the story scripts mentioned in the categories to analyse them narratively. I did not separate the script from the whole story because I wanted to preserve the sequence of the script with the storyline (Riessman, 2008). This helped me to understand the links between the ideas and the whole story, as well as to identify when a participant returned to an idea again in their story. After analysing, new ideas from the stories appeared, and the relevant scripts were re-categorised, which led to some old categories from the code and categorising stage changing or being removed. I kept the names of the parents with the scripts to demonstrate the differences and similarities in ideas between parents while ensuring the names were clear. The narrative analysis of the stories led to the construction of the initial themes. In this stage, the reconstructed categories were changed, and some were discarded or merged with other categories to create themes.

#### 4.3.3.4 Review themes: Reading stories using an analytical lens

Until the review themes stage, each participant’s narrative was analysed alone using a theoretical lens (thematic narrative analysis), which helped in identifying themes. Then, I analysed the stories a second time using a conceptual lens via the social and individual models (critical psychology and medical sociology) (for terms see Section 2.3), which were used to help interpret the themes further. Thereafter, the interpreted meanings helped to create sub-themes or refine the themes I had chosen.

In the themes reviewing stage, I was interested in how the initial themes engaged with different models of disability. In the first part of this stage of analysis, I used the individual model: medical sociology theories (see Section 2.3.1) to understand how parents used biomedical ideas of ADHD to discuss their children’s behaviour. I focused on the stories in the categories under the theme conceptualisation of ADHD and medicalisation (initial themes), including those in which parents discussed their children’s behaviour using psychological and biomedical discourses, as well as those about collecting information on ADHD, ‘diagnosis’ and ‘treatment’. Using Conrad’s (1992) concept of medicalisation (see Section 2.3.1.3) was beneficial in understanding the process that led parents to medicalise (‘diagnose’ or ‘treatment’) their children. By focusing on the context of medicalisation (Conrad, 1992), I explored the social and cultural factors that led the parents to adopt a biomedical understanding of ADHD. I also used Timimi’s (2005) ideas on ADHD as a social construct to understand the link between culturally deviant behaviour and ADHD ‘symptoms’ and behaviours. The theory was also beneficial, with stories of parents that understand ADHD as deviating from the social norm and the expectation of understanding the cultural differences in deviant behaviour and the implications for the children and their parents. Both the medical sociology medicalisation theory and critical psychology literature were strongly supported by Arab and Western studies of ADHD and childhood to explain differences in the parents’ ideas concerning the biomedical perspective on ADHD.

The second analysis used social models of disability (see Section 2.3.2) to identify issues and challenges in the social environment facing parents with children with ADHD. The analysis focuses on stories of barriers encountered by parents when seeking support and services, as well as in society. I used the social model of disability (Oliver, 1996; Thomas, 1999) to address the material and non-material themes. I explored the social barriers that affected the parents of children with ADHD, and I reviewed all the stories to identify the social, institutional, environmental and cultural barriers that parents faced and that caused families to suffer psycho-emotional effects (see Section 2.3.2.3) or social exclusion.

What remained were stories in categories that did not fit either previous themes yet shared the context of different and personal views of ADHD and its impairment effects. Some parents’ stories discussed ADHD positively, while other parents engaged with religious and cultural discourses. I used Thomas’ (1999) discussion of impairment effects, as well as Swain and French’s (2000) affirmative model to discuss and further analyse the stories. I also drew from the Islamic and Arab cultures to analyse the ideas and attitudes of the parents towards the impairment and its effects, providing a cultural understanding of ADHD.

#### 4.3.3.5 Writing up: Discussion of the narratives

The discussion step contains three sections: constructive narratives, the themes and summaries of the ADHD perspective in the Kuwaiti context. The first section included a narrative of the participants, that is a summary of the main narrative used to reconstruct two different readings (see Section 4.5). The main purpose of this summary is to introduce and give a background to the participants and their lives. The second section offers a different perspective on ADHD in a typology that answers the research questions (see Chapters 5, 6 and 7). Smith (2016) stated that a typology is a process of ‘moving from the analysis of participants’ stories to the wider narrative analysis’ (p.258). It provides a more practical and organised answer to the research questions on the parents’ experiences (Phoenix and Orr, 2014). The last section presents the main ideas from the previous themes and sub-themes to answer my research questions (see Section 8.1). The main ideas were discussed using the broad literature on disability, ADHD and Kuwaiti culture.

## 4.4 Parents’ stories

### 4.4.1 Farah

Farah is a married working mother of four. Ali is four years old and was diagnosed with ADHD. Farah lives in an apartment in her husband’s family’s house, where all her husband’s siblings live with their families. Farah is a very social person and used to attend many social and family meetings. Ali and Farah are very close. Farah thinks Ali feels more intensely than her other children. Ali and his siblings love one another, but they do not get along and rarely play together, as Ali’s playing is described as chaotic and disturbing.

When Farah was pregnant with Ali, she felt that his movements were different from her other children. After Ali went to kindergarten, Farah thought Ali had academic difficulty, saying that he did not understand the information like other children. Farah gets embarrassed in public because of people’s reactions to Ali’s social behaviour. She believes that people judge her parenting skills. Ali’s social behaviour is also noticeable in family meetings, as Ali shouts and makes a mess, but Farah believes that he does not intend to upset the family. Still, she worries about what Ali might do in social meetings, so she remains at home most of the time.

Farah wanted to see a doctor, but Ali’s father refused. He believed that Farah was overreacting. Farah went to the doctor despite his disapproval. The doctor confirmed that Ali had ADHD but refused to give him medication without his father’s approval. So, Farah tried to become educated about Ali’s condition, following a specialist on Instagram and seeking the advice of her friend, who is a specialist. Farah tries to reduce Ali’s sugar intake, which she thinks is working. Farah and her husband have different parenting styles, where Farah tries to be structured and her husband spoils Ali, which causes problems between them. Her experience impacts her mental health. Farah believes that she used to laugh a lot, but now she is always angry. However, Farah’s primary concern is Ali’s behaviour, not her mental health. Farah wants to see the doctor again to get more educated about Ali’s condition.

### 4.4.2 Noor

Noor is the mother of a child with ADHD named Fahad, who is now over 18. Fahad’s father, siblings and nanny were always supportive. Noor discovered Fahad’s hyperactivity when he was three years old. She took him to a professional and he was diagnosed with classic ADHD. Noor started educating herself and her family about ADHD to understand more and to learn how to cope with the challenges it presents. Noor took an online course and a programme for parenting a child with ADHD from the United States, where there is more experience with ADHD.

When Fahad went to nursery, he felt rejected by his teachers, which affected his ‘symptoms’. Fahad was very sad, comparing the rejection from the nursery with the acceptance at home. This experience impacted both Fahad’s and Noor’s mental health. Noor then started to look for a special centre for therapy in Kuwait. She used to use a specialist in play therapy, which was very useful for Fahad. In his second year of school, he was rejected and the school advised Noor to take him to a special needs school. When Noor moved Fahad to the special needs school, it was great in the beginning and he felt loved. However, Fahad faced many challenges because of his impulsivity, high volume, hyperverbal speech and hyperactivity. As the problems with the school continued, Noor went to the Ministry of Education. Noor was asked to go to the disability support system, but they could not help her until she registered; after doing so and seeing a doctor who gave the diagnosis, there was no additional support. The hospital only provided medication with no other options. She felt lost and knew that there the school had no support systems for children with learning difficulties nor did the school understand how to educate such pupils. Noor tried to find the right school for Fahad. Despite high fees, the special needs school did not know how to cope with learning difficulties. The challenges with special education continued until Fahad entered adolescence, when he went to the United States to continue his studies.

### 4.4.3 Reem

Reem is a mother of four children. Her middle child Zyad who is now 18 years old, was diagnosed with ADHD and learning difficulties. Reem is a housewife who has devoted her time to her son. Reem’s story started with Zyad going to kindergarten and being rejected after one year because of his behaviour. In the second year, she was fed up with complaints from the kindergarten, so she decided to see a doctor. However, she was not convinced with the diagnosis as the doctor ignored Zyad’s eyes glasses need. Zyad continued to study in a private elementary school. Reem faced many challenges with the school and Zyad’s difficulty in learning. She hired a teacher to support Zyad, but it was insufficient as Zyad’s academic achievement decreased. She started searching for information about Zyad’s difficulties until she decided to get him diagnosed and access the disability support system. Reem faced financial challenges getting the diagnosis because the places to get the diagnosis were expensive. In addition, the appointments at free government places were inconvenient. She also faced rejection from people around her as she got the disability certificate which might stigmatise Zyad in the future. However, Reem ignored people’s opinions. She believed that there was no shame in obtaining the certificate to access the support Zyad needed. In sixth grade, Reem moved Zyad to a special needs school, only to find that the school was no good because her son was not getting an education. She waited two years, hoping the school situation would improve. In eighth grade, Reem was fed up and moved Zyad back to private school. However, Reem had difficulties finding a school that would accept Zyad’s impairment. One of her friends suggested a school for Reem’s son in a social support group. Reem took Zyad to the school without telling them about his impairment. Zyad was accepted, but Reem spent a lot of time supporting Zyad with his studies until he graduated from high school. At the time of the interview, Reem said that she did not take her son out of the disability system, because she needed their academic support at university.

### 4.4.4 Rawan

Rawan is a married mother of four children; Mona and Talal, Waled and Hamad. All of her children have ADHD and learning difficulties except Talal, who has only ADHD. Three of them are now over 18, and Hamad is 12 years old. Both Rawan and her husband are employed. Rawan's story starts with Mona having academic difficulties in mainstream school. The school specialist suggested that Rawan move Mona to a special needs school. After understanding more about learning difficulties from the specialist in the special needs school. Rawan decided to access the disability support system to move Mona to a special needs school that met her needs. She was motivated to access the support system to get her children to a special needs school. However, she later discovered that they were also eligible for financial support. She had difficulty convincing the children's father. He refused to move Mona to the special needs school. But, she finally convinced him to get the diagnosis and disability certificate to access the support. Mona was finally in a place that fitted her learning differences.

Rawan also got Talal diagnosed in fifth grade to understand the cause of his behavioural problems in school. Although Talal had trouble with teachers and the school system, she mentioned that it did not affect his academic achievement. Rawan then tells stories about Hamad, who shared the same academic experience; all the children have high IQ scores, but had learning difficulties in primary school. After Rawan's experience with Mona, Hamad was diagnosed and moved to the same special needs school. However, unlike her experience with Mona, she mentions facing social interaction difficulties with support services. Rawan also faces financial problems because of decreased benefits from Waled's experience in the special needs school. Rawan's social support circle helped her to face the challenges of professional interactions and the disability support system. Above all, working together with her husband was the most effective support that helped her raise her children to be successful. Rawan and her husband built a home environment that accepts their children's abilities without making them feel abnormal.

### 4.4.5 Marleen

Marleen is a divorced mother of two boys with ADHD, Omar and Salem, who are now over 18. Marleen is a foreigner who barely speaks Kuwaiti Arabic. Marleen could not remain in her job because of her childcare responsibilities, so she received financial support from social welfare. She had minimum support from the father at the beginning because he did not believe in Omar and Salem’s disabilities.

Her story started when her sons were babies. Marleen noticed differences, but it was not a problem. She believed that her children were amazing. The problem began when Omar and Salem went to school. Omar had trouble sitting and focusing in class, while Salem had concentration issues. Their difficulties in school prompted Marleen to access professional medical services and get a diagnosis. The doctor suggested that she apply for disability support. Marleen faced many challenges to figure out how to access the support system. After she succeeded in accessing the support system, her sons received academic and financial support from the disability support system.

Marleen then illustrates the story of Omar, who moved through four different special needs schools. The schools were not qualified to meet Omar’s needs. Marleen describes different challenges with Omar’s teachers, the school environment and the system. Omar and Marleen's negative experiences with the special needs schools motivated Marleen to insist that the disability support system support Salem financially at his old private school. She believed that the private school could provide Salem’s academic support. Marleen did not have any social support except from a friend who had a child with autism. Her family was not in Kuwait, but she remained in contact with her husband’s family. Marleen did not want to tell the family about the children’s diagnoses because she was afraid they would look at Omar and Salem differently. The huge responsibility of having two children with ADHD caused Marleen to face mental health problems. Although she got professional medical help, she felt that it was not helpful. Marleen decided to support herself to get over the challenges. Marleen educated herself through books and websites about coping with ADHD. Nevertheless, she mentioned that her experience raising Omar and Salem was the most effective way to cope with everyday challenges.

### 4.4.6 Ahmad and Laila

Ahmad and Laila are married with three children; two girls and a boy. Nasser, the middle child, was diagnosed with ADHD. Nasser is attached to his mother and sister and spends most of his time with his family. Ahmad believes that Nasser does not have friends because he is sensitive and does not know how to communicate with other boys. The parents have noticed his different and disruptive behaviour since Nasser was young. Still, Ahmad thought Nasser was just being a boy. The parents also got complaints from kindergarten about Nasser's continuous talking and movement. However, the parents thought Nasser was just being naughty. When Nasser got into the second grade of primary school, the maths teacher complained about his lack of ability to concentrate and identify with other children. The teacher mentioned the possibility of Nasser having ADHD. This got the parents attention and prompted them to look for information about ADHD. They noticed that Nasser had most of the ‘symptoms’. They searched for a place for a diagnosis and figured out that Nasser had ADHD. Ahmad and Laila got their son medication, but the school still complained to Laila about Nasser’s behaviour. The parents decided to move their son to a special needs school. Although they applied for disability support, the process was long. They waited two years before getting Nasser into a special needs school. Ahmad is satisfied with the special needs school support. However, Ahmad does not like to label Nasser with a disability certificate because of the stigma related to the label. At the time of the interview, the parents had just moved Nasser to a special needs school.

### 4.4.7 Sara

Sara is a mother of four children. Her third son, Bader, is diagnosed with ADHD. She is married and lives in her husband’s family’s house. She works as an education specialist. Bader got the diagnosis from participating in a training programme for specialists. Sara described Bader as hyperactive and impulsive. The main issue in her experience was her son’s hyperactive and impulsive behaviour, which caused problems for him and herself. She illustrated that he has difficulties in social interactions with people. In family gatherings, Bade often got in trouble. He was blamed for any problem because his behaviour was seen as disruptive and disrespectful. This put an emotional burden on Sara, but she was able to support herself.

Bader used to go to a mainstream school. The teachers complained a lot about the child because of his disruptive behaviour. Sara believes that her son was moving around a lot, but he was not disrespectful in school. Conversely, Bader loved the school and got excellent grades. Sara used different interventions to teach Bader to control his behaviour as a child in school. Yet, Bader still struggles with his social behaviour with people around him. Sara mentioned having trouble teaching Bader at home because he was constantly moving. She believed Bader was very smart and had unique ways of studying. So, she decided to let him study alone. Sara mentioned that Bader was always under her supervision because he was easily distracted and got in trouble with his friends. Bader is now over 18 and graduated from university but still struggles to make friends.

### 4.4.8 Yousef

Yousef is a married father of four. His 10-year-old, Jacob, was diagnosed with ADHD and learning difficulties. Jacob did not have friends until this year. He prefers older friends but has difficulty maintaining friendships. When Jacob was 5 years old, Yousef got him into behavioural therapy to enhance his communication skills. Yousef said the therapy was very useful because Jacob still remembers and uses the social behaviour that he learned in therapy. Yousef is very close to Jacob. He spends the day helping his son in his office, but Jacob sometimes gets bored from being with him in the office for 10 hours.

Six years ago, Yousef’s concerns about Jacob’s social difficulties and inability to settle prompted him to visit a doctor. Despite the doctor’s affirmation that Jacob had no problem, Yousef was still concerned. He followed a friend’s advice and went to an ADHD specialist who recommended giving Jacob medication. Yousef was initially unsure, but after reading about it, he agreed. Jacob has been on medication to manage his hyperactivity since he was four years old. Yousef thinks that Jacob is calmer with the medication. Jacob registered in the disability support system when he was seven and the process was very simple. Yousef got Jacob’s report from the doctors that he was visiting for the medication and provided it and the other requirements from the Public Authority for Disability Affairs. The disability system supports the family financially by giving Jacob a salary and paying his school fees. Jacob used to study in a private English school that Yousef paid for until the disability system took over payment.

Later, Yousef moved Jacob from the private school to a special needs school. Jacob has been in a special needs school for two years now and he is doing well, except in Arabic, which is normal considering that he started at an English school. Jacob’s teachers think that he is very respectful. The only problem Jacob had was with his behaviour, wanting to play, which most of the time is considered a disturbance.

## **4.5 Conclusion**

This chapter presented the practical processes of research recruitment, interviews and analysis. In the recruitment section, eight Kuwaiti parents of a child with ADHD were enrolled using criterion and snowball sampling. While the former was useful to minimise the search range for participants, the latter was useful for sensitive and hard-to-find samples, such as parents of children with disabilities, as it allowed me to research the participants and build initial trust and comfort (Woodley and Lockard, 2016). I also detailed the sample size, the character of the participantsand the place of enrolment. Towards the end, I justified some changes made to the recruitment plan by describing the process of enlisting the participants.

Moreover, the interview section demonstrated the method and process of collecting the data. I used narrative interviews to collect the stories, creating an unstructured setting with broad questions and using aids to prompt authentic and spontaneous stories from the parents (Jovchelovitch and Bauer, 2000). I then described the process of creating the interview and the strategies used to ensure the narratives were both ethical and rich. Next, in the analysis section, I located and used methods of broad narrative analysis within the literature. I used narrative thematic analysis to explore the topics related to the parents’ experiences of rearing a child with ADHD, as well as to present the stories to communicate meaning about the topics. Lastly, I discussed the impact of the research context on the analysis process, and I described the steps in my analysis and the reasons behind them.

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# **Chapter 5**

# **Parents’ understanding of ADHD: medical sociology, critical psychology and disability studies perspectives**

Introduction

This chapter presents the ideas and attitudes of the parents shaped through their journey with ADHD. The stories were analysed drawing on the perspectives of medical sociology (Conrad, 1992), critical psychology (Timimi, 2006) and disability studies (Cameron, 2014). The approaches are used as an analytical lens to provide understanding about the social process of the parents' ideas and attitudes toward ADHD. Tuckett (2013) suggested that the social process of understanding human behaviour underpins the cultural and social environment. Thus, the discussion, which is based on the previous approaches combined with the parents’ stories will not only highlight the parents' perspectives on ADHD, but the overlap between their ideas and the social and cultural meanings of knowledge and the definition of ADHD in the Kuwaiti context. However, it is important to know that the focus here is not on presenting the biomedical perspective of ADHD, such as symptoms, causes, diagnosis or treatment, but to discuss the former as a social construction based on context and history**.**

## 5.1 Parents’ journeys in understanding ADHD

The overarching theme in this chapter focuses on the developing, complex and shifting understanding parents have about their children’s behaviour, as they begin to understand this behaviour as a consequence of their child ‘having’ ADHD. This theme explores the different stages that parents move through in their understanding. Each stage is presented as a sub-theme. However, although this chapter is presented through a discussion of the stages of understanding, it is important to note that parents do not necessarily move through the stages in a linear way, nor are the stages completely discreet or disconnected from one another. In the same way, not every parent experiences each stage as they come to understand ADHD. Rather, parents' understandings are messy, complex and shifting. There are five sub-themes which explore the complexity of parents' understanding of their children’s behaviour as they come to understand this behaviour as a consequence of ADHD. I introduce each of these themes in turn.

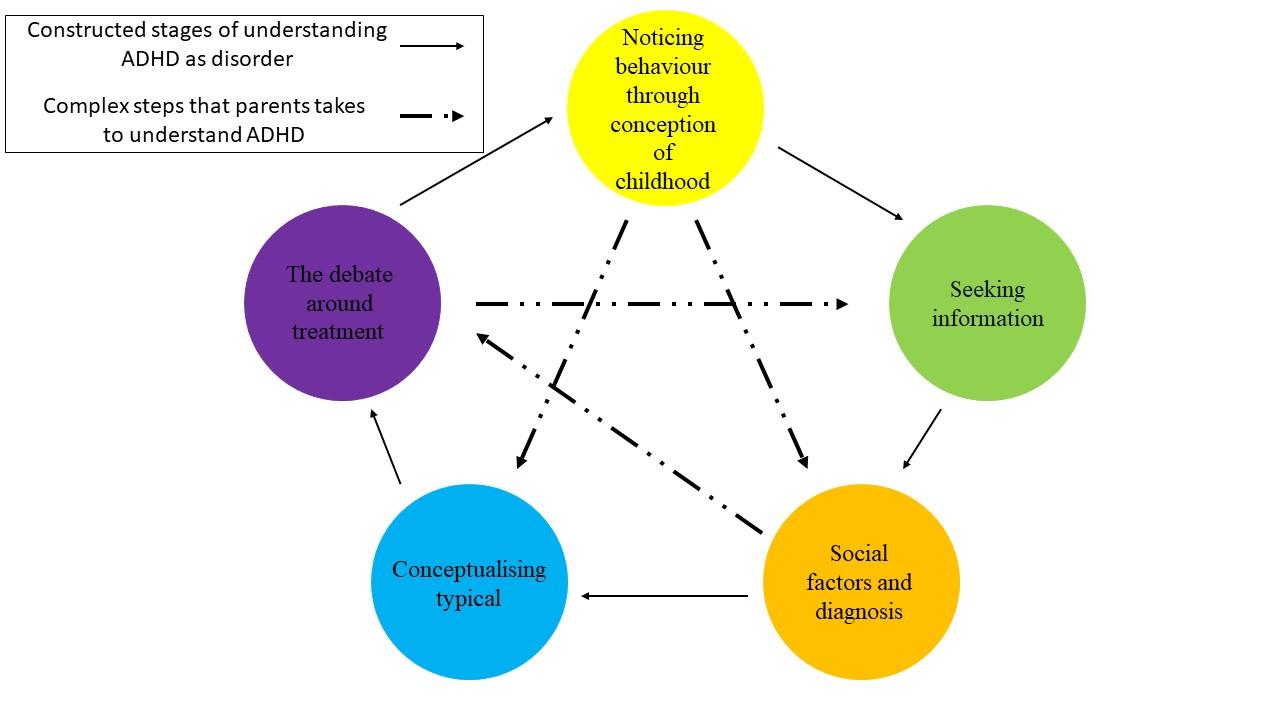
The first sub-theme is termed ‘Noticing behaviour through conception of childhood’. This theme refers to the moments where parents start to notice their children’s behaviour *as being like* behaviours that they associate with ADHD. This means that they begin to understand their children’s behaviour as different from what they understand as normal child development and behaviour, which they begin to attribute to their children having ADHD.

The second sub-theme is ‘seeking information’. This sub-theme refers to the stage where the parents start to search for information about ADHD from a variety of sources available in their everyday life, such as the internet, social media, lectures and online courses about ADHD. This sub-theme explores the ways in which information seeking leads them to understand ADHD as a biomedical ‘disorder’, as the available sources of information are dominated by the biomedical perspective.

The third sub-theme is called ‘Social factors and diagnosis’. This theme focuses on the parents’ experience of seeking a ‘formal diagnosis’ for their child and how this shifts their understanding of their children’s behaviour and of ADHD.

The fourth sub-theme is ‘Conceptualising typical’. This refers to the effects of social and cultural values on parents' understanding of their children’s behaviour and of ADHD.

Finally, the fifth theme, ‘The debate around treatment’ explores parents’ preferences in terms of interventions for children with ADHD, including medication and behavioural interventions. (See Figure 6: the parents’ journey with ADHD)



**Figure 6:** The parents' journey (will changed after the correction)

## 5.2 Noticing behaviour through conception of childhood

This sub-theme discusses the ideas that parents had about their child’s behaviour and about ADHD before the ‘diagnosis’, but at the point when parents began to understand their child’s behaviour as different and associated this difference as ADHD-like behaviour. According to the Kuwaiti literature, public awareness of ADHD and learning difficulties began to emerge in 2011 (Alamal, 2011). In addition, Altjali (2015) suggests that there is overlap in information about children, which leads to misunderstanding of ‘mental health disorders’ such as ADHD. The overlapping information was reflected in parents' stories, as in the beginning of their journey towards understanding ADHD they demonstrated various perspectives on noticing ADHD-like behaviour in their children. It was often in early infancy that parents began to notice differences in their children’s behaviour. Only Farah began to notice differences even before the child was born. She said:

To be honest, I gave birth to him after treatment because I had a problem with the pregnancy. Then I had my son. Praise to God, since he was in my belly his movement differed from his sibling. I mean his sibling was different. Their movement was normal. As for him, my belly was shaking a lot. I mean I shielded, I covered my belly. I didn’t want anyone to see it. Since he was in my belly, I have known he had ADHD. Praise to God. Since then I felt that he was different from his siblings.

Farah's observation of the differences in her child's behaviour started when he was in her uterus. Intentionally or not, Farah reflected on her experiences, drawing on biomedical understandings of the social causes of ADHD by mentioning her difficulty in conceiving. This is consistent with Thapar et al. (2012) which showed that pregnancy complications were a factor in the causes of ADHD. She described his movement and her reaction to the movement by colouring a picture of the child to demonstrate his over-activity. This element of the story is consistent with the biomedical perspective of the child as abnormal compared to his sibling. The time at which she chose to start her story also suggests the idea of ADHD being something that is part of the child, because of her difficulty in pregnancy.

In other stories, the parents started noticing differences in their children after birth. Marleen said:

My oldest son was so energetic. Since he was born actually, I noticed that when he was about 4 months old, when I woke up and checked on him in bed, he would never be in the same place. He always flipped over, he always took his clothes off in bed. Even with his diaper and he would throw it, he always jumped on the bed. As he grew bigger, he always climbed out of it a little bit, they wrap their little toes around the bar and scale themselves up to get out. He likes keeping himself busy. He never sits still.

Unlike Farah, Marleen did not use any medical terms or discourse to explain the difference in her child. Yet, she tells a story of her child’s behaviour that is similar to stereotypes of infants with ADHD being hyper-active, naughty and uncontrollable (Mclntyre and Hennessy, 2012). Marleen's story was told from the time that her child was an infant, which might indicate her belief that the behaviour of her child was part of who he was from birth. Unlike Farah's story, where there was a sense that Farah was embarrassed by the difference, Marleen's description does not convey a negative reaction to the child's behaviour. She portrays the child as a different and energetic son, but sees this as natural. She understands that a child with ADHD might be seen as different and difficult, but she understands this behaviour as simply how he is.

Sara also started her story by describing her son's different behaviour:

Even in the postpartum period, my son would sleep once a day. Not like other babies. He would be awake more than asleep. He did not crawl then walk. The development happened quickly. He developed earlier than his siblings. His sister was normal. His brother had a problem, so he took longer, which is normal. For him, in the fifth month, he started sitting down. In the sixth month, he crawled. Before ten months, he was walking. Since he was a child, if he saw something, he wanted to grab it. It was clear, he was different.

When my son was little, I told my family, this is the only child who did not sleep in my lap. I gave him space and a blanket. His bed was wide. I would leave him to move and move and move as he laid down. Then suddenly, it was as if the power would cut off inside him, and he would sleep.

His father used to say ''His battery is dead; he is out of charge''. It was strange. You could see him in his peak of activity, then suddenly he slept. I mean, he was unlike his siblings who would get tired slowly. No! Also, the amount of time he slept was longer. He did not have trouble sleeping. What I know about children with ADHD is that the amount they sleep is little. For him, no, he slept enough hours, but he did not take a nap. He was constantly on the go.

Sara illustrated the idea that ADHD was part of the child’s differences by taking her story back to the beginning of her child’s life at home. Cameron (2014) asserts that the discussion of abnormality occurs in reference to a discussion of normality. Sara compares her son with his siblings, which might indicate the abnormality of her son's behaviour. It also shows the way her son’s development was different from his siblings’ development and sleeping patterns. Sara describes her daughter’s normal sleep patterns and development stages, from which her son differed. Although Sara’s stories are underpinned by psychological ideas about ADHD, which locates deviant behaviour in the child, she challenged the biomedical perspective of ADHD that children often have trouble sleeping (Craig et al., 2017). This gives a sense that the mother was informed about ADHD. Her interpretation of her son's abnormal behaviour is as an inherent part of the child, which then removes the characterisation of the abnormality as an illness.

‘Pre-diagnosis’ and in the initial moments of noticing differences, the parents’ discussion of their children’s behaviour was situated in the concept of normality. Titchkosky (2000) suggests that understanding normality happens through evaluating ourselves in terms of norms. The interpretation of behaviours and conditions does not underpin natural rules, but social rules constructing norms in society (Cameron, 2014). In reflecting on the stories, children were understood from the stance of psychological development theory, which assumes that children develop in a universal and predictable pattern (Cameron, 2014). The parents’ descriptions of their children’s characteristics and ADHD-like behaviours are seen as abnormal through a psychological understanding of childhood. ADHD is not seen as something that the children acquired from the environment, but as a difference they have had since they were born or even before. Moreover, the difference in the way parents draw on theories and describe the child’s ADHD-like behaviour indicates variation in the acknowledgment and understanding of childhood psychology. This indicates the influence of psychological discourses on the parents’ understanding of normal and abnormal child behaviour, even before a diagnosis.

## 5.3 Seeking information

As we saw above, parents began to notice differences in their children; they then began to associate this with ADHD, which they understood as a biomedical ‘disorder’, present since birth. Once parents had begun to notice differences, they sought further information about ADHD. Parents sought information about ADHD from a variety of sources. Exploring the parents' stories of searching for information about ADHD illustrated the available sources of information in the Kuwait context, as well as the information needed by parents at this stage. However, it is important to note that I illustrate the results first to highlight the resources and the ideas developed by the parents from the sources of information. I then discuss them in terms of the literature. For example, Farah started looking for information because of social challenges that she encountered in a family meeting. In the story below, she describes her way of managing her son’s behaviour based on her resources of information before the diagnosis:

I follow someone on Instagram and when she posts something, I read it. I consulted my friend because she is a medical specialist, and she has experience. She also had a doctor that she saw for her son. I got bits from here and there. I also searched the internet using Arabic. I used YouTube. From studies that I found I learned that the behaviour cannot be stopped, but you can reduce it. So, I am trying to reduce the behaviour.

Farah sought information from social media, YouTube and medical professionals to understand her child’s behaviour. She portrays the behaviour of ADHD as something that cannot be changed, like high blood pressure or diabetes, where the symptoms can only be reduced. Her idea of ADHD was evident later in her story as she tried using dietary interventions to reduce the hyperactive behaviour in the child. The sources of information that Farah engages with confirm her belief that ADHD is a ‘disorder’.

Yousef, who had concerns about his son’s behaviour and suspected it was associated with ADHD, was suspicious about his son’s behaviour. He went to the hospital on many occasions trying to get information about what might be wrong from the doctors, only to return without an answer. However, before a friend introduced him to a doctor who talked about ADHD and ‘treatment’, he took time to research the subject before the ‘diagnosis’. He said:

I searched the internet using Arabic. I also used YouTube if I was very interested. However, I read about it. I mean, I know how to cope with [my child’s behaviour]. I read that people with ADHD used to be seen as possessed with demons or they would be excluded [from society]. I mean currently, they give them medication. ADHD went through stages before it reached the medication stage. Even the medication went through stages.

I read about the medication, but I do not recall the details. The doctor suggested medication [for my son]. I hesitated in the beginning, but I think it is useful for him and us. From people I know, children often up to 16 or 17 years old, [then] they cut off the medication because they know how to control themselves. They do not need it. I think my son needs behavioural therapy to improve his behaviour and his interaction with other people.

Yousef highlighted YouTube and the internet as his main resources for information about ADHD. His idea of ADHD as a ‘disorder’ that needs medication is in line with the biomedical perspective on ADHD. His words: “from people I know, often until 16 and 17 years, [then] they cut off the medication because they know how to control themselves” show that his ideas about ADHD are similar to Farah’s, considering ADHD a continuous condition. Farah and Yousef were also similar in the idea that social problems were the first reason that parents were compelled to search for information. Like Farah, Yousef used social media and the internet to seek information about the diagnosis of ADHD, which confirmed the belief that ADHD is a biomedical ‘disorder’; however, Yousef does not understand this as a fixed and unchanging condition, rather he believes that in time people with ADHD can ‘control themselves’ as they grow older.

In other stories, it was the parents' engagement with schools which led to them seeking information. Laila and Ahmad (interviewed together) discussed their son’s experience in mainstream school. Ahmad reported that the school had serious complaints about the child's behaviour: “moving a lot, easily irritated, unable to focus, while sometimes very quiet.” However, in the eighth grade, a mathematics teacher brought Laila’s attention to the possibility that her son had ADHD. They stated:

Ahmad: I gathered information in order to understand. I used Google to search for ADHD. I notice some of the symptoms in [my son's behaviour]. For example, he did not sit at the table properly and moved around a lot. He was uncooperative with his friends, indeed he had problems with his cousin and uncle. He was easily irritated and quarreling with them. They did not want him. These were some of the signs.

Laila: he did not focus on what he was doing. For example, [if] he was playing with something and saw someone playing with something also. He would stop what he was doing and play with the other boy. So, he could not focus on the task at hand. He focused on the surroundings. He easily got bored. We started to understand that our son had ADHD.

Ahmad: I mean, when you search the internet for ADHD, you get a lot of information. You get a link for diagnosis. We did not know if the information was correct. We were just trying to gather ideas. However, we noticed that the information was similar to [the behaviour of] our son.

Ahmad and Laila depended on the internet for information about ADHD. They mentioned ‘self-diagnosis’ as the primary resource they used to identify ADHD in their son. Laila’s justification for understanding her child’s behaviour as a result of ADHD reflects the formal criteria for diagnosing it. However, the parents were also suspicious of the information on the internet.

Rawan’s reasons for seeking information were like the previous story. She experienced prejudice from her daughter's teacher because of the misunderstanding of her ADHD-like behaviour as failure and lack of achievement. She said:

I experienced many situations with the teacher. [Imitating the teacher's words], [your daughter] is no use; she is a zero on the left (meaning she is a failure). When the specialist saw me, she told me how about moving her to [special needs school]. She guided me.

Rawan's stories were a bit different from the previous stories, as the education specialist suggested the special needs school for her daughter. Rawan’s story illustrates ADHD as a problem that needs to be solved through experts who know best about the child’s condition. Reem shared a similar experience to Rawan, as her son had challenges in school and with studying. She said:

I was researching [ADHD] for a long time. When a lecture [about ADHD] was announced in Kuwait, I went and listened. After [the event] I started reading, listening and I followed [on Instagram] a doctor that specialises in ADHD. She also had books that I read and read until I realised I needed to get [my son] diagnosed.

For Reem, the sources of information were lectures about ADHD from medical professionals. Her decision about diagnosis indicates that she thought of ADHD as a condition that needed a diagnosis to solve the challenges concerning education. Noor also discussed lectures as a source of information:

I went to a conference outside Kuwait and I joined an online course for parenting- training about ADHD. This knowledge is available in America. It is amazing. They have the knowledge. We should learn from them because they do research and studies that develop experience [with ADHD].

Noor reported that she obtained information through online courses and parenting programmes outside Kuwait. Noor’s resources of the internet and US psychiatry are referencing what Conrad and Burgey (2014) called the vehicles that increase the globalisation of ADHD. Timimi (2010) argued that despite differences in cultural socialisation of children, the influence of Western ideas about heath and childhood is clear in the way parents think, classify and cope with children's behaviour using medical and psychological explanations. El-Haddad (2003) supports Timimi (2010) argument illustrating that the changes in education sources in Arab society play a powerful source in socialisation. Noor words give an explicit indication of the impact of psychiatric understanding of ADHD on her ideas about ADHD, in which it is understood as a ‘disorder’.

In discussing ideas from their stories about ADHD and the information needed before seeking a diagnosis, the information that parents obtained from available sources in the context of Kuwait came from the biomedical perspective, seeing ADHD as a ‘mental health disorder’. While in some countries, such as the UK and France, parents’ perspectives combined biomedical and psychosocial understandings of ADHD (Edwards et al., 2012; Malacrida, 2004), in Kuwait, parents’ initial understanding and the information accessible to them was dominated by the biomedical perspective. This also supports Conrad and Bergey’s (2014) argument on the dominant role of medical and psychiatric professionals in the emergence of ADHD globally. Parents’ sources of information, such as education specialists or the internet, were the main tools reflecting the US psychiatric understanding of ADHD.

Additionally, medical professional information about ADHD is the first line of information that parents access in seeking to understand ADHD. Medical professionals and child specialists were the most common resources from whom parents accessed information. The parents’ focus on medical information indicates the importance of medical and scientific information. Conrad (1992) asserted that the domination of psychiatric practice is not a product of the biological condition, but rather the medical trend in Western society. In reflecting on the Kuwaiti context, the results are consistent with Khullar and Coughlan’s (2018) argument that the Kuwaiti context is dominated by the discipline of psychology.

Moreover, the parents' choice of resources indicates their need for effective communication with experienced people about ADHD. Some parents in earlier stories mentioned books and the internet as a source to look for information. However, the majority depended on social media and child psychologists. This is consistent with Sciberras et al. (2010), who stated that parents prioritise verbal information and interaction with professionals over written information and the internet. In telling their stories, parents might have mentioned social media and child psychologists because they were seeking resources in the form of ''expert'' professionals that they could communicate effectively with. In other words, social media might be a better space to present cases and videos of people with ADHD than the internet or books. It also gives space to discuss challenges and questions. The results are slightly different from Al-Daihani and Al-Ateeqi (2015) examining Kuwaiti parents' preference of information sources. They suggest that parents prefer doctors, physicians and social workers as sources of information over social media. The parents in the current research still prefer psychologists, but they also like using social media for information.

Another difference between my results and Al-Daihani and Al-Ateeqi (2015) in resource preferences was seen in courses and lectures about ADHD. Sciberras et al. (2010) reminded us that researching information about children with ADHD is a continuous process. As the stories about seeking information in this study focus on the parents in the stages before the ‘diagnosis’, it might be that the parents might find lectures and courses useful as an introduction to ADHD. This contrasts with Al-Daihani and Al-Ateeqi (2015), who discuss different sources of information without mentioning lectures, courses or programmes for parents. This might be because of the quantitative nature of that research, which builds on the view of the researcher, limiting the exploration of the parents’ view of useful sources.

## 5.4 Social factors and diagnosis

This sub-theme focuses on the parents' ideas and attitudes toward ADHD. This sub-theme encompasses the process of thinking about and/or the practices that parents went through during the stage of seeking a ‘formal diagnosis’. It includes the parents' further developing ideas of ADHD, and the influence of ‘diagnosis’ on their understanding of ADHD, and the social and environmental factors that impact the parents' understanding of ADHD. Social and environmental factors refer here to social policy as well as school and cultural values regarding childhood and parenting, which encourage parents to seek the ‘diagnosis’. This focus on social factors is based on the idea that the diagnostic tests, despite being perceived as ‘medical’ and ‘scientific’, have been criticised as subjective and influenced by social practice (Davies, 2018). The investigation of the parents’ ideas of ‘diagnosis’ is not to question or to uphold the validity of ADHD as a ‘disorder’, but to explore the influence of cultural and everyday practices on understanding ADHD beyond it being a ‘disorder’ (Singh, 2008; Radcliffe and Timimi, 2004). The analysis was done by exploring the parents’ stories of ‘diagnosis’, which provided some insights into the way parents understand ADHD, between ‘disorder’, ‘deviance’, and learning difficulty, as well as the social factors within the stories that contributed to the parents' understanding of ADHD.

Some parents sought a ‘diagnosis’ for an explanation and confirmation of their assumption about their children's ADHD-like behaviour. For example, social situations and extended family in Farah's story were the main motivations for seeking out doctors, despite her husband’s opposition:

To be honest, my husband refused to let me see a specialist. He did not accept it. He said, "You are exaggerating. Just wait for a while and then the boy will calm down, and this will be a memory." He kept telling me that. Look [talking to me] I read, but the father honestly refused. I went to the hospital and the doctor said I had to get the father's approval...I tried to convince [my husband] in different ways, because I wanted to learn more especially, I am a social person. Yet, I could not.

I entered the doctor's office, and the boy did not sit down for a second. [The doctor] wanted to talk to him. Nothing. I mean [my son] only said ‘hi’ and then left. [The doctor] saw me very eager to know and understand ways [to manage the behaviour]. This was at the peak of the naughtiness crisis. He told me, "It is ADHD, but I cannot give you medication." I said: “just give me the name of the medication”. He said: “I will not give it to you”. He refused, he refused. He told me the father had to be present and his signature was necessary.

Farah illustrates a complex response to the ‘diagnosis’ – between rejection and acceptance of the ADHD ‘diagnosis’ of the child's condition. She mentioned that her husband’s refusal to accept the ‘diagnosis’ came from the idea that naughtiness is part of childhood. Farah might share similar opinions with her husband, as she also described the difficulty with her son as a ‘naughtiness crisis’. However, she also mentioned that she had read about ADHD, which might have impacted her understanding of his behaviour. She described her son's behaviour to the doctor as hyperactivity and an inability to communicate. Farah also mentioned the doctor's response of her son having ADHD and needing medication, which supported her view. Farah might see the ‘diagnosis’ as an opportunity to understand how to manage her son's behaviour, which has kept her from her social with community.

In a similar way, Yousef describes his experience with medical professionals after social challenges with his son’s behaviour.

I went to the paediatric neuropsychologist; I had been going there for 6 or 7 years. They told me that my son was healthy and there was nothing wrong with him. They said he was just active, but I did not believe the boy was normal. After a time, a friend visited me and said he knew a doctor who had discussed this condition and he recommended his treatment. I began to follow him online, and I read about the medication recommended to me by the doctors. I hesitated whether or not to give the medication at first. However, I believed it would be beneficial to him and us. I went to have him diagnosed. He had ADHD and required medication.

Yousef presents a case where parents become the ‘agents of medicalisation’ (Conrad, 2007), because his story indicates that ‘diagnosis’ is a solution to the social challenges of the child’s behaviour. Becoming an agent of medicalisation means that the patient, or in this case the parent, is sometimes the one who advocates and pushes the medical professional for the ‘diagnosis’ (Conrad, 2007). Yousef visited the Revolution Clinic for 6 or 7 years because he thought his child's behaviour was abnormal, which might indicate that he was already suspicious that his son's behaviour was ADHD, but seeking a ‘diagnosis’ for him was a way to confirm and find solutions to help his child’s behaviour. However, his hesitation regarding medication, but not ‘diagnosis’ could mean that medication was not a management strategy that he hoped to gain from the ‘diagnosis’. This is similar to Edwards et al.'s argument that parents’ acceptance of medicalisation (‘diagnosis’ and ‘treatment’) of ADHD involves a process of evaluation and negotiation of biomedical perspectives on ADHD. They give examples from the Irish context, where parents might accept the biomedical perspective of ADHD but seek alternative medical and educational interventions as opposed to medication (Edwards et al., 2012). Yousef might have thought of his son's behaviour as ‘abnormal’ and a ‘disorder’, but he did not think of it as an illness that required medication.

Farah and Yousef's stories were similar in how parents access medical services, asking doctors for explanations and solutions for the child’s different behaviours. Rafalovich (2001) argues that ‘diagnosis’ educates children and their parents about ADHD by providing them with support, information, and coping strategies. Parents advocated for the ‘diagnosis’ because ADHD-like behaviour presents a challenge in social contexts. Most parents consider the doctor or child specialist a reliable source in understanding abnormal behaviour such as in ADHD. This highlights the influence of the child developmental psychological discourse surrounding the parent, one that encourages them to think of their child as abnormal and to medicalise their child (Khullar and Coughlan, 2018). However, the parents’ opinions were not always in line with a biomedical approach. This can be seen from Farah’s description of her husband’s opinion of their son’s behaviour as being ‘just’ that of a child, which comes from the understanding of childhood in the Kuwaiti context. It is also seen in Yousef’s hesitation in using medication, which might suggest that he saw his child’s behaviour as deviant in comparison with the expectations of ‘normal’ behaviour in the social context within which he lives, but not an illness that needed medication. There were mixed ideas about childhood and normality that reveal the complexity of the parents’ understanding of their children’s behaviour and their engagement with ADHD.

In Chapter two, I discussed the impact of globalisation on Kuwait in producing hybrid beliefs mixing Arabic and Islamic culture and Western psychological ideas of childhood (Timimi and Leo, 2009). Western knowledge affected the lifestyles of the families and their understanding of childhood and parenthood. The contrast between the Arabic cultural authoritative style of parenting and the Western permissive style increases social and behavioural problems, when a child’s behaviour does not fit social expectations. Obedience and respect for one’s elders are important social expectations of children, and authoritative parenting is most dominant in Arab society (Dwairy, 2006). However, the invasion of psychological and developmental psychological information into the Kuwaiti context has induced inconsistency in parenting styles, which impacts parents negatively and questions their parenting efficiency (which is mostly experienced by mothers) while creating socialisation challenges for children who behave in a way different from social behaviour norms (Dwairy, 2006). In reflecting on the previous sub-theme stories, parents described searching for information on social media and the internet, which might have introduced them to the psychological perspective on childhood. However, the literature indicates some resistance in the Kuwaiti context to changes in some social-cultural values (Wheeler, 2000). The mix between Western and Kuwaiti Arabic and Islamic conventions is illustrated in contradictions in the parents' stories of understanding childhood.

Other parents sought a ‘formal diagnosis’ for their children as a way of solving the problems their children encountered in school. For example, Laila and Ahmad's son experienced problems in mainstream schools, with Ahmad describing that the school complained a great deal about the child's behaviour: ‘moving around a lot, easily irritable, unable to focus while sometimes very quiet.’ Ahmad and Laila had been searching for a solution, until Laila's friend advised them to visit a centre.

[My friend] said: ‘I am taking courses at this centre, go and ask about this school’. We searched and went to the centre. They did a test on [my son] and told us he could not enter the school unless he was entered in the disability committee, so we took him.

The parents' story describes continuous complaints, which pressured them to search for and consider the suggestion of the ‘diagnosis’ and move their children to a special school. The condition for getting into a special needs school was having the ‘diagnosis’. This is similar to the discussion in Conrad (2007, p.152) of medicalisation (diagnosis and treatment) where ‘social forces that influence wellbeing’ are not addressed and the focus is always on the individual. In reflecting on the previous stories, Laila and Ahmad's son was having trouble because of the school's complaints, but the focus was on diagnosing the child and changing his school, instead of considering educational support at his old school.

Rawan had a similar experience, but she expanded the discussion of her decision regarding ‘diagnosis’ further. To give context to the story, Rawan obtained the ‘diagnosis’ in order to get a disability certificate that legitimised her daughter's placement in a special needs school. Her experience with ADHD started after experiencing trouble with teachers, who continuously complained about her daughter. She was asked by a specialist to move her to a special needs school.

I entered the special school, and I felt relieved. They got a specialist that could see my misery. She sat with me, calmed me down and explained everything. I was very emotionally tired. I got off work and got lost on the way to the special school. I went to many places before I came to this special school. I was emotionally drained. I felt relieved and the paediatric neuropsychologist told me it was ok. I saw her three or two times then she asked for my daughter to get tested.

‘You have to get a disability certificate,’ she said. To get my daughter to this special school, she had to have a disability certificate. Of course, I did the test and after I was done, I let the father know. It was proven that she had learning difficulties. She used the [Wechsler Intelligence Scale for Children] and it was proved that she had a learning difficulty. Then she told me about the process in PADA (Public Authority for Disability Affairs). ‘They got her a disability certificate to allow her to study with us in the morning education program.’ The special school takes the student from the Ministry of Education for a specific period, then sends them back to mainstream school. They have the same curriculum. Thanks to God she joined the special school and she was able to learn. I mean I got the disability certificate to get them to pay for the school.

Rawan portrays the special school as a compassionate and therapeutic place that understood the differences in her daughter. This echoes Haegele and Hodge's (2016) discussion of education strategies in the medical model. Special school classrooms can work as interventions where the focus on impairment rehabilitation and normalisation is considered to a great extent (Haegele and Hodge, 2016). After struggling with different schools, they were finally in an environment that might support the daughter and protect the mother from negative experiences. For Rawan, the ‘diagnosis’ was a condition that she had to accept to understand and support her daughter without considering her to be ‘less’ than other children. She mentioned that the education in the special needs school she chose was parallel to a mainstream school, so the child would be able to return to mainstream schooling. It seems that Rawan was justifying her own decision to move her daughter to the special school, which meant more support but with the same curriculum as a mainstream school.

Finally, Reem's experience with the ‘diagnosis’ was also related to education challenges but not complaints from school. She said:

He was bullied a lot. I remember I used to get him two or three teachers to support him with academic difficulty in school. the school requirements were a pressure on him because I got him into private school. They pressured him and he had to memorise a lot. He used to get excellent grades in the second and third grades then in fourth and five grades, his academic performance started to deteriorate. In the fifth grade I got my son diagnosed. The boy had dyslexia, dysgraphia and ADHD. For ADHD he was considered to be mild. He did not need medication; he did not get to the medication stage. He was normal in everything except the study. My son’s social skills were ok, unlike the other children [with ADHD] that I hear about who are not able to make friends.

Reem cited the reason that drove her to seek the ‘diagnosis’ was her child’s deteriorating academic performance. This is similar to Ghost et al.'s (2016) findings that the parents of children with ADHD might seek a ‘diagnosis’ and ‘medication’ to improve their child’s academic performance and ensure success in school and life. The pressure from school was such that her son could not keep up. Her story indicated that she wanted to understand the problem underlying her child's lack of achievement. Although she mentioned the school pressure on her child, she also considered the opinion of a medical professional about her child's behaviour. This reflected the individual orientation of understanding ADHD, in that it always places the problem within the individual (Conrad, 2007). The story indicated that Reem's idea about ADHD was shifting between difficulty in learning and a ‘disorder’ as diagnosed by a medical professional.

The previous stories of ‘diagnosis’ due to educational challenges reflect the fears of parents with regard to their child's academic life and future. The concern of parents about their children's academic achievement can be explained through a sociological discussion of parenting. Harden (2005) illustrated how the responsibility for children in a neo-liberal society is understood as part of the parenting role. Apart from the system promoting a free market economy and ‘social government’, it increases individual responsibility to use freedom and social rights to meet the government's expectations (Richardson, 2005). One of the government's expectations is the normalisation of children, which is often the responsibility of the parents (Mallett and Runswick-Cole, 2014). Reflecting on the Kuwaiti context, globalisation led to neo-liberal ideas colonising the globe (Davies, 2018) in which parents are the main source of control and management of children's abnormal behaviour; while children are seen as victims, innocents that need protection. Parental acceptance of the ‘diagnosis’ might result from fear about the child's future and being blamed for the child's failure.

The experiences of Rawan, Laila, and Ahmad with mainstream schooling illustrate ambivalence toward ADHD and how it was managed through traditional social control strategies, such as complaints, as well as medicalised social control strategies like recommending ‘diagnosis’ and special schools. Advocating for ‘diagnosis’ indicates some awareness of ‘childhood development disorder’, especially ADHD. In the individual model in the Kuwait section (Section 2.3.2.6) of the Literature Review, I mention that the ADHD awareness campaign about learning difficulties was first run in 2011 by CCET and KALD for laypeople and educators (Alamal, 2011). The recent awareness of ADHD might explain the variation in parents' experiences as, for some, ADHD is situated in a cultural and social understanding and represents failure, where ‘naught’ children are responded to through complaints.

Another factor that plays a role in parents' advocating for a ‘diagnosis’ is disability law, which accepts ADHD as a disability. Conrad (2007) suggested that one of the interdependent forces that plays a role in medicalisation (for example ‘diagnosis’) is government legislation, which identifies ADHD as a disability that requires medical intervention. Accessing the disability system is important for parents because of the practice of mainstream schools being unable to tolerate different behaviour in children, which prevents teachers (who are trained only to identify the differences and not to tackle them) from carrying out their responsibilities in the education system. This might motivate teachers to advocate for ‘diagnosis’ and the option of a special school. The increased complaints from schools and children's failure to meet school expectations pressures parents into searching for alternative solutions. Special schools seem to be safe, capable places that fit children's differences. This parallels Rafalovich's (2013) argument that medical knowledge sometimes empowers parents because it offers resources that support in parenting a child with ADHD. It shows consistency with the argument of studies that find parents of children with a disability sometimes use medicalisation to access different support or to remove social stigma (Valentine, 2010; Gosh et al., 2016). The parents in this study could not obtain support without their children being diagnosed.

## 5.5 Conceptualising the typical

This sub-theme discusses the wider social and cultural factors that influence the understanding of ADHD as a ‘disorder’. Timimi (2005) aserted that ADHD is not just a ‘medical disorder’ but a socially challenging behaviour that makes associated behaviour problematic. After receiving the ‘diagnosis’ and gaining experience of living with a child with ADHD, parents started to develop ideas about ADHD that can be understood as different from the biomedical perspective. Parents in particular discussed two main ideas about ADHD. First, the parents’ stories suggested the idea that understanding ADHD differs according to time and social context. This idea is based on analysing stories where parents talked about their own past experiences with ADHD-similar behaviour. The stories highlighted the effect of historical and social factors on a different understanding of ADHD between the past and the present. Second, some stories indicate the impact of gender on understanding ADHD as deviant. By this, I mean ADHD is seen as deviant rather than the social norm for boys and blame is placed on allegedly incompetent mothers. This is based on the analysis of stigma which emerged from the parents’ stories. The stories highlighted the way mothers, not fathers, as well as boys, are part of understanding ADHD behaviour as a social deviance.

### 5.5.1 Genetic explanation

[My children's ‘diagnosis’ helps me to understand them and what they are going through. I had a really hard time in school. I didn't know what I had, but I could not focus. Nobody was there to help. Even when I had a tutor in maths, I did not get the algebra. When I got to the class and the teacher was teaching, with all the noise it was like my brain went blank and I could not understand it. So, when I noticed these things with my children, both of them, I knew what to do (in a louder voice) because I wanted someone to teach me, I realised, and I tried teaching them myself. I took my son at a young age to see a doctor for ‘diagnosis’. He diagnosed my sons with ADHD and dyslexia. I said ''Aha!'' It’s like the light went on. [Marleen’s story]

The parents' stories described ADHD as a condition that children inherited from their parents. The main idea in Marleen's story was that her children's ‘diagnosis’ allows her to understand her own experience and link it to her children's behaviour. As seen in the story above, Marleen compared her own experience in school to her children's experience, which indicates the assumption that they share similar conditions. Her word ''Aha'' might be interpreted as her finally understanding what was going with her school experience. Marleen's own experience in school allowed her to teach and understand her children. Stories regarding the heredity of ADHD concur with Parer (2010) that children with ADHD might inherit biological differences and social experiences that most of the time are not interpreted in social terms.

Similarly, Rawan linked her children's difficulties in school to her husband's family.

From my husband's conversation, it was clear that he had difficulty [studying] until high school. He did not get a degree easily. Additionally, when he used to talk about his brothers, they were the same. I realised, but I did not confront him. Inside himself, he knew. He saw his children. Perhaps, he saw himself in them. But we did not discuss whether I thought he was like them or whether I was like them. This is just between us, [the children] are like their father.

Rawan observed from her husband's family stories of school that both her husband and his brother shared similar challenges with school and learning. Her words ''he sees himself in them'' indicate that the father was reliving the same experience through the children. Similar to Marleen, Rawan tried to explain the challenge of her children's condition through her experience. However, the challenges were shared by the husband's family. Rawan understands ADHD as a condition inherited through the family.

Unlike the previous stories, Yousef clearly states that he might also have ADHD.

From my simple analysis, I discovered that I might have ADHD. However, I was moving around a lot. I went outside (into the neighbourhood). My son is always in the apartment. He does not go outside. Before, I used to go outside and play football. Life was simple. My mom and dad did not have any concerns [over my safety]. I went outside, and my neighbour went outside. I mean, it was a safe environment. I went out without shoes, and I got out all my energy. You do know if someone is hyper, because he would get it out in the neighbourhood. I can't imagine myself. I mean, I was in first grade, and I walked home from school. I am talking about the 70s. It was a long way, and I still walked home. Now, someone in high school would not walk home. A child should move around and go out.

Yousef interpreted his son's behaviour as something related to heredity. However, the interesting point of the story is that he thought his experience was different because of the contextual and historical differences that allowed him to copy behaviours. This reflects James and Prout (2003) and Timimi (2005) on childhood perception that not only differs culturally but also historically.

The contrast in the stories between the parents’ and the children’s experience of social reactions toward their ADHD indicates a lack of tolerance of the children's different behaviour, as opposed to the parents' experiences of ADHD behaviour in society. This was also reflected in the previous mother's story. As opposed to Marleen or Rawan's husband, society and the school were more accepting and supportive of the child's different behaviour. Marleen had a maths tutor to help her, while Rawan's husband's family did not give up on him and he got his degree. The parents' experiences were different to the experience of their children, who were diagnosed and in some situations treated with medication. Despite thinking of ADHD as a condition passed through generations, Yousef's story indicates that changes in lifestyle and parenting practices significantly impact his child’s ADHD-like behaviour.

The parents' story described ADHD as a condition that children inherited from their parents. Some parents demonstrated similar challenges and behavioural experiences while reflecting on previous ideas about ADHD. Their reflections are, for the most part, consistent with a biomedical perspective on ADHD that attributes the causes of ADHD to neurobiological and genetic factors (Faraone and Larsson, 2019), which indicates that ADHD is more likely to be transferred within the family. Parents did not use biogenetic terms, nor did the story suggest that the parents themselves had a ‘diagnosis’ of ADHD, but the parents' story suggests that understandings of ADHD differ according to time and social context.

### 5.5.2 Society and culture explanation: ADHD and gender

Laila: Unfortunately, I have heard that those who have ADHD tend to be isolated. I mean [our son] prefers to stay with us at home; he does not want to be social.

Ahmad: He is usually with his sisters – I try to pull him away from this tendency but find it difficult due to his condition.

He keeps resisting playing with other boys. I keep insisting, and he eventually goes and plays.

He is comfortable when he is with just one friend. When it is a group, he does not know how [to socialise]. He is sensitive; every time someone mocks him, he comes home or gets sad. He does not want to sit with the group, just because of a simple word. It is normal that boys mock each other. [Ahmad and Laila's story]

Parents described abnormalities in their children’s behaviour as ADHD, relaying stories about stigma that either they or their children encountered because of such behaviour. These behaviours were often linked to the ADHD discourse and symptoms. The first idea about ADHD seen in the parents was deviance from the social and cultural discourse of boyhood. Ahmad's story of his son's everyday social interactions with peers discussed what he considered abnormal social behaviours by comparing his son's behaviour with other norms of boyhood. He describes his child refusing to socialise with other boys because them mocking him, which the father indicated may have been normal funny behaviour among boys. He highlighted his belief that being sensitive and introverted is abnormal behaviour for boys. His story also emphasises the idea of friendships and social acceptance as important expectations and norms for boys, which Ahmad indicated his son was unable to meet. Laila believed that her son’s behaviours were linked to ADHD's negative impact on socialisation skills. Ahmad portrayed the home, with Ahmad’s mother and sister, as a safe environment that his son preferred, yet his son’s introverted behaviour was not considered socially acceptable by the father.

The idea of ADHD as behaviour which is deviant from the norms of childhood was also expressed by Yousef, when asked to talk about his son, Yousef said the following:

He does not have friends…He cannot communicate with [other children], nor do they know how to communicate with him. Maybe this year he had one friend, but no more; maybe he prefers older friends, but friends who are older than him cannot stand him – he annoys them, and he does not have the social skills to deal with them.

Yousef considered his son’s lack of communication and ability to make friends to be abnormal behaviour. Yousef mentioned what he considers to be an important childhood skill, communication, but his son is unable to interact with peers and make friends. He explained that his son’s rejection by peers was due to a lack of communication skills, which was interpreted by those peers as disturbing behaviour, thus causing the peers to reject him.

In the stories above, fathers expressed concern about the lack of social skills and friendships developed by their sons with ADHD. Yousef's concern over his son’s inability to make friends due to lack of communication and Ahmad’s efforts to encourage his child to socialise both suggested an understanding of ADHD through the cultural discourse of normative boyhood in the Kuwaiti context. This is consistent with and could be explained by Arab cultural values and understandings of childhood. Arab families are typically concerned with their children’s social behaviour because it is connected to important values of honour and shame that are often judged by society (Timimi, 2005). The social behaviours of children could honour their families, but also dishonour them (Hammad et al., 1999). Moreover, Arab families put a lot of expectation on sons, as they are seen as the source of social and economic support for the families (Hammad et al., 1999). This relates to the concerns noted by the fathers in the present study, as they may have been worried that such abnormal behaviour by their sons would bring shame to the role of the father in educating their children ‘properly’ regarding social behaviours.

For the mothers, ADHD is understood as a learning difficulty. Rawan shared a story about her experiences at a mainstream school:

From grade one in primary school, I felt that she was smart in everything, but there was no academic achievement. Nothing. From this moment I started to know. I went to the parents’ meeting; the teachers told me: ''let her repeat the year, she is not geting any achieving this year''. The teachers were disappointed, and I did not understand why.

The first time I went to the parents’ meeting, [the teacher] looked at me as if I was the mother of the student that hurt her, the one that [obtained a failing grade]. She told me, “Your daughter is not geting any achieving this year. This is a mistake.” I wish that I could show her my daughter now [because she is successful now] and show her what it means to be “not geting any achieving this year”!

Rawan was blamed by the teacher for being the mother of a daughter who lacked academic achievement. The abnormal academic behaviour of Rawan’s daughter led the mother to face harsh comments from her daughter’s teacher. Rawan was confused because of her observations conflicting with the teachers’ comments. In the interview, she mentioned this situation had occurred twice, once before her daughter went to a special needs school and once after. The repetition of tension in Rawan’s story was palpable as the mother repeated the same situation and the words ‘not geting any achieving this year’ to confirm the teacher’s misunderstanding about her daughter's achievement. Rawan wanted to prove to the teachers that they had misunderstood her daughter’s ability to succeed by not fitting the school’s expectations of students.

However, another parent, Sara, also experienced stigma, adding to the previous ideas. Sara linked the abnormal behaviour of her child not only with her role as a mother, but also as an education specialist.

The teachers said if he was not smart, we would not give him [good marks]. He is naughty but not disrespectful. He is disruptive for the teachers – he laughs a lot. The teacher said: “I am teaching. He starts to get bored, so he sits on the table. I turn around to see him putting the table on his head. I asked him why he did that. He says, ‘I am bored. I do not know what to do.”’ You know the teachers from the Education Ministry –do not understand. So, every time I go to school, I feel embarrassed. They know I am a specialist and he is always had problems with his behaviour. They did not expel him because he was not generally disrespectful.

Sara mentioned that her son did not have problems with academic achievement or performance, but she still received a lot of complaints from her son’s school. She described his abnormal behaviour at school, which included class disruptions. Sara felt ashamed because she was an educational specialist, and the teacher complained about her child’s misbehaviour. The blame here was doubly felt compared to the previous stories, because Sara was a mother and a specialist. Unlike in the other stories, where the mother was usually blamed by a female teacher, the teacher in Sara’s story was male. Her son used to study in mainstream school, and she outlined the way that she as the mother was often blamed, not the father, despite the school being an all-male school.

Sara’s story suggests that work increases the stigma that a mother encounters due to the abnormal behaviour of her child. Sara's story reflects what Goffman (1963) called ''courtesy stigma'', which means that both the stigmatised individual and their relatives are stigmatised by society. The denial of the ADHD label and classing the behaviour as deviant exposes Sara to the accusation of being a bad mother. Maktabi (2016) argued that despite an openness to the mother working and splitting responsibility between raising children and earning an income, the mother still faced harsh stigma. This is because any failure in the children is understood as reflecting the failure of the mother to perform her role. This is usually linked to the mother’s work leading to her failing in the main responsibility of the Arab mother, which is taking care of her home and children (Al-Azemi, 2010; Fargues, 1995). Sara’s interpretation of the opinions behind such stigma suggested that she was not blaming herself because she was a mother, but because she was also an education specialist.

## 5.6 The debate around treatment

This sub-theme explores the parents’ ideas about ADHD through treatment, which is a term used here to indicate different interventions that parents used to manage their children’s behaviour. Behavioural therapy was more effective than medication as a strategy for children with ADHD. This idea was identified through the parents' ‘treatment’ stories, where parents describe their expectations and concerns about treatment for ADHD.

### 5.6.1 Confusion around medication

Some parents thought ADHD was a ‘disorder’ that needed ‘treatment’. In other words, they saw that their children were biologically different and had an illness, and they agreed on medical ‘treatment’. For example, Yousef said:

[The doctors] said his was just active, but I believe the boy is abnormal.

Yousef’s story is situated in a hospital, where he thought his son’s fidgeting was abnormal. He thought his son’s behaviour might have a medical explanation from the doctor’s perspective. Another episode supported this idea, as he noted:

After a little time, a friend visited me and said he knew a doctor who had discussed this condition and recommended his treatment. I began to follow him, and I read about the medication recommended to me by the doctors. I hesitated whether or not to take the medication at first. However, I believed it would be beneficial to him and us. I went to have him diagnosed. He had ADHD and required medication.

He is overactive. I mean, I give him the treatment currently. But sometimes, I think I should stop the medication to rest in the summer. When I stopped the medication, his behaviour increased. With the medication, he is different, his fidgeting is less, and he is calmer. He is different when I stop the medication. The child is abnormal.

Yousef's decision to medicate his son was not made without further research, which changed his perspective on medication and resolved his fears. It was not long before he started doubting the effectiveness of the medication. He repeatedly mentioned his child’s behaviour when he stopped giving him medication; this might indicate that he wanted to convey a strong message about the medication. The disappointed feeling from Yousef’s story indicates that he thought the medication was a way to remove the unwanted behaviour, while medication only decreases the symptom of ADHD. This could be explained by DosReis et al. (2009) who observe that parents used medication as a problem-oriented approach and not as an illness-oriented approach. Yousef used the medication because of his inability to control the child’s behaviour in everyday life, while the medication is said to target dopamine and norepinephrine neurotransmitters in the brain to decrease symptoms (Antshel et al., 2011). This might have made him doubtful and unsatisfied with the results of the medication.

Another example was presented by Laila and Ahmad, who share similar experiences of using medication. Laila said:

In the old school, I started to give him the medication. When the development clinic gave me [the medication], he became calmer. At the time of the study, he started focusing. [In the current school] they help us, they give him the pills in the school. I give [the school] the box, and they give him [the medication] at school. This is very helpful. I give him one at home and the second they give him at school. If he needs it, I give him half of the pills when I teach him. But I cut it out altogether in the summer and spring break. I cut it out because I want him to take a rest. I do not want him to take the pills.

Unlike Yousef’s example of using medication for his son’s overactive behaviour, for Laila, the purpose of medication is to increase the ability of her son to calm down and concentrate on his studies. The removal of medication during vacations indicates concerns about the effect of the medication on the child. This concurs with Ghosh et al. (2016) that parents of children with ADHD might tolerate the risk of medication, in order for their children to gain academic achievement and secure their future with an academic degree, but also be worried about the side effects of medication. Moreover, the story also conveys that the mother was able to manage the behaviours without medication. However, the problem of behaviour appears at school, and the standard way of learning requires the child to sit down and learn. The idea of Laila’s motivation for medication whilst at school was supported in the story below, when her son was in mainstream school:

[The teacher] said, "He is better now, but he is still naughty, he does not understand, he does not sit down, he does not know how to read". Ok! (As if she is talking to the teacher) "What is your job? Teacher, you should teach him." I hope teachers understand that no mother will accept her child being mocked in front of her. (As if she is talking to the teacher) "You're supposed to know how to cope with him." The teachers have to take courses about [ADHD] and how to deal with it. There are families that do not want another school. They want this school.

By listening to her story, I could sense the anger and hopelessness she felt after giving her best and accepting medication about which she had some concerns (seen in the previous story). The anger in the story might reflect oppression from the teacher, who did not understand the effort the mother was making to control the behaviour. Clearly, from her words “some families do not want to move their son to another school”, she was trying to make me understand that the ‘diagnosis’ and ‘treatment’ was an obligation required to keep her son in mainstream school and avoid complaints from the school. Laila’s story echoes Ghosh et al. (2016) that parents might advocate for ‘diagnosis’ and ‘treatment’, but this does not mean their perspective on ADHD is medical-oriented.

From these two stories, it is clear that parents had doubts and were not fully satisfied using the medication. This can also be seen in Korean parents’ perspective on this ‘treatment’ (Moon, 2012). In this study the parents did not believe in the medication, because it did not improve their children’s academic achievements (Moon, 2012). The similarity between Korean and Kuwaiti parents is that the parents’ motivation behind the medication was not to reduce the symptoms, but to modify the child’s behaviour. Kuwait and Korean culture share some social values in respecting and obeying elders, and the child’s failure to behave within the social norms is considered humiliating for the adult responsible for the child (El-Haddad, 2003; Moon, 2012). However, the medication not only failed to increase academic achievements in mainstream school, but also failed to remove disruptive behaviour in class. Both Yousef, Ahmad and Laila accepted the ‘diagnosis’ and used ‘medication’ to manage their children’s behaviour. They illustrate the benefits of medication, but also demonstrate the limits of medication in their lives.

### 5.6.2 Behaviour therapy and socialisation

The parents' stories also provided alternatives to medication interventions that were child-centred approaches, such as behaviour therapy and diet interventions. For example, Sara tried a diet intervention to control the behaviour of her child in class. She said:

When he was young, I started to teach him how to control himself. Sometimes he said: ''Why did the teacher scold me? Ok, I cannot sit still; she wanted me to sit still all the time''. I started to minimise some types of food. I did not give him crisps; I did not give him chocolate. When he came back from school, I let him eat, and then he went and played; then, he would sit and study. He started to say, "It is true I do not want to eat, and when I do not eat, I become better; if I start sitting down more, the teacher will stop scolding me because I move around''. This was in elementary school. I remembered when he was in elementary; he thought that he did not eat sugar and crisps, and this calmed him down. No, he started controlling himself more because he was hyper, and I told him to watch himself. So, he wanted to see if it was true. So, he started concentrating on whether he was himself calm or not. He concentrated so that he did not make trouble and became calm in class. ''Yes, because I did not eat" (imitating her child).

Sara used a medical intervention in the form of a food diet to make her son's behaviour fit the school's expectations. This is similar to the medical model that works to normalise a child's behaviour. However, she challenged the effectiveness of the diet as the intervention illustrates that her reason behind the strategy was to modify the behaviour of the child depending on his focus and control. This might follow a medical model perspective, but contradicts the link between food and ADHD behaviours. Sara thought that her son had to fit the expectations of a social context but did not think the solution was a medical intervention.

Like Sara, Noor is an example who discussed the usefulness of behavioural therapy for Fahad's mental health.

I started looking and searching for centres in Kuwait. I found a place. It was one of the first who started play therapy. I had a specialist come to our house to train Fahad. I mean, we all benefited from this experience. My son got more comfortable with the therapy. He felt that people loved Fahad and accepted him.

Noor's son was facing challenges not just in school, but with social rejection that affected his mental health. Play therapy was important in providing social and emotional support. Moreover, as most children with ADHD have trouble with social interaction, Yousef and Reem also used behavioural therapy for their son's trouble with social interaction.

Yousef: To be honest, when my son was 5 years old, I saw educational therapists who changed my son's social behaviour. Although most of his words are in English, my son still uses the words and behaviour that he acquired from the therapy. He shows respect to me through his behaviour. He also talks wisely. [Yousef story]

Reem: When he was in grades four and five, there was a period [when] he saw a specialist. She was a specialist for children and teenagers. He was yelling a lot, and once he left the house, and we did not know where he went. We kept looking for him, and we found him in the mosque. This was the only problem that I faced, and I went to a doctor. We were seeing her for a while. I used to leave him with her and then I took him. I did not know the strategies that she used. Mmm, I do not remember, but I think she asked for his father to be present, but his father did not come. He rejected the whole thing. ''You always think there is something in the child and there is nothing wrong with him.'' (mimicking the father). Later he understood his child’s problem.[Reem story]

The stories indicate that children with ADHD might face negative social interaction experiences. This means that the parents saw the ADHD behaviour as deviant from the social norms in society. This challenge might be more relevant in a society that values social meetings with family or friends daily or weekly (Al-Thakeb, 1985). Both parents thought that the strategies used in behaviour therapy were more suitable to fit the challenges they faced in everyday interactions with other people. The stories of two types of alternative medical intervention indicate aspects of ADHD that the Law of Disability no. 08 ignores, which is that therapy intervention seems useful, based on parents' stories. ADHD behaviour and labels come with marginalisation, lack of support resources and social injustice (Timimi, 2014). It seems that the non-medical intervention recommended by the parents' experience was more fitting to the social and cultural challenges that parents experienced.

In discussing the results with reference to the literature, and especially in the US, because the Kuwait context follows the US perspective of ‘diagnosis’ and ‘treatment’ (Khullar and Coughlan, 2018), Rafalovich (2013) showed that the common US narrative of the ADHD medicalisation process starts with ‘diagnosis’ and ends with medicating the children. This was not the case with parents' experience of ‘treatments’. The parents' stories illustrate acceptance of the ‘diagnosis’ process in understanding the child's condition. The story of medicalisation then took a twist and often resulted in the rejection of the children's medication. It was tempting to explore the reason for rejecting the medication within the parents' stories. Unfortunately, parents usually did not talk about the reasons, except in Rawan’s story, she said:

ADHD does not impact comprehension and understanding, but sometimes it does. I mean my [older son] is overactive but smart and he understands normally. I mean I notice that ADHD always comes with intelligence, but you cannot control this point. Some can control the child in the class, but other parents might not be able to and require a medication intervention. For me, my children did not need it. I got inattentive and was absent-minded in the class. Their attention is very short. They cannot memorise things because their memory ability is weak. The inattention was very clear.

Rawan is a mother of four children with ADHD. One of them has hyperactivity and impulsivity, while the others have more inattention. The initial assumption that I made from Rawan's discussion was that she did not seem to be refusing medication. She thought that medication was not for every child with ADHD. The separation of the discussion about each of her four children with ADHD indicates that she sees medication as only for children with hyperactivity. However, her example of other parents' decisions to give their children medication provides the idea that medication is only for those who cannot control the movement of their children. She thought that a lack of attention and issues with memory in her other children were not enough reasons to medicate them. Rawan's story presents medication as a last resort that parents used to control hyperactivity and that her children's conditions did not demand medication.

In discussing the results, medication was the first-line solution offered by the government (according to Disability Law no. 08 in the disability practice section 2.2.5). However, medication options were not enough of an intervention, as parents faced other challenges from the social context, such as negative attitudes from teachers or other people. Parents therefore tried to empower themselves and their children through behaviour therapy and diet interventions.

Moreover, the parents' conceptualisation of ADHD was a struggle between a deviance that needed modification intervention and a disorder that needed medication treatment. Despite the differences, most parents' motivation for the intervention was to resolve behaviour problems at school or social interactions in everyday life. This was different from the US perspective, where medication is often used to reduce ADHD symptoms by targeting dopamine and norepinephrine neurotransmitters in the brain to improve behavioural outcomes, moderate comorbidities (such as learning difficulties) and improve academic performance (Antshel et al., 2011; Coletti et al., 2012). Even parents who gave their children medication had considerable concerns about the side-effects.

## **5.7 Conclusion**

This chapter presented complex and overlapping ideas about ADHD as a ‘disorder’ that parents keep shifting from to understand their children's behaviour. It also highlighted the variety of different ideas about ADHD as ‘deviance’, ‘disorder’ and different from the social norm. It illustrated that despite the dominance of the biomedical perspective on ADHD, parents described and explained their ideas about ADHD drawing on different cultural and information sources. Last, it also revealed the way parents negotiate and question their choices of ‘diagnosis’ and ‘treatment’. This theme focuses on the social origin of parents' ideas of ADHD as a disorder, which illustrates only the perspective of impairment and not disability. Thus, in the next chapter, the themes present ADHD in wider political, economic, environmental and cultural contexts from the parents' experiences to explore the barriers they encounter in everyday life.

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# **Chapter 6**

# **Disability barriers in social life**

Introduction

This chapter demonstrates the social barriers that parents struggle with in everyday life when parenting a child with ADHD. The focus is on how society obstructs the lives of families with children with ADHD, instead of focusing on removing the barriers that children with ADHD face. Here, social barriers are understood as difficulties and challenges because of the social environment and attitudes in society that prevent children with ADHD or their parents from having a quality of life like other people. They will be addressed from two perspectives, presented in the parents' experience. First, I discuss material social barriers, such as environmental barriers and institutional structures, that disable, exclude, and/or disadvantage the family from social participation (Oliver, 1990). Second, I examine non-material social barriers, which parents describe as impacting on the family, such as people’s attitudes and social stigma. These impact the families’ psycho-emotional states, making them feel less valued and confident(Thomas, 1999; Reeve, 2004). The social models of disability (see Chapter 2, Section 2.3.2.2**)** as a lens for discussing the parents’ stories are important, because the discussion highlights the issues within the practice and suggests a suitable source and support for improving the lives of families of children with ADHD.

However, the two types of social barriers also overlap. By this, I mean that the disadvantages and stigma that parents encounter in social environments and structures might sometimes lead to psycho-emotional effects. Therefore, the material and non-material social barriers are discussed together through three sub-themes. The first sub-theme, ‘barriers to accessing support for the family due to ineffective services’, refers to the challenges that parents face as a consequence of support and services for families that do not fit children with ADHD needs. This theme focuses on the stories of parents after they accessed disability support systems and their experiences with such services. The second sub-theme, ‘communication as a barrier to receiving support and services’, refers to the challenges that parents face in making decisions about their children’s lives because of limited information and communication with institutions and professionals. It focuses on the stories of parents’ interactions with services, medical professionals and social support groups. The third sub-theme, ‘psycho-emotional effects on children and parents’ lives of institutions and society’, refers to families encountering negative attitudes from society, that is, in everyday encounters in social situations. Each of these themes is presented in the results discussion in figure 7: The themes and sub-themes of the stories analysis which illustrate the focus on chapter 5 6 7 as well as the results and how each chapter related to each other.

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**Figure 7:** The themes and sub-themes of the stories analysis. **Key for the theme map:** The theme map shows all the parents' ideas about ADHD from the analysis. The oval shapes refer to themes and sub-themes; within each oval shape are the ideas that every theme contains. The oval shapes were merged to illustrate the overlap in the parents' ideas about ADHD. For example, the ovals of Chapter 7 and Chapter 5 share a point that is different, which means that parents were thinking about ADHD as a ‘disorder’ and a difference in learning. The ideas of each theme follow the direction of the titles

6.1 Barriers to accessing family support due to ineffective services

This sub-theme is concerned with the material barriers encountered by parents of children with ADHD in Kuwait in terms of service and support. The parents described the service they received from the disability support system as a barrier that did not fully address their children's needs. The theme is illustrated by the parents’ stories of service provision and issues encountered by both parents and the children.

The first set of issues raised by parents concerned the quality of special needs schools based on their descriptions of their children’s experiences, such as an inadequacy of education, teachers’ ignorance and reluctance, limited options in terms of various family circumstances, and non-acceptance by academic services. The second set of issues raised by parents addressed the impact of social understanding of ADHD on decreasing the support needed and increasing financial problems. Parents’ stories of their everyday lives illustrated different barriers, such as the inability of the parent to work, and the inconvenience of medical services that increased their financial burden. This will be analysed through the stories of parents’ interactions with society and educational institutions in everyday life. The sub-themes are presented below, discussing the issues and challenges faced by parents and the needs the parents suggested should be addressed to better support their families.

## 6.1.1 Barriers to children and families in schools

Parents’ stories of their experiences in special needs schools showed the barriers that children and parents encountered at school. It has been argued that special needs schools are a material barrier for children and families to overcome because they exclude disabled children from their local communities (Oliver, 1996). However, other scholars argue that special needs schools might not be considered social barriers for all disabled people because they provide a place where some support can be found to fit the needs of certain disabilities, such as learning disabilities (Anastasiou and Kauffman, 2010). The parents’ stories about special needs schools were situated between these arguments, as the parents thought special needs schools were better places for their children, given the lack of awareness or support in mainstream schools; however, they were disadvantaged because of the challenges they encountered in special needs schools, shown below.

### 6.1.1.1 Inadequacy of education as a barrier to education

The parents evaluated special needs schools as providing inadequate education. As mentioned in an earlier chapter, special needs schools were the only option for parents of children with disabilities, because mainstream schools were neither prepared nor able to support their educational needs. Parents discussed the special needs school with frustration and disappointment, as they believed that their children were not receiving a suitable education. For example, Reem, the mother of a child with ADHD called Zyad who is now 18 years old, tried moving Zyad into a special needs school for two years after experiencing a lack of support from his mainstream school. In the extract below, Reem discusses the reasons she moved Zyad back to a mainstream school.

Unfortunately, in Kuwait, we do not have a school that we could call specialised for ADHD. When Zyad was in the sixth grade, I took him to a special needs school that was supposed to care for children in this category, paid for through PADA. I found out no, no use and of a very low standard. Despite their inclusion for all disabilities [such as] Down Syndrome and ADHD, there was no education. I was patient with them [through] sixth and seventh grade. Then I moved Zyad into a mainstream school and I kept silent. I did not say anything to him. I did not talk about the problem.

Reem stated that the special needs school clearly received a lot of financial support to prepare and provide education, but did not provide the support needed. She characterised the school as “no use and of a very low standard”, illustrating her frustration with a school that was supposed to be better at copying with special needs students. Reem’s story presents an example of Oliver’s (1996) argument about issues with special education that might affect disabled students’ educational and social needs. By that I mean, the special education system fails to actively educate disabled people to prepare them for adult life, which increases the idea that disabled people are unqualified and may even lead to social exclusion (Oliver, 1996). Reem’s story illustrates the idea of special needs schools and the inclusion of children with disabilities leading to inadequate education, which might be linked to a lack of understanding of children with ADHD educational needs. Reem might have been scared for Zyad’s future if he was unable to get an education and become prepared for life. This indicates that special needs schools seemed to be a disadvantage for Reem and Zyad because the school did not pay attention to to his different learning needs.

The lack of education and support was also illustrated by Marleen, the mother of Omar and Salem who are children with ADHD. She had to change Omar’s school four times because of issues with teachers, administration and negative attitude towards Omar. In the extract below, she evaluated the special needs school in comparison with the mainstream school.

Omar started at [special needs school name], but it was very difficult for him. Because you know they don’t have a support system…Omar's ADHD means he is hyper and can’t sit still, he can’t concentrate, so they don’t have time. This school nowadays has 24, 25, 28 students per class. They don’t have time for one student. They do not have time for any of them; they just teach them blah blah blah and give them paperwork. They teach very quickly, and even mainstream students have a difficult time. They teach them so fast. So, I got Omar out of there and took him to [another special needs school].

Marleen asserted that Omar did not have the special needs education that she expected from the special needs school. For her, the special needs school did not seem different from a mainstream school. There were a lot of children in one class, so the teacher did not have time to focus on the students. It seemed that the special needs schools were similar to mainstream schools, as they were also restricted by time, so they had to teach students very quickly. Omar was considered ‘hyperactive’ and ‘inattentive’, and he needed more support to learn. Marleen suggested that this type of learning was difficult for ‘mainstream students’, indicating that it might be even more difficult for children with ADHD to learn as quickly as other children.

The two mothers’ stories are consistent with Dowling and Dolan (2001) and Lynn et al. (2012), who asserted that parents experience poor-quality service provision due to a lack of understanding of disabled children as more than simply disabled. Reem’s view of special needs schools as ineffective supports Swain et al. (2003), which describes a problem with social inclusion in education institutions, as the focus is mainly on providing a place for students with learning difficulties and offering them an education. However, social inclusion in education means focusing on the process of special needs schools in terms of curriculum, teaching, organisation, environment and management. Anastasiou and Kauffman (2012) developed the idea of inclusion stating that meeting the social inclusion needs of disabled children is as important as meeting their educational needs. For Swain et al. (2003) and Anastasiou and Kauffman (2012), the problem of inclusion goes beyond the segregation of disabled students in a special needs school. It is the failure of the special needs schools to be special about their ways of teaching, and having a one size fits all approach to the curriculum. This is similar to Marleen’s observation of the missing quality of special needs schools for Omar. From the two stories, it seemed that the children were studying in special needs schools, but their learning needs were ignored, and their education was inadequate.

### 6.1.1.2 Professional ignorance and reluctance as barriers in education services

The second issue parents discussed regarded teachers as vital resources of support for their children. They believed that the teacher’s reluctance to deal with their children’s behaviour was because of their ignorance about the children’s impairment and ways they could support them. For example, Marleen discussed the implications of special needs teachers’ lack of experience or acceptance of teaching Omar:

This school complains a lot about Omar, and it is a special needs school, not a mainstream school, with support. They are supposed to have special needs teachers. Omar stops concentrating, he stops handing in his work, he is moving around a lot, all these things. This is the school where I sent the paper about how to deal with special needs like dyslexia, ADHD and ADD; I even wrote them a letter. I don’t remember what the letter said but it was something like…I am sending my son to a special needs school and that is you, you are supposed to know how to deal with them, how to send them to time out, how to prepare schoolwork and help them learn and encourage them to sit still. If they are not sitting still, that means you are doing something wrong.

In earlier parts of her story, Marleen stated that Omar has been in four different special needs schools; this episode was from Omar's last school. Marleen was so fed up with complaints from the special needs schools that she decided to educate them about ADHD. Her story showed that despite being a special needs school, the teachers were ignorant of teaching strategies to support Omar. This is consistent with Fisher and Goodley (2007) that the importance of acknowledging disabled children is greater than their label. Marleen's description of Omar’s behaviour and her reaction to the teacher illustrated her disappointment with the support provided by the teachers. A lack of understanding by the teachers added a burden to the mother and increased the ADHD-like behaviour of the child.

The teacher’s reaction to children with ADHD is also discussed in Rawan’s story. Rawan’s stories included her four children: Talal, Mona, Waleed, Hamad who are different ages, all children except Talal studied in the same special needs school. By comparing Mona with Hamad, who was 12 years old, she highlighted the changes in the teacher’s efficacy.

Now, [the school] is not like before, but they still connect with Mona. I am confused that they have teachers who do not understand the students. She told me ‘I cannot control Hamad, he is always making the other children laugh’. I went to the other [teacher’s] table and another teacher told me: ‘Hamah is amazing’. This is the same school, but it depends on the teacher. I thought maybe Hamad did not like the subjects and would like other subjects, or maybe the teaching style is different. I mean, the teacher [who thought the child was amazing] used games but the other one made Hamad hate the subject because he had to memorise a lot. The Arabic teacher, oh my God, Hamad hates Arabic, but he loves the teacher. The Arabic teacher told me: I understand Hamad, I let him perform the lesson instead of becoming the clown of the class, at least he helps me. They have fun because Hamad is teaching the lesson and he understands what he reads.

It depends on the teacher’s strategies. The teacher makes the student love the subject and do better. Hamad does not like Arabic language, because he finds it difficult and he cannot [learn Arabic] but Hamad loves the teacher. This is because the Arabic teacher understands him. Maybe if Hamad had another teacher, he would present Hamad as a failure because Hamad cannot read or write. As for the teacher standard, maybe the school went through [different] circumstances or they did not hire teachers like before.

Rawan’s comparison illustrated the differences between teachers’ styles of teaching. It seemed that teaching style affected Hamad’s learning and behaviour. She suggested that a memorisation learning style was not suitable for Hamad. Her son was excited and learned by performing and through games, which she found not all teachers were capable of. Bourke-Taylor et al. (2010) demonstrated that strategies and interventions in education provision can obstruct the educational support of disabled students. Communication with parents about their children and their needs might facilitate the education process (Bourke-Taylor et al., 2010). Rawan’s experience with Hamad’s learning might help an educator in the teaching process, but her story illustrated a complaint rather than the teacher having effective communication with the parents. Oliver (1996) asserted that educational specialists should not only acknowledge special skills for disabled children, but should also be committed to providing the support needed. This also applies to teachers in the Rawan story. The level of commitment was illustrated by the differences in the teacher’s ways of accepting Hamad and getting to know more about his way of learning.

### 6.1.1.3 Lack of flexibility as a barrier to access services

The poor quality of schools and variation in teacher efficacy increased the limitations of parents’ choices in accessing education services. Despite the availability of special needs schools, parents felt constrained in their options because of the lack of consideration for family circumstances and lack of understanding of ADHD. Noor also had trouble with teachers, yet her options for special needs schools were limited because of the language barrier.

You go to a school that is supposed to be special; you realise that they do not know everything. They’ve got one or two [teachers], but they do not cover all student needs. You see, the quality of the school is a problem. You want to take your son to a mainstream school. Your son learns through the English system, and there is no support in a mainstream school. You want to go to another government special needs school that is great in Kuwait, but it does not accept students who speak English. Then what can I do? I have to go back to a private special needs school. Ok, where do I take Fahad?

The changes that Noor encountered were related to the previous barriers to special schools. She critiqued some teachers’ efficiency and linked the problem with the expenses of special needs teachers, which not all schools could afford. This is consistent with Bourke-Taylor et al. (2010, p:134) and Al-Kandari (2014), who suggested that the opportunity for parents to obtain suitable education provision is a ‘hit and miss’ process because of the difficulty of attending to variations in family circumstances and the poor quality of schools to support their children. Regarding the former barrier, Noor had fewer options for schools that could support Fahad, especially those that some parents of children who started with the English system might encounter. She suggested that not all special needs schools lack quality. The local special needs schools were good, but the problem was that the school system only accepted students who spoke Arabic. Fahad spent a long time in a private special needs school that had an English system, so it was difficult for Fahad to switch to Arabic. This reflects Thomas’s (1999) discussion of the unequal relationship between disabled people and the societal structures that leave parents disempowered. Noor was disempowered because of a lack of school flexibility to fit her circumstances. This limited her options to an English system school that, in her opinion, was not good.

Noor was not the only parent who faced a language barrier. Yousef, the father of a son with ADHD called Jacob, had a similar situation, but his response to the language barrier was different.

I first registered at a private special needs school that specialised in Jacob’s condition. They did a test and told me that Jacob could not write. I told them: this is why I registered here. Anyway, I did another test at [another special needs school]. They accepted Jacob and it was better. However, I did not want to register in a special needs school. But Jacob is doing ok. He is weak in the Arabic language; I mean this is my second year. I registered with Jacob in grades 3 and 4, but I am thinking in the summer to provide him with additional support.

Jacob’s first school was a private English system school, which was not prepared to support children with ADHD. Therefore, Yousef applied for disability support to register for special needs schools. Yousef’s story highlighted the issue with special needs schools. Similar to Noor, the language in local special needs schools was a barrier for Jacob. However, Yousef responded to the barrier by thinking about getting additional support, which might increase the financial burden on the father. The lack of flexibility around families’ circumstances, such as language barriers, in the two previous stories reflects what Cameron (2014) called the “systemic barrier”, which he defined as a lack of flexibility in practice to acknowledge the differences in people’s lives.

### 6.1.1.4 Academic professionals’ negative attitudes as a barrier to academic services

Parents talked about the negative attitudes they encountered, as some special needs schools rejected children with ADHD. For example, Yousef described how he applied to a special needs school for Jacob who had learning difficulties, but they did not accept Jacob because he had different learning difficulties. This might be interpreted through Bazna (2009) who observed the lack of benefits available for children with learning disabilities, suggesting that schools might refuse children with learning difficulties because of the lack of understanding about impairments with learning difficulties or because they might need more support than that school could offer. These negative attitudes in academic services are clearly illustrated in Reem’s journey of finding a school for Zyad.

The hardest period for me was when I wanted to transfer Zyad from the school [special needs school from the story above] in the ninth grade. He broke my heart. It was the hardest period that I had experienced. I was alone, and Zyad’s father had nothing to do with him. The pressure was all on me. I applied to the school; they rejected Zyad. I applied to another because they said they did not have nine grades and they would put him in eighth grade. I said OK and I accepted. I took Zyad, and he did not pass the exam. Ok, he has a learning difficulty. How do you examine him? When I talked to Zyad, he said: ‘I know, I did not want them to put me in the eighth grade’. I hated the school because they were demanding. I took Zyad who was in ninth grade. I told them Zyad had dyslexia and dysgraphia [in addition to ADHD], and they told me Zyad did not know how to write. If he knew how to write, I would not bring him to the school. They rejected him. Then, my friend told me about a private school closer to my home; she knew the principal. I took Zyad and I asked my son to be silent and not tell them about anything. I told the principal that Zyad was weak [academically], and that he failed the exam twice. I told them ‘I came to you because of my friend’s advice’. In the end, they accepted Zyad; it was a good school, better than the school before. The administration was understanding and supportive. They treated my son like he was their own child. They have few students. So the problem is, if you want to transfer your son with learning difficulties to any school other than a special needs school, they do not take him.

In her earlier story, Reem mentioned that Zyad was not getting a proper education, which led her to move him to another school. However, the other school did not accept Zyad because he had a lot of learning difficulty-related problems, in which the school supposedly specialised. This fits Thomas’s (1999) description of disablism, which describes the ways in which disabled people are faced with the impairment effect that causes negative social perception of impairment. People with impairments do not recognise the disadvantages imposed on them because of the social structure and common cultural practices that place disabled people in inferior situations (Thomas, 1999).

Reem was surprised by the way special needs schools refused special needs students. It was Zyad’s right to be accepted into a special needs school, regardless of the category of impairment. However, the unequal power between the mother and the services led to difficulties in attempting to secure a place for her child with ADHD. This left her confused about where to place Zyad. At the end of the story, Reem revealed that she concealed Zyad’s condition to allow him to be accepted by the school. Although the private school was not a special needs school, they offered Zyad the support that other special needs schools had failed to do. This story illustrates different school responses to a student who is weak and a student with learning difficulties. Reem's story indicates negative attitudes and rejection, which might be because the school seems to stereotype children with a learning difficulty and lacking the ability to learn because of this more than academically weak students.

## 6.1.2 Financial barriers

The parents’ stories of everyday life coping with social attitudes and services illustrated the different barriers that caused the family a financial burden. This could be explained from a social model perspective. Barnes and Oliver (2012) asserted that most problems with disabilities are related to poverty and financial support due to a lack of opportunities to work. The financial burden can also affect parents as caregivers of disabled children. Moreover, as mentioned in an earlier chapter, Kuwait’s Law of Disability provides many privileges to people with disabilities, which often cover all aspects of their lives. However, the government’s financial support differs according to disability. Parents were not complaining about the financial support which seemed to be enough, but the issues in the stories was with the level of services provision because of misunderstanding disabilities, such as ADHD, which increased the financial burden. This sub-theme discusses the way the understanding of ADHD in practice is associated with the financial barriers faced by parents.

### 6.1.2.1 Barriers to work

Some parents described facing difficulties in securing a job that understood the disabled child’s care needs. For example, Marleen stated:

You cannot work. I had two with dyslexia and ADHD. It is impossible to work because no job is going to let you leave your job and run to your children. They’re not going to do that, they will fire you, so I decided to get support from social welfare and have time for my children after the divorce.

Marleen’s sons’ special needs school complained a lot about Omar and Salem’s behaviour. She often had to leave work to resolve the challenges that her sons faced in school, which eventually led to her leaving her job. This shows consistency with disability studies about parents’ experiences, showing that the main disadvantage is the inability of the mother to work, because of her care responsibility for the child with the impairment (Dowling and Dolan, 2001; Goodley and Runswick-Cole, 2012; Green et al., 2011). In linking the story to the Kuwaiti context, Disability Law no. 08 recognises the difficulty that parents face in having caring responsibilities and allows parents of disabled children to leave work early and take vacations (Kuwait’s Constitution, 1962). However, this does not apply to parents of children with learning difficulties, such as ADHD, because they are considered mild impairments. The Law of Disability’s perspective of ADHD also reflects the individual model perspective of care, in which care is defined as the care for everyday needs that some people with disabilities need help with (Swain et al., 2003). For children with ADHD, the meaning of care differs in terms of resolving social barriers in service provision. Marleen’s story indicated a lack of understanding of ADHD beyond impairment difficulties. Her story illustrated that ADHD caring responsibility might be linked to social attitudes towards children with ADHD. This is consistent with Thomas’s (1999) argument of disability as a product of the impairment effect and disablism. The school’s misunderstanding of Omar and Salem behaviours as troubled and disruptive was the impairment effect that disabled Marleen and caused material barriers, leading to a financial burden. In earlier themes, I mentioned that special schools are not always efficient in understanding and accepting children with ADHD. This exposes families to negative attitudes and financial barriers. Marleen’s story presented a good example of the link between the social understanding of ADHD (impairment effect) and financial burden.

### 6.1.2.2 Barriers in health services

Some of the parents discussed the quality of services provision as a social barrier that caused a financial burden on their families. Despite the Disability Law’s efforts to cover the needs of children with learning disabilities, the health provision to provide ‘diagnosis’ and disability certificates has had many issues that have pushed parents to pay for private sector healthcare to get the disability report and access the PADA disability support system. Reem’s son Zyad accessed the disability support system, but the costs of the tests and ‘diagnosis’ were expensive. She stated:

It is very expensive. To get the report, I had to pay a lot of money. Not all people can. There are people who would carefully consider it, while others will not. I hope that we have places similar to dyslexia centres where families can ask questions, and it is less expensive. There are some places for free, but they have to open a file in the Kuwait Centre for Mental Health. This is very hard (because of stigma). Other places were ok, but there were no appointments available. The service is free, but the appointment date is far off.

Reem’s stories indicated that government health services underpinning the disability support system were available; however, the issue was that appointment times for a diagnosis were unsuitable. This is consistent with Woodcock and Tregaskis (2006) which examined perspectives on services and support in parents of children with a disability in England. They argued that parents faced barriers in accessing and meeting medical appointments for services because of the long process and decisions from professionals being made without communicating with parents. This pushes parents, such as Reem to access expensive private services to get tests, diagnoses or even information, which burdens the family financially. Reem’s family was in a disadvantaged position and had a financial burden, despite the existence of a disability support system. This could be improved by providing more health services to decrease the amount of time parents have to wait before accessing disability support.

# 6.2 Communication as a barrier to receiving support and services

The second sub-theme will present information and communication as a social barrier that constrains the parents of children with ADHD in making decisions about their children and/or overcoming challenges they face in their everyday experience of disabling society. Communication between parents of children with ADHD and institutions and professionals who provide care to support their needs is important, as they might perceive care differently. This cannot be achieved simply through a better attitude towards disabled people (or their carers), but through listening effectively and granting access to information to understand what disabled people need from services and support (French and Swain, 2004). The analysis focuses on the stories of parents that include challenges with services or professionals because of a lack of communication and information. Moreover, parents highlighted the impact of communication through stories contrasting with those about the challenges, in which they detail the role of social support and advocacy groups providing parents with information and social support through the challenges they encounter in their experiences. This sub-theme will discuss the importance of communication and information in parents’ experiences by examining the main issues and then highlighting the strategies that parents took to overcome these issues.

## 6.2.1 Lack of communication with parents as a barrier to decision making

The first issue related to communication was the lack of parents’ participation in decision making. Some parents’ stories of ‘diagnosis’ revealed that limiting the parents’ opinion on their child’s behaviour mattered in their experience of accessing services and support. The parents explained that decisions about ‘diagnosis’ and support were usually controlled and influenced by the doctors. Thus, parents’ opinions about their children were usually dismissed, or worse, they were blamed for pushing the ‘diagnosis’ on their children, because the doctors did not see physical impairment. However, in the stories of parents who had enough experience and information about ADHD, the doctors’ control was challenging, as parents empowered themselves through medical and psychological information.

For example, Marleen challenged medical authority by using her information about the nature of ADHD in an interaction with doctors, in which she challenged their knowledge. This led to a tense situation between Marleen and the doctor regarding Omar’s entitlement to a disability certificate, which is a key requirement that enables access to PADA (Public Authority for Disability Affairs) services and support. She stated the following:

I was standing in the hospital – I was taking Omar for testing. We were talking, and then we asked about the doctor we used to see before. [As if talking to the doctor] “My son has dyslexia and ADHD, and we need to see the doctor.” He looked once at Omar and said he did not look like he had a problem. I said, “You think it is on the outside, that he’s got to be crippled – this is inside, and you cannot see it.” The doctor said, “But there is nothing going on here – nothing.” So, if they don’t see it, these children will suffer.

Marleen’s description of the doctor’s reaction indicated his negative attitude towards her child with ADHD. According to Link and Phelan (2001), the situation of stigma indicates different levels of power between the stigmatiser and the stigmatised person. Power is an essential factor for stigma, and this power is usually generated from social, political, and economic factors that the stigmatiser position holds within certain contexts (Link and Phelan, 2001). The doctor was holding the power to give a certificate of disability that allowed the family to get the support needed, while he had a stereotype of disability as being “crippled”. This led to stigmatising Marleen’s son because the doctor understood disability as a visible physical impairment, but ADHD is an invisible impairment. However, Marleen’s attitude towards the situation of stigma illustrates that balancing power could not be done without communication and being informed about ADHD. Marleen was able to educate the doctor on what ADHD is, and she questioned the doctor’s judgement regarding her son’s impairment. She discomfited the doctor by critiquing his understanding of disability. This supports Swain and France’s (2004) suggestion of balancing the power between people with disability and professionals through providing information and using effective communication.

Rawan’s experience further illustrated Marleen’s point; she narrated an interaction with a doctor in which the doctor insisted Waleed was “normal”.

You enter the doctor’s office after you have got over both the child’s challenges and your own challenges [accepting that she had to enter the disability system]. The doctor saw all kinds of conditions. Someone comes [into the doctor’s office] – Waleed can walk, so the doctor thinks Waleed has a high IQ. The doctor said to me, “Why are you here? Your son does not have anything.” “OK, please sign the paper”, I say. “I won’t sign, I won’t let him pass” [i.e., give him access to the disability system]. I go home. I do not know if the doctor will sign it or not. He set out to annoy me and left me not knowing if the paper [disability certificate] would pass or not.

The struggle with medical professional power over the lives of disabled people was clear in Rawan’s situation with the doctor. It revealed a lack of medical professional understanding of disability, which added to the mother’s confusion and tension. This was made worse by the doctor’s refusal to communicate and listen to the mother. In contrast to Marleen’s reaction to a lack of medical professional understanding of disability, Rawan decided to ignore it, smooth things over, and interact in a way that would get her the disability certificate for Waleed. She understood the confusion around ADHD that might lead a doctor to characterise Waleed as “normal” and therefore not eligible to access the disability support system. In these two stories, the mothers were eager to communicate and make the doctor understand their children’s differences. Moreover, the mothers’ experiences were similar in that they used the ADHD discourse to empower themselves to advocate for the rights of their children.

Rawan’s and Marleen’s stories not only demonstrated a lack of communication and limitation of parents’ opinion in supporting their children, but also highlighted the role of information in challenging the power of medical professionals and parents advocating for their children’s rights. The doctor is in a society that values medical information and considers the opinions of a doctor to be more credible than the opinion of the parents about the child's difficulties and needs. In the Kuwaiti context, even if a parent advocates the ‘diagnosis’ of their child to obtain support from the disability system, according to Disability Law no. 08, the key remains the doctor who is providing a disability certificate that legitimises the child’s right to receive support (Kuwait’s Constitution, 1962). The invisible nature of ADHD makes the process of obtaining confirmation from the doctor regarding the child’s disability with ADHD challenging for parents. Despite the fact that the disability policy recognises ADHD as both a learning difficulty and a disability, ADHD legitimacy as a disability might prevent some children with ADHD from gaining the support needed. This indicates the importance of increasing awareness of ADHD in the health institution.

However, the previous stories illustrated resistance to medical control. The parents’ interactions with professionals were based on a need and dependence on the doctor’s judgement to issue the disability certificate and provide the needed support; however, stigmatised groups do not have to be helpless victims or passive. Link and Phelan (2001) suggested that stigma usually happens in the context of power, which always meets resistance. “Stigmatised groups actively use available resources to resist the stigmatising tendencies of the more powerful group” (Link and Phelan, 2001, p:378).

Reflecting the process of stigma in the stories in general, the doctors’ medical authority led to labelling the children with ADHD as not legitimately disabled, which encouraged the parents to use medical knowledge to challenge and resist the doctors’ authority and misinformation about ADHD. This would not have been possible without parents having more access to and empowering themselves with information. These examples were parents with long experience with ADHD, which might not be the case for new parents who need support due to parenting a child with ADHD.

## 6.2.2 Removing the barriers: support groups as sources of communication

The stories below are relevant to the communication sub-theme and emphasise the importance and usefulness of social support groups in the positive experiences of parents of children with ADHD. The parents’ stories indicated many social support sources, such as family, friends, and advocacy groups, that helped by providing information and emotional support for the parents during their uncertainties and overwhelming experiences of parenting a child with ADHD. For example, Laila stated:

My Egyptian friend in high school, I told her about my problem [finding a special school for her son Nasser]. She told me that she taught a course about disability in a centre. She advised me to ask them. So, we looked for the centre and did the test. Then, they told us to access PADA, and we changed Nasser’s school.

Laila demonstrated that being able to talk to a friend about the issues Nasser was facing opened the door to information and support for her son. Green et al. 's (2011) study of parents of children with disabilities illustrated that groups and communities of other parents in a similar situation were supportive both in meeting challenges in demanding care and helping face negative attitudes in the social context. These parents’ stories about accessing the disability system were often ambiguous and difficult; however, communication and being able to talk to a friend were key supports for the parents. In another example of social support with issues of securing a special needs school for children, Reem said:

I said to myself, “Where should I take him?” Even private schools lied to me. They asked me to come the next day, and they said that the school would be closed. Praise upon God. My friend told me about a private school close to my house. She told me, “I know the principal. Why don’t you take your son to that school?” So, I took Zyad to the school and asked my son to be silent about his disability. I told the principal that he was academically weak. So, he got into the school. It was a really good school. The administration was understanding and supportive of my son.

Reem expressed her frustration at finding a school for her son, after trying to get a lot of special needs and private schools to accept Zyad. Her friend’s connection and information about the private school close to her home solved Reem’s problem. These examples illustrate issues that should be supported by the disability system. However, from the parents’ stories, it seems that they were on their own after accessing the disability support system. These findings are also consistent with Goodley and Tregaskis (2006) on the experiences of parents of disabled children, where information that parents found from sources other than professional was beneficial in meeting their requirements.

For Rawan, the source of support was the family. She said:

My husband was the only one who could feel me, but I said to myself, ‘The teacher will not break me, I will not be broken.’ The teacher told me, ‘Mona will fail. She will.’ When I talked to my family and friends when I was down, I told them, ‘Mona will not fail.’ I heard these words from teachers for a year. They said, ‘Let her fail and Mona will get better next year.’ I always reminded myself that their words would not come true and that Mona would succeed in a place better than her mainstream school.

Rawan constructed a community of people who supported her emotionally. She portrayed herself as a fighter against the negative comments from the teacher about Mona in her first mainstream school. Rawan’s ability to talk about her experience to other people who supported her, especially her husband, was essential in keeping her fighting for Mona. This is consistent with Bourke-Taylor, Howie, and Law (2010), which illustrated that parents with social support are more satisfied emotionally and are better able to manage the demanding role of raising a child with a disability than parents without social support.

In a slightly different way, Noor said:

My husband, my children, my family, and my friends gave me unlimited support. Although they were confused and surprised that I had moved Fahad into a special needs school, they did not hurt my feelings.

Noor thought that support from the family came through accepting her decision to choose a special needs school for Fahad. Noor’s understanding of support reflected the social model discussion of care, which indicates that society should be supportive of disabled people and/or their families in a way that helps them make decisions about their lives (Swain et al., 2004). This does not mean that disabled people might not need support and services to meet their needs; however, there are differences in perceiving care as support or as a burden, or in allowing people with a disability and their carers agency in the control of their lives (Roulstone and Prideaux, 2012). This was reflected in Noor’s words “they were surprised…[but] they did not hurt my feelings”, indicating the kind of support she needed was acceptance and support.

Rawan’s discussion of social support was again illustrated as she described the teachers and professionals in Waleed’s mainstream school:

I was lucky. I started working at a boys’ school, so I took Waleed with me. I was close to his teacher. The teacher told me: “I am teaching, and your son is in another world”. I asked her to keep an eye on Waleed, because his sister had learning difficulties. So, I had the teacher’s support. The education specialist in the school was also supportive and close to me. I was also in the same school. So, I continued to ask the teacher about Waleed, until we were sure he had learning difficulties. Then, I took him to a special needs school. I mean, the support from my work helped me. Thanks be to God.

Rawan's relationships with teachers and school specialists was essential in her experiences of social support. Rawan’s idea of social support can be interpreted as creating allies, which is defined as getting support from people who have privilege and power because of their position. Evans et al. (2005) asserted that creating an ally is not simply about a positive attitude towards disabled people, but also about communicating effectively with disabled people, to be educated and aware about the disability and the needs of disabled people. Their statements were similar to how Rawan created allies, not only within her family, but also with education professionals with whom she engaged in conversation about Waleed’s different learning. She was able to connect with the teacher and explain Waleed's difficulties to the school, which prevented her from experiencing negative comments, as with her first story with her daughter (from an earlier story). Thus, Rawan's ways of creating allies helped to create a positive and supportive experience for her.

The final type of social support was offered by the advocacy group. Reem said:

I used to know an Egyptian mother, through talking together I knew that her child had a disability. She knew of an advocacy group. They gathered every month. Mothers of children with disabilities gathered and each told her story as a support. I told her that I had registered because I had a son with the same disability. This was the first time I knew the group. I continued attending the meetings. Each person described her experiences with her son. We discussed the support they received, the best doctors, and the names of good schools. They talked about the difficulties they faced.

Reem illustrated the way sharing stories and experiences was a source of support. The group was a place for sharing information and challenges, as well as suggestions for solutions. This is similar to the findings in Green et al. (2011) on the experience of parents bringing up a child with a disability, They found a support community was effective against structural and attitude barriers that put an emotional and physical barrier on the parents. However, Reem’s story demonstrated that despite the advocacy group’s efforts, she only encountered the group by accident. As a background to this story in the Kuwaiti context, there are some advocacy groups that help parents and advocate for their rights. They work as representatives of parents’ needs and rights in PADA (Alraimedia, 2010). However, few parents like Reem, who faced difficulties, know about an advocacy group for ADHD families. Further, Reem referred to an advocacy group of mothers, not fathers, which indicates that these groups were constructed only for the mothers. This is understandable, as mothers are the ones who are blamed and expected to take care of their children’s academic challenges. However, the support might also consider fathers who may want to be involved and understand their children with ADHD. The results revealed that the experiences of parents with social support were positive, as they gained different ideas of support than parents without a social group support. However, all the parents referred to the importance of communication and effective listening to the parents’ needs and requirements.

# 6.3 Psycho-emotional effects on children and parents' lives from institution and society -barriers that affect what children and parents can do and can be

The third sub-theme concerns relational and non-material social barriers. By this, I am referring to society’s negative attitudes towards children’s impairments. These attitudes are due to stereotypes and expectations of childhood in society that might construct a barrier which limits the family’s participation in the social context. The stigma also makes parents feel less valuable and causes upset for themselves and their children (Thomas, 1999). This sub-theme was illustrated by the parents’ stories. They experienced continuous negative feelings and behavioural attitudes from family, extended family, teachers and the community, which led to them feeling frustrated and ashamed.

This sub-theme was discussed through three types of stories. Stories about society misunderstanding and having negative attitudes to ADHD as a barrier for the family were discussed repeatedly. This type of story demonstrates the way society lacks knowledge about ADHD, which might lead to negative attitudes towards children living with it and placing blame for it on their mothers. Stories about ‘the Disability Certificate and its stigma as a barrier for the family’ highlight cultural values related to invisible disability as a factor that can lead to devaluing a child’s ability and shaming the families of children with ADHD. Lastly, stories about school and stigmatisation as an emotional barrier for the family demonstrated the expectations for pupil’s behaviour, a source of emotional burden on the children and their mothers, as well as a barrier to continuing education for children with ADHD.

## 6.3.1 Society misunderstanding and negative attitudes as a barrier for the family

The parents experienced negative attitudes from society towards their children with ADHD, which not only affected their emotional well-being, but also their ideas about themselves and their children. For example, Marleen discussed her fear of her ex-husband’s family’s reaction:

They are good people, but I do not talk [about her children’s impairment] because of the stereotypes here in Kuwait. I do not talk to many people about it. Sometimes they do not accept people with ADHD or dyslexia. Or they look at them differently.

Marleen expressed her reticence over her children’s impairment because of the social stereotypes about children with ADHD that would effectively devalue her children. She demonstrates what Reeve (2004) refers to as ‘internalised oppression’, as she accepts the negative attitudes of her former husband’s family and society, attitudes that her children might encounter if she exposes their impairment. Despite her fear of her children being seen as ‘other’, she thinks of her extended family as ‘good people’. This might indicate that she understands her family’s behaviour to be a ‘normal’ reaction based on negative stereotypes.

Additionally, Marleen’s fear of telling her family about her children’s impairment supports Thomas’ (1999) argument about the psycho-emotional barrier associated with hidden disabilities like ADHD. Individuals with hidden impairments might not face disablism, but they are always at risk of being revealed, which leads to the psycho-emotional feeling of being exposed (Thomas, 1999). Moreover, the attitude of others not only causes these psycho-emotional responses, but also restricts their activities (Green et al., 2011; Reeve, 2004). This applies to Marleen’s experiences, as her fear of her children being exposed limited her emotional support from her extended family. Hiding the children’s ADHD ‘diagnosis’was an option for Marleen because of the circumstances of her divorce, which meant that she was in less contact with the extended family. In another part of her story, she stated, ‘I did not have anyone’. She only had one close friend, who had a child with autism. This made it easier for her to hide her children’s condition.

Hiding an impairment is difficult for some parents who encounter negative attitudes from their extended family. Some of the mothers lived with their husband’s families. The extended family’s attitudes towards the child’s impairment affected the psycho-emotional wellbeing of the mother. Farah shared an example of internalised oppression, as she felt ashamed of Ali’s behaviour at family gatherings:

During a family gathering, they could not stand Ali and his behaviour. I mean. I do not blame them. He is my son, and I was barely holding myself together. I mean. The family gets really angry at Ali. I got annoyed. I do not blame them, but at the same time, I feel that it is not his fault. It hurt. I felt he was doing something without noticing that he was annoying them. So, I went to my apartment.

Farah felt that her family rejected Ali’s impairment; their attitude towards Ali hurt her emotionally as his mother. The tension in the story was clear, demonstrated by her words, ‘I do not blame them; he is my son and I was barely holding myself together’ and ‘it hurt. I felt he was doing something without noticing’, reflecting the internalised oppression of social expectations. She recognises that Ali is not responsible for his behaviour, but still does not want to disturb others. However, Farah decided to resist her extended family’s negative attitude by retreating from the stigmatising situation. Thoits (2011) interpreted the action of retreat as a kind of resistance; a person will do so to protect the self from being devalued by others. Farah expressed her confusion as she accepted her family’s attitude towards Ali’s behaviour. Yet at the same time, the negative reaction of getting ‘really angry at him’ still hurt, so she chose to avoid it by withdrawing.

Parents have not always been ‘passive victims’ (Thomas, 1999) of ‘disablism’; they empower themselves against a society that devalues and has a negative understanding of impairment. Take, for example, Sara’s dialogue with her son’s (Bader) uncle about the child’s behaviour:

Bader is hyperactive, and sometimes his behaviour is seen as lacking respect because he likes to laugh. When Bader starts playing and laughing with his uncle, it gets out of control. His uncle started to get angry and started yelling. My son starts talking back to his uncle and becomes disrespectful. The (social) pressure on me increased because some of the household members, like his uncle, said that he was not raised well. I waited until Bader left the room and then I spoke to his uncle. I told him, ‘You know Bader, he was raised in this house. My son is not a stranger. Bader has been with you for years and you know Bader likes to laugh. You are older. You are the one who should establish boundaries. Do not laugh and play with him because sometimes Bader forgets that you are his uncle and will go too far with the joke.’ (she means his behaviour will start becoming disrespectful)

Sara described the emotional burden she encountered because of Bader’s behaviour, which made his uncle doubt her role as a mother. However, she illustrates resistance to the stigma, describing the way she educated Bader’s uncle about her son’s behaviour. This was similar to a study by Manage et al. (2017) on parents’ strategies for resisting stigma. She demonstrated that some parents challenge stigma by using information about impairment to embarrass and cause discomfort to those that stigmatise. Using education strategies in response to stigma reverses the blame and instead places it on the uncle, who lacks the ability to understand ADHD and cope with the child’s playful character. Sara’s stories indicate that parents with enough information about ADHD could resist stigma and advocate for better social interactions with their children (Green et al., 2011). Education strategies were also expressed in Laila’s everyday practices in her husband’s family home:

At first, they rejected the ‘diagnosis’, but I told the family because I wanted them to know and understand as we live in the same house. I want them to understand Nasser's condition. They rejected my decision, but I did what was best for Nasser. Additionally, the way they interacted with Nasser made it clear that they did not understand his behaviour. They have to excuse him because he has ADHD. For example, his grandmother refused to understand that Nasser had a problem. If he does anything wrong, she punishes him like any other child. I keep reminding my family to excuse Nasser.

Laila did not hesitate to tell her husband’s extended family about her child’s ADHD. By telling her family, she advocated for better understanding and social interactions that considered her child’s ‘symptoms’. Laila’s attitude could be interpreted as an attempt to create ‘the wise’. Goffman (1963) defined the wise as social support individuals related to individuals living with a disability. For Laila, the wise could have been her own extended family as they were supposed to support her and her son. Despite her efforts, it seems that offering her family information and education was not enough to prevent Laila (or Sara) from feeling frustrated or hurt by society’s negative attitudes.

Based on Laila, Sara and Farah’s stories, it seems that the home is a significant factor in creating stigma. The parents exclusively linked their place of living to the stigma they face. One source of the stigma that impacts the children and their parents comes from their family and relatives. Farah imagines a comfortable environment in a private home where her child could be who he is without blame. Both mothers would seem to be less stigmatised in private houses. I discussed how social welfare provides a home for Kuwaiti citizens, while disabled people are a priority for such support (Kuwait’s Constitution, 1962). However, not all disabled people are privileged with the ability to facilitate getting a home faster than other Kuwaiti citizens. ADHD is understood under the Law of Disability no. 08 to be a learning disability and children with ADHD are only supported academically. The parents seemed to face stigma from the people they live with. Thinking about ADHD as an impairment and learning difficulty, without considering the social barriers that limit strategies used to decrease the stigma goes beyond awareness. Awareness of ADHD was put into action in 2011, but it will take much longer to influence society and its values, according to which the behaviours associated with ADHD are merely disrespectful and naughty (Alamal, 2015). Facilitating parents’ chances of supporting their children while living in private homes might decrease the stigma that comes with social and society awareness.

## 6.3.2 School and stigmatisation as an emotional barrier for the family

The parents also discussed the severely distressing emotions caused by education professional’s attitudes towards their child’s behaviour. Unlike the previous experiences with family members, where impairment was a cause of shame and frustration, the stories of school stigma focus on the school’s negative attitude influencing the parents or what Thomas (1999) called ''disablism''. For example, Noor’s story illustrated Fahad’s first year in nursery:

Every day, Fahad came back from school crying. He’s smart and understood that the school did not accept him. Fahad has love and acceptance at home; suddenly these people rejected him. This affected his well-being. It was hard for me to see Fahad rejected at school and feel depressed. I wished to die before I witnessed this situation.

Exclusion from the environment can make people with disabilities feel unwelcome or different from others (Reeve, 2004). Yet, rejection from school affected the psycho-emotional states of not just the children but also their parents. Noor described Fahad’s reaction to rejection from the school, but the impact of the school’s negative attitudes was also the reason for her emotional distress. The school’s failure to cope with a child’s impairment makes them feel bad about themselves, unwanted and unloved. The mothers had to spend energy supporting her child emotionally due to the stigma caused by the school, which did not accept their differences, instead of enjoying the parenting experience.

In a similar situation, Marleen talked about an episode in the car with Omar after being expelled from school:

They called me and I would pick up Omar. We would talk about what he did at school or how he did not pay attention in class. When I was on the way home, Omar would look at me waiting for me to say something and I would look at him and say it is not your fault. I said they should have been better prepared to help you and you still have to keep learning and keep working.

Marleen described the barrier caused by lack of competence in special needs schools and the inability to get Omar's attention, not the child’s behaviour. Her observation supports Toye et al. 's (2019) study on educational professionals from Scotland, which illustrated that educational professionals could increase stigmatising beliefs and exclusionary attitudes towards children with ADHD as a result of not acknowledging ADHD. Marleen painted a picture of Omar’s behaviour, which might reflect the guilt that her son felt after being expelled. Omar’s behaviour could be seen as a sign of internalised oppression, as he blamed himself for being expelled from the school (Reeve, 2004). However, Marleen’s attitude, emotionally supporting and encouraging her son against the stigma that he faced from an unprepared school, represents resistance to internalised oppression (Reeve, 2004). Throughout both stories, Marleen believes that the problem with the schools is a lack of tolerance for the children’s differences. The comparison between the two stories also demonstrates that both mainstream schools and special needs schools do not have enough awareness of ADHD, which puts an emotional burden on families (Toye et al., 2019).

## 6.3.3 Disability certificate and stigma as a barrier for the family

The parents’ stories also demonstrated that the disability certificate was more stigmatised than the label of ADHD, which led the parents to live in fear of exposing the disability certificate. ADHD is a label given after an assessment in a children’s psychiatric clinic. A disability certificate is considered a requirement for accessing the disability support system. The parents described the different cultural meanings between the label and certificate in relation to stigma. For example, Laila and Ahmad reflected on their decision to get a disability certificate:

Laila: I did not want to get [the disability certificate], but I had to because I wanted to move him to a special needs school. It was a condition (for the disability system support). I did not want to go to PADA and get Nasser this kind of certificate. Society and people here do not understand [learning difficulties]. I would not understand that there is a disability such as this without talking to a specialist. Nasser is very normal, but he is naughty. We thought he was just naughty.

Ahmad: I mean, [in Kuwait], someone who has a disability certificate is understood as mad. They do not know how to understand the disability. Nasser just has learning difficulties.

Laila: There are lots of learning difficulties. Why are they considered a disability? It hurts.

Laila and Ahmad were confused, caught between the necessity of a disability certificate for their son Nasser to get support and the fear of society’s understanding of a disability certificate. The parents’ fear and confusion were due to the differences in the social meaning of the ADHD diagnosis and the disability certificate. To give a bit of background and understand the parents’ fears, the meaning of disability in Arab culture depends on the Arabic language, as disability refers to a biological, mental or physical limitation (Hagrass, 2005). However, as Ahmad described, children with ADHD usually appear typical, while they present difficulties in learning. The invisibility of the impairment among children with ADHD in a society that understands disability as a physical limitation leads to considering children with ADHD to be mentally impaired.

There is a problem with viewing mental impairment as a consequence of a disability certificate. Gharaibeh (2009) suggested that this impairment is more stigmatising than a physical or sensory impairment. An individual with a mental impairment is seen as less mature and lacking the ability to think rationally, to work or to be married (Eissa Saad and Borowska-Beszta, 2019). This was very noticeable, as parents mentioned that calling children with ADHD disabled might associate their mild impairment with stigmatising attributes such as ‘madness’, which have different meanings in Arabic. One of the meanings of ‘madness’ is mentally retarded or an idiot, which is usually used to refer to people with a mental impairment (Eissa Saad and Borowska-Beszta, 2019).

The parent’s story is in line with the criticisms of the social model of a unified focus on disability without considering the impairment (Morris, 1992). Focusing on disability issues in general might ignore the issues of minority groups, such as those diagnosed with ADHD. Reflecting on the Kuwaiti context, a disability certificate was an important step in ensuring the legitimacy of children seeking support (Alwatan, 2010). However, Laila questioned the reason for calling them disabled. She sheds light on the importance of understanding the cultural and social contexts when considering a disability certificate as a condition for support (Griffiths et al., 2005). The negative stigma attached to the disability certificates for children with ADHD is suggestive of a ‘non-material barrier’ that parents have to go through to get the necessary support (Thomas, 1999). However, the sources of stigma that parents face are systemic structural barriers from the disability support system that made the families afraid of revealing the certificate of disability.

Unlike Laila and Ahmed who were internalising the possible oppression, Reem stated:

I accessed the system for educational support. I still want their support for university. Everyone told me to close Zyad’s file in the disability support system, but I told them, ‘Why should I?' The government supports him, and Zyad really needs that support. I am not taking something forbidden. He will still need support from the university. He could have special support. The university could help him. Why should I close his file? They say, ‘What if people knew? Zyad cannot get married if they know he is disabled.’

Reem was facing a negative reaction from the community about her decision to get a disability certificate to access support. Building on what was previously discussed in Ahmad and Laila’s example of living with a disability in an Arab country, society assumes that the impairment is a sign of a hereditary defect, which affects the social standing of the family and excludes its members from marriage (Al-Thakeb, 1985). Despite Reem’s rational stance regarding Zyad’s right to support from the government, the disability certificate influenced ‘what matters most’ in terms of childhood expectations (Yang et al., 2013). Yang illustrates that ‘what matters most’ happens when stigma affects a person’s ability to fulfil the pressures of the social state or the ability to play an essential role, such as marriage or work in Arabic society. Reem’s story reflects the role that children play in society, which is the social and economic stability that the label of disability threatens (Hammad et al., 1999). She discussed marriage which is a valuable role and considered particularly important. Reem’s experience reflects Laila and Ahmad’s fear of the stigma resulting from the disability certificate, as it could extend throughout the child’s life in the future.

# 6.4 Conclusion

This chapter explores the experience of parents of children with ADHD in dealing with their children’s disability in the social context. It focuses on the social environment and social attitudes as barriers that disadvantage and exclude families with children with ADHD from social participation. It started by discussing issues with the quality of special needs schools, which caused the parents an emotional burden and limited the ability of children with ADHD to get an appropriate education. Moreover, parents encountered a financial burden because of insufficient support and services for children with ADHD, with the Law of Disability no. 08 showing a lack of consideration to families of children with disability needs and circumstances. Additionally, the chapter discussed the lack of effective communication with parents from professionals and institutions (health and education). The stories illustrate that despite the availability of support and services, parents could get lost in the process of accessing support. It also highlights the role of information and group support to empower parents to solve challenges that they encounter in everyday life. Lastly, it demonstrates the psycho-emotional burden that parents encounter because of misunderstandings and negative attitudes from institutions and society.

The chapter addressed some cultural values and environmental and contextual factors that influence the manifestation of the social barriers that disadvantage parents of children with ADHD. The next chapter will expand the discussion of cultural values and beliefs. However, while this chapter focused on the social aspects of the parents' experience of parenting a child with ADHD, the upcoming chapter addresses the personal and private aspects of parents' understanding of the impairment.

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# **Chapter 7**

# **ADHD and impairment from a social relational model of disability**

Introduction

This chapter discusses the parents’ perspective on impairment created from their experience of living with a child with ADHD. Section 2.3.2.1 discussed British disability studies, showing that *impairment* is broadly understood as limitation of the biological function of an individual, while in contrast, *disability* is understood as a social or physical restriction that prevents inclusion in society (UPIAS and Disability Alliance, 1976). However, there have been some criticisms regarding the discussion of impairment that fall outside the scope of the materialist social model (Thomas, 1999; French and Swain, 2000). For example, social relational models have been used to argue that a disability is also a product of the interaction between the social environment and impairment (Reindal, 2008). Feminists scholars such as Morris (1992) and Thomas (1999) assert that the materialist social model focuses on structural barriers while ignoring the personal aspects of disability (Cameron, 2014). These scholars did not argue for abandoning the social model. Rather, they add two ideas to the social model, that an impairment could cause disability, and the investigation of the disabled people's personal and private experience with impairment is essential in understanding disability. Thus, further discussion of impairment is important to highlight its relationship to disability and to illustrate how disabled people constitute their own understanding of impairment (Reindal, 2008).

Thomas (1999, p.133) asserted that "[i]mpairment is, in large measure, a social phenomenon because it is socially produced, involving the interaction of real biological and social factors." ''Social factors'' is understood in this chapter as the cultural or social environment. For example, what is considered lack of attention and hyperactivity in one Kuwaiti social environment might not be in another. By these definitions, impairments are always biosocial in character (Thomas, 2012, p.211).

Thomas (2004) argued that disability affects disabled people from inside and outside. From the inside, society's ideas of impairment could make disabled people feel worthless, restricting what they can do or how they think about themselves. For example, from the inside, a child with ADHD might not want to go to mainstream school because of how they think about the negative response towards their impairment. From the outside, social ideas about impairment could lead to a negative attitude toward disabled people as an effect of their impairment, which restricts what they can do. For example, a child with ADHD might be refused entry to a school because of their impairment. Impairment is a combination of how disabled people think about their impairment and how impairment is negatively represented in the cultural and social contexts. Thus, some disabled people might personally accept the negative representation of their impairment in their society and culture, which leads to restricting what they do and how they feel, as illustrated in Chapter 6. Others might resist a negative representation and develop a different understanding of their impairment, the latter is the focus of the current chapter. The concept of impairment can be further explored by looking at the social and cultural factors and their effect on the parents' lives and their development of ideas about ADHD.

I will also discuss impairment understood through the affirmative model, which was established to address the social perspective of impairment as a personal tragedy. Swain and French (2000) argued that the experience of impairment might not be tragic but valuable. They did not deny that living with an impairment might be difficult, but this is not all the impairment experience is about (Cameron, 2014). The affirmative model developed from the materialist model of disability (Cameron, 2014). It understands impairment as “physical, sensory and intellectual differences to be expected and respected on [their] own term[s] in a diverse society” (Cameron, 2008, p.24). This definition obviously differs from that in the materialist social model, in which impairment is only seen as ‘the functional limitation within the individual caused by physical, mental, or sensory impairment’ (Barnes 1991, pp.2-3), whereas the affirmative model added the idea of impairment as the *differences* within an individual from others in society (Cameron, 2014). Impairment is explored in this chapter using the affirmative model by highlighting how disabled people, or in this current research, the parents of children with ADHD, understood impairment from their own experience in a way that challenged the tragic cultural perception of impairment (Swain and French, 2000). Cameron (2014) suggested that impairment might not be negative or a problem, but the social reaction to impaired people is because they see impairment as deviant from the social norm. The model helps show disability encounters in everyday interactions in society because disabled people have to act in certain ways, such as confirming the social expectation of impairment as tragic and dependent.

After reading the parents’ stories of their experience with impairment, the approaches in this chapter were selected to reflect the parents’ individual and collective stories about their children’s impairment that the relational model, which focuses on social and structural barriers in the environment, failed to address (Cameron, 2014). Thus, alternative ways of understanding impairment are suggested that could be beneficial for discovering how to better support differences of children with ADHD instead of looking at ADHD as a deficiency.

The overarching theme of this chapter is parents’ personal ideas of impairment, in relation to children with ADHD. These differ from the biomedical perspective in the sense that parents believe that their children have an impairment caused by biological factors, but they do not necessarily regard these impairments as a ‘disorder’. However, parents' understanding of their children’s behaviours, which they attribute to them having an impairment (ADHD), is not fixed or stable, but influenced by their personal experience and background within the social and cultural context.

The overarching theme is developed through two sub-themes. The first sub-theme, “Culture and religion in understanding ADHD as an impairment,” discusses how parents perceive impairment, specifically in relation to ADHD, based on their religious beliefs and cultural values (explained below). It focuses on instances when parents used their religious beliefs and cultural values to understand the challenges of impairment and/or impairment effects that sometimes cause disability. The second sub-theme, “Diversity affirmation,” explores ways in which the parents positively negotiate what they see as differences from childhood norms in the impairment of children with ADHD. It focuses on the events in the parents’ stories where parents' understanding of their children’s behaviour challenged the negative biomedical perspective and social understanding of ADHD. These themes are discussed in detail below.

## 7.1 Culture and religion in understanding ADHD as an impairment

The first sub-theme focuses on the influence of Arab culture and the Islamic religion on parents’ ideas of ADHD as an impairment. Kuwait culture has many elements such as religion, customs, language and media. The current research focuses on the religion and customs of Arab culture following the parents' stories. *Arab culture* refers totheshared values and beliefs that build and unify the Arab identity and culture. The Islamic religion is based on the teachings that Muslims take from the Qur’an and the *Sunnah* about all aspects of life (see more in Chapter 2, Section 2.2.4). In Islamic teaching, impairment is considered part of ordinary human life (Al-Aoufi et al., 2012). In Arab culture, however, impairment is viewed as a threat to a family’s reputation, as Arab culture asserts and values conformity to community (Hammad et al., 1999). Islamic religion and Arab culture have a robust connection that is sometimes complicated to talk about (Al-Qaradawi, 2009). For example, both Arab culture and Islam share Arabic to describe and understand disability and impairment (Turmusani,1999). As I discuss in Chapter 4, language could be a tool for describing and a source of meaning (Al-Amer et al., 2016). I think the similarity in the language between the two elements of the culture creates a misunderstanding. To elaborate, some words and values common in Arabic countries and familiar to Arabic people might be traditional, but they are thought to be Islamic teaching and vice versa. Despite the similarity between culture in Arab countries, the economic, political and social aspects of Arab countries differ, leading to different interpretations of Islamic teaching and Arab customs (Al-Dakhil, 2008). Thus, the analysis of Islam and Arab customs and/or beliefs reflects Kuwaiti society, but might have some relevance to other Arab countries (see Chapter 2, Section 2.2.4).

The main idea behind this sub-themes is that despite the dominance of the biomedical perspective and the social challenges faced in the experience of parenting a child with ADHD, the Islamic faith and Arab cultural norms of childhood were major factors in parents’ understanding of impairment. This sub-theme can be seen in the parents’ stories, where they reflected on their experience as a parent of a child with ADHD.

However, parents combined the two aspects of culture to different degrees. Thus, the sub-theme highlights the ways in which parents used Islamic beliefs and Arab values to account for their children’s impairment and/or impairment effects. It shows the following three ways in which parents attempt to facilitate their role as parents despite the social challenges. First, the parents used their Islamic faith to accept the impairment and also to support themselves emotionally to overcome the social challenges, seen in ‘Religious explanation of ADHD’. Second, the parents drew on both Islamic teaching and Arab values to negotiate the differences and value of the impairment, seen in ‘Challenging childhood through religious beliefs’. Finally, parents used Arabic cultural values to explain the impairment and the social challenges associated with it, seen in ‘Children with ADHD are naughty children’.

### 7.1.1 Religion explanation of ADHD

Some parents believed that ADHD was a test from God. In Islam, life is a test that Muslim go through to be evaluated in the afterlife (Al-Thakeb 1985). There is no perfect life, but all people are tested in one way or another with money, health, or children (Al-Thakeb, 1985). For parents of children with ADHD, the impairment was a test that parent’s responded to differently. For example, Yousef said:

When I see my child’s hyperactive behaviour, I feel happy. That is because once I was going to the psychiatric hospital for his treatment, I saw medical conditions that broke my heart. I said thank you to God. Sometimes, I see girls and boys in such conditions that their mother has barely got herself together. I feel their mother will explode. So, I think this is a test from God. Praise be upon Him, He gave me the easiest test. So, I thank God for Jacob's condition.

Through his story about the hospital, Yousef believed that the impairment of ADHD and its effects of hyperactive behaviour were a test from God. He compares what he sees as the burden of raising certain other children with those of his own and concludes that dealing with ADHD is easier. His words, “He gave me the easier job” indicating his Islamic religious perspective of looking at impairment as God’s plan. Bhatty et al. (2009) illustrate that Muslims understand impairment as a trial and a way to strengthen their faith in God, while the way to salvation comes from praying to God. This was illustrated in his response of, “thank God for ADHD rather than other impairments”. Yousef’s comparison underpins the explanation of health and illness from an Islamic perspective in Bhatty et al (2009), which sees them as a “continuum of being”. This means that health and illness are not static, but something that could change at any time. Yousef thought that his son’s impairment could be worse, therefore he was thankful to God.

Moreover, the impairment associated with ADHD is having to decide to put children on medication. Yousef’s story takes place in a hospital, where he is looking for medication for Jacob’s impairment. His beliefs about the impairment as God’s bidding did not stop him from seeing the impairment as a ‘biomedical disorder’ that needed ‘treatment’. Muslims accept impairments from God, but also look for ways to remove the impairments and their effects. This belief follows the prophet Mohammad when he says, “Allah has not sent down any disease without also sending the cure for it” (Al Asqlani, 1986, p.5354, cited in Al-Aoufi et al., 2012). Yousef’s story illustrates the interaction between his idea of ADHD impairment as a medical condition that needs ‘treatment’ and the idea that a child’s impairment from ADHD is a test from God.

### 7.1.2 Religious belief as a support

Another way of seeing the impairment associated with ADHD is through religious belief, which is that it is a blessing from God. Parents believe that if God predetermined impairment for their children, he also blessed them with many advantages. The parents thought that impairment effects were not always negative. Parenting a child with ADHD might be disadvantaged in one way and blessed in another way. For example, Farah said:

Ali is kind, sympathetic, and makes you laugh. He feels me. You might be surprised but Ali does feel me. I told people to praise God, he gave Ali something [ADHD], but he also put something in Ali that made me be patient with his behaviour. Ali is so kind in a way that he can sympathise and feel if I am sad or happy. I mean I could be feeling sad from the inside and Ali will say, “Mama what is wrong? What is wrong with your face?'” I mean I feel that he can feel my emotions.

In earlier stories, Farah says that raising Ali with ADHD was a burden, yet in this story she was describing the way that the constant care for Ali makes her very close to him. She portrays Ali as highly emotionally intelligent, as he was “sympathetic” toward his mother. However, the way she talks, one might think she feels that Ali’s impairment is a blessing in some ways. Words like, “praise God, he gave Ali something [ADHD], but he also put something in Ali that made me be patient with his behaviour” reflect Muslims’ belief in God’s justice. This is consistent with the argument of Bazna and Hatab (2005) that Muslim society sees disability as something inevitable from God that has a moral and religion purpose.

The moral purpose in Farah’s stories is that as a result of impairment, she has been blessed with a child who can feel her and support her emotionally, and so she was discussing the impairment effects of ADHD. The kind character that comes with Ali’s impairment helps Farah to be patient with the extensive role she plays as a mother. Acceptance and patience toward God and fate is a virtue according to Islamic teaching. Al-Aoufi et al. (2012) argued that being caring and patient with people with disabilities is linked to the principle of reward and punishment. Showing patience and caring for people with disadvantages in their lives will be rewarded in the afterlife (Al-Aoufi et al., 2012). These principles were also shared by Reem’s ideas of the effects of Zyad’s impairment:

I always pray and say, “God, you did not give Zyad to me to suffer. You gave him to me so I can enjoy my life with him”. This was my prayer. I want to enjoy life with Zyad, not suffer. It taught me to be patient and to accept him with all his defects. You do not see the bad side only; you have to see the good side.

Reem illustrates acceptance of the impairments associated with ADHD, whether they are good or bad. For her, a child with or without ADHD is a blessing from God that a mother should be thankful for. In her earlier stories about her son, she describes him as socially accepted and loved by his friends, but with academic problems in school. She thinks that despite the impairment, children are given by God to parents to enjoy their parenthood and learn from them. Reem was discussing the effect of the impairment of her child with ADHD on her role as a mother and on her life. Her idea about childhood is based on the Islamic perspective of children as gifts from God (Hamzah, 2019). Islamic teaching advocates for (and trusts) parents to appreciate and nurture this gift with Islamic principles (Hamzah, 2019). Similar to Farah, she thinks the way to enjoy God’s gifts and blessings is through patience and acceptance. For her, this acceptance includes the good and the bad of her child’s impairment.

In general, the examples above indicate that the social-relational model idea of impairment could explain parents' ideas of impairment concerning ADHD as socio-biological (Thomas, 1999). Chapter 5 illustrated that impairment is thought of from a biomedical perspective. Here, the parents highlight the social and cultural aspects of the impairment. They illustrate the role of religion in understanding the challenges of parenting a child with an impairment. The parents' stories illustrate how parents' faith might help them alter negative ideas about how the child's behaviour impacts on their lives and attend to the positive idea of having a child with ADHD.

Additionally, the parents' acceptance of both sides of an impairment underpinned the affirmative model of disability. As I explained above, the affirmative model is not about just the positive or arguing that impairment always has to be negative, but about discussing the impairment differently than being tragic (Cameron, 2014). In reflecting on the above parents' ideas, parents were not denying the difficulty of parenting a child with ADHD and the challenges faced in the social context because of the behaviour. However, they also saw the positive side of having a child with ADHD.

### 7.1.3 ADHD as an impairment from God to be thankful for

Lastly, some parents thought of the impairment as something to be thankful for. Parents’ comparison of the difficulty of living with their children with ADHD and the difficulties that come with other impairments led them to appreciate that their children were blessed with health. For example, Sara said:

I said to myself, “This is not the end of the world”. I am seeing other parents who have worse problems than my problem (with ADHD). It is nothing compared to their problems. Thanks be to God. It is true that ADHD is causing a lot of problems. However, thanks be to God, Bader does not have cognitive defects and he is achieving academically. I always say thank you to God. It gives me acceptance for Bader and satisfaction with myself. So, I go to sleep and I wake in the morning like nothing happened [meaning the social challenges that have happened].

Sara’s profession as an education specialist exposes her to many challenges that other parents might encounter. She compares her challenges with Bader with the challenges other parents face, and based on this comparison, children with ADHD seem healthy because their impairment does not affect their bodies or their minds. This might be why Sara says “thanks be to God'' in relation to her son. Her ideas about impairment can be explained through Islamic perspectives on health. From an Islamic perspective, health and disability come from God. Despite the degree of disability, it is considered part of the health circle (Bhatty et al, 2009). This means health is not something static; anyone can get a disability or disease. So, Muslims have to be thankful to God, because without his protection, any type of health or disability could be worse.

The idea of health and disability as a circle gives Muslims hope that with God’s help, their lives can be better. For Sara, the understanding of disability from an Islamic perspective helped her to accept her child’s impairment and gave her emotional support with the challenges she faces because of Bader’s behaviour. Sara’s attitudes are consistent with studies on Iranian mothers that show that mothers’ religious positions on impairment as God’s will help them to be optimistic and emotionally supportive toward their child’s impairment (Kermanshahi et al, 2008). Grounding the impairment idea in Islamic principles helped parents see the impairment in a positive way and also gave them support with the social challenges they face based on the impairment. Sara’s understanding of Bader’s impairment and its effects through a religious view created support for her to be calm and more resilient while encountering difficulties.

### 7.1.4 Challenging childhood through religious beliefs

Some parents’ ideas about impairment were optimistic and ambitious, in the sense that parents were very hopeful and positive about the academic achievements and future of their children. Parents believed that ADHD was an impairment that was affecting the children’s academic achievement and behaviour, and yet the parents believed that their impairment would not prevent their children from achieving and being successful. Parents understood that their child’s achievement, because of their impairment, might not be similar to society’s expectation of achievement, but it could open new possibilities. An example of thinking positively was illustrated through Rawan’s description of her children’s impairment and her expectation of their success and achievement in the present and the future. She said:

I strongly believe in my children’s ability. I mean, sometimes I say to myself, ‘So what, they have difficulty academically, they have other ability in God willing. They are brave and they have fluency in communication. So, they are fine. They can learn and succeed without getting full marks’. I do not want to say this in front of my children because I want them to work hard and succeed. Yet, I say it to myself so I get satisfaction. I mean they are successful in their social relationships and in making friends that love them. They also have a lot of skills. Some of them draw while others have photography skills. It is not important to be academically superior.

Rawan’s story was a good example to illustrate the way Islamic and Arabic cultural values work together to construct the parents’ understanding of the impairment of their children with ADHD. Arabic cultural values are illustrated when Rawan talks about academic achievement. ADHD ‘symptoms’ might affect a child's achievement and performance, which conflicts with Arab society's emphasis on academic achievement (Farah et al, 2009). For her, the children’s abilities are not less valuable than other children’s or society’s interests. This is clear when she mentions that she is proud of her children’s successful social relationships while negotiating the idea of them not being excellent in their academic achievements. Her perspective shows consistency with Arabic cultural values. A positive social state and harmony with society are also considered important values in Arab society (Hammad et al., 1999). Rawan’s idea about her children’s impairment was divided between acceptance of the good skills that come with ADHD and negotiating academic difficulties from the cultural values of academic achievement.

Rawan’s stories could be interpreted as normalising the differences in her children’s achievement. This is based on the argument of Mckeever and Miller (2004) that parents tend to normalise the development and the ability of their children to illustrate their children’s value. Rawan was describing how in addition to her children’s difficulties, they had a lot of valuable capabilities that other children do not have. By describing the ability of her children with ADHD as being artistic or good at photography, she illustrates different perspectives on achievement than the usual Arabic cultural expectation of childhood.

However, Rawan’s words, “they have other ability in God welling” indicate that she was optimistic about her children’s ability. This is because thinking positively about the disability reflects Islamic religious principles that advocate positive attitudes toward people with disabilities (Al-Aoufi, 2012). The Islamic perspective on disability encourages Muslims not to underestimate or generalise about others who are different, but to respect and understand differences between people (Al-Aoufi et al., 2012; Bhatty et al, 2009). Islamic studies of disability illustrate that differences (including disabilities) from a general Islamic view are considered normal and that people are evaluated on spiritual aspects. This teaches people to seek the good within themselves (Bhatty et al, 2009). Rawan’s words might reflect an Islamic orientation in her interpretation of the impairment and choosing to look for positive abilities in her children’s differences. Her faith helps her to see and negotiate the advantages of ADHD in the children's lives, which helps the children to achieve.

### 7.1.5 Conceptualising ‘naughty child’ through a cultural lens

The last type of story about impairment underpins the cultural values of childhood in Arabic culture. The way parents used the term “naughty” presents an interesting idea of the way they understand the values of childhood and use them to develop ideas about the impairment of children with ADHD. It was used continuously by parents to interpret the behaviour of their children; it is interesting, however, that mothers used it differently than fathers. For example, Ahmad said:

Ahmad: Nasser is the only boy among girls. The girls are polite and Nasser has a twin sister. She is also polite. We thought it was the naughtiness of boys. Although the school complained about him, I thought he was just naughty.

From Ahmad’s stories, I noticed different expectations for boys and girls. In his words, “boys’ naughtiness”, there was indication that naughty is normal and stereotypical for boys. Despite complaints from the school, he thought that Nasser’s behaviour was normal according to social expectations of boys. Ahmad’s perspective was shared by the father in another story.

In Farah’s story, she was negotiating the idea of getting a ‘diagnosis’ of ADHD with her husband after encountering challenges from people’s negative reactions to Ali’s behaviour. She refers to the previous period as a “naughty crisis”. She said her husband’s reaction to the behaviour was interesting. He said, “You are exaggerating. Wait for just a period, then the boy will calm down, and this will be a memory”. Farah’s husband’s reaction was interesting because his response indicates carelessness. He might believe that boys who are naughty are normal, and that this will fade as they get older. This father’s view was similar to that of a father from Hong Kong who thought that ADHD behaviour was normal child behaviour or a lack of discipline (Wai-Ming Ho, 2020)

However, in Sara’s stories, the mother used the term naughty in the opposite way to describe the negative response to Bader’s behaviour. She said:

They all say that you just say they have ADHD because they are your children and you accept them. People always interpret Bader's behaviour as naughty. For example, Bader used to have a friend from outside our family. Bader used to go to their house to play with him. However, suddenly my son stopped going to their house. Maybe because the mother of Bader’s friend thought that my son was naughty. So his friend started coming to our house. However, even my mother-in-law asked Bader’s friend not to come. She said to her son: “do not let your son go to [his friend]”. They would not accept Bader.

Sara’s stories indicates the use of the term naughtiness in a negative way to describe Bader’s impaired behaviour. This was interpreted from the neighbour’s response to Sara’s son’s behaviour. She interprets other people’s reactions to Bader’s behaviour as rejection because of his naughtiness. In comparison to Ahmad’s stories, naughty behaviour was not accepted by society. Sara used the same discourse about the cultural interpretation of the behaviour of a child with ADHD.

However, most of the characters in the stories were mothers that did not accept the naughtiness of Bader. It seems there are differences in the amount of tolerance between fathers and mothers toward the naughtiness of boys. The evaluation of children's behaviour as deviant depends on the cultural values system and expectations of a certain society (Timimi, 2005). However, from the stories, the evaluation and interpretation differ between fathers and mothers in the same culture and context. The stories show consistency with Alazemi (2010) observing the difference between fathers and mothers. He suggested that differences in stress between fathers and mothers towards children with learning difficulties was linked to limited engagement in the parenting process (Alazemi, 2010). This could apply to the different tolerance levels of parents to the children’s naughty behaviour. Fathers might be less engaged with their children than mothers or teachers, so they are less likely to witness the naughty behaviour in their children or be blamed for the behaviour. This supports Olsvold (2019) on fathers’ perspectives on ADHD ‘symptoms’, which posited that fathers felt an emotional burden because of their children's behaviours that did not show consistency with normative expectations in a situation where they were held responsible for the children's behaviour. Unlike mothers who are held more responsible for their children’s behaviour and are often blamed for it (Dwairy, 2010).

## 7.2 Diversity affirmation

The second sub-theme in this chapter focuses on parents’ ideas about ADHD that challenge the negative social perception of children with ADHD. It explores stories in which parents used ‘symptoms’ or labels of ADHD to describe the different influence of ADHD behaviour on their children’s lives. The analysis focuses on the tension in the parents’ stories between the positive aspects of ADHD from their experience and the negative social perception of ADHD as deviant from the social norms of childhood.

It is important to acknowledge that this sub-theme draws on the assumptions of the affirmative model to explain the stories, with some influence from neurodiversity studies (see Chapter 2, Section 2.3.2.3), which believes that ADHD is a difference in the brain and not a disorder (Armstrong, 2010). This assumption of neurodiversity may help to understand the strength of students with ADHD in order to create a positive environment that enhances their ability (Armstrong, 2010). It may also improve social attitudes towards ADHD and decrease its stigma (Armstrong, 2010). However, this research does not contribute to the validation of the neurological claim that the brain is just different in ADHD (Rothstein, 2012), because the aim of this study is to explore the social construction of ADHD and not the reality behind it. Thus, this study focuses on the difference itself, for example, as manifested in different lifestyles or circumstances, that must be respected in social interaction and supported to enhance the abilities of children with ADHD (Cameron, 2014). McWade et al. (2014) reminded us that we explore and utilise the differences in people instead of focusing on creating similar abilities. This sub-themes focuses on presenting various ways of understanding ADHD to support children with ADHD in coping with their difficulties and to help them reach their potential.

For example, Marleen told a story about her experience with Omar’s parents’ day in pre-kindergarten.

Omar was in a small school before kindergarten. It was parents’ and teachers’ day, so I came to watch. The teacher was Arabic. It was an Arabic school, and the teacher's friends were there. They were like osh osh osh [means keep quiet] check out this boy. Omar was running and looking at this and that and not sitting and stuff. Then she asked Omar a question. She wanted to embarrass me in front of other mothers. She asks Omar something. She thought he would keep going and not pay attention. He stopped, he stopped and answered her correctly, and went back to doing what he was doing. I smiled, yeah, because they think if the kids are like that, they are not concentrating. They [children with ADHD] are constantly listening. So, you have to be careful.

Marleen’s story takes place in a school setting, where Omar’s behaviour did not fit the expectations of a normal student. By her description of the behaviour, I can deduce some of the social norms expected of students, who should sit down and pay attention in order to understand and answer the questions asked in the lesson. She portrays the teacher as ignorant of Omar's ability to listen, despite his different behaviour. The teacher was confident in her expectation of his continuous movement impacting Omar’s ability to focus. However, the shift in Marleen’s story as Omar stops and answers serves the purpose of the whole story. I can conclude from the story that a child with different learning behaviour is not inferior to other children. Children with ADHD behaviour might be hyperactive, but that does not influence their ability to focus. When using the neurodiversity perspective to create a positive environment (Armstrong, 2010), Marleen's story might suggest acceptance of the child’s moving around by creating lessons that involve moving the body to include Omar in the class. Marleen’s story also engages the affirmative model, which focuses on illustrating the different ways disabled people (or, in the previous story, the parents) describe their lifestyle in their own words to illustrate disability interacting with impairment and advocating respect (Cameron, 2014). Marleen indicates disability in the teacher’s negative behaviour encounter with her son's different way of learning, because Omar’s impairment contrasts with the social norms of students. She advocated respect and recognition of the different way that Omar learned. In a different setting, Sara tells a story about Bader’s learning habits.

Bader did not sit still. I felt like I was talking to myself. This is why I let Bader study by himself. I got tired of being nervous. If I asked him to sit down, Bader would say, “I am listening”. For example, you are teaching him now, and he keeps walking. You would ask Bader, “what did I say?” He would tell you to keep reading or teaching; you are saying this and that. I told myself maybe he had a good short-term memory, and he just memorised these things. So, after a while, I asked, and he answered me. Bader knew, but he had to keep moving.

I mean, my oldest daughter had to sit in a place where she could be alone. If a fly passed by, she would forget the information. She did not want anyone to come into her room or want to talk to anyone. She would finish her studies and explain them to you. She has to explain them to you.

Bader's style was “let me move”. For most students, you could set a study schedule. For example, today, you have to study Maths and tomorrow Physics. No. For Bader, today, he would study Maths, Arabic, Chemistry and Islamic Religion. Bader would study four subjects in one day. Bader said that he got bored because he did not like the routine. So, one hour or two of Arabic and three hours of Maths. Then, on another day, Bader would continue them. I mean, his style is chaotic. My son has ADHD, and he is chaotic.

Sara describes the different cognitive abilities in children with ADHD. The challenge that Sara encountered was not with Bader’s ability to understand, but with her attempt to fit Bader’s learning style into a standard schedule. She also seemed annoyed by Bader’s chaotic behaviour when she used to teach him. After being emotionally distressed, she finally understood that Bader had a different way of learning. She gives an example by comparing Bader with his sibling who had a more ''standard'' way of learning. The idea that I gained from this story is that a child with ADHD is smart, but the only way to find this out is through accepting the difference in the way their brain works.

Sara’s idea about the learning style of children with ADHD is consistent with the neurodiversity perspective. This advocates celebrating children with learning differences and recognising the strengths when teaching children with ADHD (Armstrong, 2010). Sara's story ended with embracing Bader's learning style, despite it being different from his sibling. Rothstein (2012) argues that we see biological differences in children as either abilities or disabilities based on how we understand the social norms of childhood. In both stories, the mothers used a description of ADHD behaviour to challenge negative stereotypes of ADHD in regard to their children.

However, as I illustrate in Chapter 5, the parents were applying a biomedical perspective because cultural and social conditions in Kuwait make biomedical ideas dominant in discussing and understanding children with ADHD differences. The parents did not use neurological or biological language to describe the differences. The mothers indicated only the children’s condition and ADHD-like behaviour, which differed from that of children without ADHD. Armstrong (2010) explains that the neurodiversity perspective advocates a positive attitude and belief concerning biodiversity – one that values the differences in the brain. The mothers’ descriptions might engage with neurodiversity ideas about the differences, but they were more indicative of different learning styles. The descriptions are more in line with affirmative models (Swain and French, 2000) that advocate not only challenging the normality of children with ADHD, but also asserting their different learning styles.

From the stories above, I conclude that the parents show that exhibiting ADHD behaviour does not weaken their children’s academic performance. This observation contrasts with studies of parents’ experience, which suggest that parents often complain about their children having difficulty in school (Charach and Fernandez, 2013; Wai-Ming Ho, 2020). Ravenscroft et al. (2019) exploring teachers' attitudes toward students with a visual impairment in mainstream elementary schools in Turkey found that teachers tended to show exclusionary attitudes due to negative stereotypes about impairment. Presumptions about students’ abilities prevented the teacher from engaging affirmatively with visually impaired students (Ravenscroft et al., 2019). This is consistent with the mothers’ stories, clarifying that some challenges encountered by children with ADHD in school or in regard to academic achievement might be linked to social norms of learning and childhood. Swain and French (2000) argue that discussing the impairment positively contributes to resisting the stigma of abnormality associated with impairment and contributes to removing the social barriers faced by disabled people. The mothers’ stories indicate a rejection of the idea of their children being lazy or inattentive by clarifying the different ways their children learn. The mothers suggest that ADHD behaviour is only seen negatively because it does not fit the expectations of normal children.

## 7.3 Conclusion

This chapter discussed the parents’ idea of impairment associated with ADHD. It demonstrated how parents construct ideas about living with the ADHD impairment through religion and cultural values. It also highlights the positive benefits of having ADHD. The idea that impairments were viewed differently not just due to Islamic and Arab cultural values, but also by fathers and mothers, highlights gender differences in interpreting the experience of ADHD. The chapter adds another aspect in understanding ADHD between the disability experience and medical impairment.

The next chapter will return to the research questions and conclude the thesis.

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# **Chapter 8**

# **Conclusion**

Introduction

In this chapter, I first answer the research question by discussing the literature and the key concepts from the data in this study. I also explain how the data enhances the existing research related to parenting a child with ADHD (Attention Deficit Hyperactivity Disorder) and disability. Secondly, I explain how the current research contributes theoretically and practically to disability studies, particularly in the Arab and Kuwaiti contexts. Based on the parents’ experiences, I identify suggestions, needs and lessons for parents, policymakers and society. Thereafter, I discuss the theoretical implications of models of disabilities within the Kuwaiti context and the practical implications for disability support systems and services. Finally, I identify the limitations and scope of narrative research, propose suggestions for future research regarding ADHD and disability and conclude the study.

## 8.1 Answering the Research Question

## 8.1.1 Parents’ perspectives on ADHD

Disability rights and support have been the subject of discussion and interest in many countries, including Kuwait. These issues are even more complicated in relation to ADHD because of their ambiguous nature. By this, I mean that although ADHD may be understood as a common ‘disorder’ globally, research on ADHD has not yet identified its biological or neurological causes, as is the case with other disabilities. There is also debate in the literature due to the subjective nature of identifying and assessing ADHD, because it depends on behavioural observation that might be understood differently from one culture to another. This leads to variation in the cross-global understanding of ADHD and the intervention and support needed for children with ADHD. Thus, before thinking about supporting children with ADHD, gaining an understanding of ADHD in context is important.

To complicate the matter, the orientation of some disability studies towards advocating for rights and support comes from the assumption that disability differs from impairment. While impairment refers to the biological body, disability is linked to the social context and environment that disadvantages disabled people. For the current research, this means that in order to understand ADHD in the Kuwaiti context, the focus must be not only on how the impairment aspect of ADHD is understood in Kuwaiti culture, but also on how disability is experienced by children with ADHD and their family’s everyday practice. This is crucial in order to address and promote rights and support that fit the families of children with ADHD in the Kuwaiti context.

Disability studies encourage researchers and policy makers to listen to disabled people, as they are the most eligible spokespersons regarding their impairment and disability encounters. The current research pays attention to parents’ understanding of ADHD based on their experience. This builds on the idea that parents have the most responsibility for their children from a social perspective, and their views are often absent in studies of disability and practice in Kuwait (full discussion in Chapter 1, Section 1.3). This perspective refers to the parents’ ideas reinforcing the norms and values that are influenced by social perspectives on disability and childhood in the Kuwaiti context. The current section focuses on parents’ ideas regarding ADHD and demonstrates their association with the social and cultural context in Kuwait to answer the first research question: How do parents construct their understanding of ADHD?

The parents’ stories showed that their ideas about ADHD were more complex than simply having a biomedical perspective that understands ADHD as a ‘disorder’. The parents’ ideas were analysed drawing on different models of disability revealing that they understood ADHD in a multiplicity of ways: ‘disorder’, ‘deviance’, ‘difference’ and ‘disability’. The parents' stories led me to draw on ideas from the models used to explain their ideas, which were the following: social, social-relational, affirmative and individual (including medical sociology and critical psychology) (see full definition in Chapter 2, Section 2.3). The employment of these models was chosen based on the ideas illustrated by the parents about ADHD.

The most prominent ideas expressed by parents was that they perceived ADHD as a ‘disorder’. As the current research focuses on the social construction of ADHD as a ‘disorder’, this situated the parents’ biomedical idea of ADHD within medical sociology and critical psychology which focus on how the biomedical ideas are constructed and influenced by the social and cultural context. This helped to explore parents’ ideas underpinning the biomedical perspective. Although the parents’ stories indicated that the biomedical perspective of ADHD as a ‘disorder’ dominated their sources of information and the options for intervention that influenced their ideas, parents were continuously questioning and challenging the idea, using their cultural values and beliefs. It was interesting to see the way parents understood and negotiated the biomedical perspective on ADHD using religion and cultural perspectives on childhood and disability. The narrative analysis of the stories helped to highlight these social factors, while other ideas of culture were discussed explicitly when the parents talked about their experiences of living with ADHD. The discussion highlights the importance of understanding the context in which a biomedical understanding of ADHD is used to understand the needs of parents and children. This discussion is new to studies of disability and ADHD in the Kuwaiti context.

The parents’ stories were explored drawing on ideas from medicalisation theory, which advocates promoting an understanding of the medicalisation process, for example ideas around ‘diagnosis’, ‘treatment’ and identifying and assessing behaviour (Rafalovich, 2013). Conrad (2007) explained that the medicalisation of children’s behaviour does not happen in a vacuum and that there are social factors that impact the adoption of a biomedical perspective. Parents started describing their experiences by explaining the behaviour and condition of their children. They often situated their understanding of their children’s behaviour in the biomedical, psychological and cultural contexts of ADHD, and these perspectives overlapped each other. However, the parents rejected psychological and biomedical ideas of behaviours such as difficulty sleeping in children with ADHD which did not apply to their children. Parents used psychological theory only to express the differences in their children’s behaviour, which indicates the influence of the biomedical perspective on society. Moreover, advocating for the ADHD label was a way for parents to understand the ‘abnormal’ behaviour of their children or to support them academically. However, the parents did not deny the impact of social factors, such as school or social pressure, which led them to search for the label. Additionally, the parents emphasised Western psychology and the biomedical label in their stories as a resource of information to understand their children’s behaviour, as well as a way to confirm professional and disability law requirements. Finally, despite medication being offered as the first option for parents of children with ADHD, the parents advocated behavioural therapy because it more appropriately addressed the social challenges that children and parents encounter with society.

The data from this study showed similarities with that of Edward et al. (2012) and Malacrida (2004), who compared perspectives on biomedical knowledge regarding ADHD and intervention efforts of parents from four countries. The researchers highlighted differences in the perspectives on ADHD and psychiatric approaches for ‘diagnosis’ and ‘treatment’ based on political acceptance or rejection of ADHD ‘diagnoses’ or ‘treatment’. The parents’ attitudes in these studies were also affected by cultural practices and perspectives regarding child behaviour and ways of controlling it. Considering these studies and the current data, it can be argued that medicalisation cannot be reduced to the biomedical aspect of ADHD, because parents continuously engage with biomedical information to negotiate the behaviour, ‘diagnosis’ and ‘treatment’ of their children. Parents’ advocating for medicalisation for their children does not always mean that the biomedical perspective is the dominant authority, and it is not always negative (Singh, 2004). The use of medicalisation may have different meanings and implications based on political and social contexts.

Second, ADHD is also understood as leading to many challenges and barriers due to society’s misunderstanding of children’s behaviour, as well as issues with the services that are provided to support the differences in children with ADHD. The parents’ ideas, revealed in their stories of barriers, can be interpreted with the help of material social and social relational models of disability. According to the material social model, previous challenges and barriers are referred to as ‘disability’ because they disadvantage and exclude disabled people from social participation (Oliver, 1990). In terms of the social relational model, the challenges and barriers are described in terms of ‘disablism’, which means that disability is not only the social and environmental barrier that prevents disabled people from social participation; there is also a social understanding of the material body (or in case of ADHD the behaviour) that causes social restriction with psycho-emotional effects (Thomas, 1999).

By using the social material model of disability to explain parents’ ideas of ADHD as a disability, I found that parenting a child with ADHD means, first, facing challenges and barriers with special needs schools because of a lack of understanding regarding learning difficulties and ADHD. Parents gave reasons for this lack of understanding, such as insufficient education in special needs schools, the similarity between mainstream and special needs schools in being strict with time spent teaching students, negative expectations of children with ADHD and learning difficulties regarding their ability to learn, and teachers needing more training to understand the different learning styles of children with ADHD. Second, parents experienced financial burdens, not because there was not enough financial support, but because of issues with the provision of services. Misunderstood disabilities, such as ADHD, create grievances and problems for parents that affect their ability to work and increase their financial burdens. Last, the parents revealed structural barriers with health provision, in that they face many issues when seeking a ‘diagnosis’ and a disability certificate; for example, it is a long process and decisions are made by professionals without communicating with the parents. This pushed parents to pay for private sector healthcare to obtain a disability report and access the PADA disability support system.

The results regarding parents’ ideas about ADHD as a disability diverged slightly from the material social model of disability, which focuses on the absence of support and services for disabled people. The parents’ stories showed that services and support were available, but that there were issues and barriers due to service provision. Moreover, the results diverged from the social model, as parents did not see exclusion in education as a problem, but showed consistency with Oliver’s (1990) argument that the special education system fails to actively educate disabled people to prepare them for adult life, which increases the idea that disabled people are unqualified and even separates them from their social activities.

The social relational model (Thomas, 1999) was used to discuss social challenges and barriers relating to the invisible nature of ADHD impairment, such as social misunderstandings of ADHD and psycho-emotional effects. I discovered that parents’ ideas of ADHD as a disability mean struggling to secure a place for children with ADHD in school because of a negative perception of ADHD. The school illustrated in the stories was ready to support students who were weak, but not students with learning difficulties, which indicates a negative perspective regarding the abilities of children with learning difficulties. Additionally, the invisible nature of ADHD may cause psycho-emotional effects and structural barriers in the process of obtaining confirmation from the doctor regarding the child’s disability with ADHD, which is challenging for parents. Parents also discussed the severely distressing emotions caused by educational professionals’ attitudes towards their children’s behaviour. Moreover, the psycho-emotional aspect was also present in the family of children with ADHD as they dealt with society’s negative attitudes towards the children’s impairments. These attitudes are due to stereotypes and expectations of childhood in society, from which ADHD is considered to deviate. This limits the family’s participation in the social context. Last, ideas about ADHD as a disability were also linked to the fear of a disability certificate because of the stigma related to it, which could extend throughout the child’s life and future. The social relational model was useful to understand the parents’ ideas about ADHD that were linked to society’s perspective on ADHD, as well as the way social perceptions could cause environmental and emotional restrictions.

The last idea revealed by parents about ADHD was the understanding of the behaviour as a different impairment that society should accept and enhance, instead of thinking of it as something tragic that negatively affects families. The examination of the parents’ stories reinforced Swain and French’s (2000) argument that impairment does not have to be tragic. It also engages with Thomas’ (1999) idea that ‘impairment’ is understood as a social construction. Impairment is often seen as unacceptable behaviour or physical 'problems' constructed by those who interact with disabled people or their carers, which leads to disabled people being disadvantaged and excluded from society.

Using both Swain and French’s (2000) and Thomas’ (1999; 2010) theories to explain parents’ ideas about impairment in ADHD, I found that parents had their own personal and private perspectives on ADHD from their experience with ADHD impairment, which differed from a societally negative and tragic understanding of ADHD. By using Thomas’ (1999) idea of impairment, I explained the link between parents’ ideas of ADHD and Arab culture and how Islamic teachings play a role in parents’ acceptance of impairment in ADHD. Parents considered ADHD a blessing from God for health and protection. Cultural values advocate that parents accept both the negative and positive aspects of ADHD impairment. The parents illustrated that ADHD might have negative influences, such as difficulty with academic learning and social activities, yet children with ADHD were seen as gifts with much potential and many abilities outside the academic context.

The affirmative model was helpful in explaining the parents’ positive ideas about ADHD behaviour, which are often misunderstood by society. The tragic representation of impairment reflects the social and expert understanding of the lives of families of children with ADHD; however, impairment may be seen as a positive attribute that has advantages (Swain and French, 2000). The parents’ stories reflected ideas of the affirmative model in their descriptions of the impairment.

It is important to acknowledge that the discussion of ADHD was further complicated by the gender of the parents, which affected their perspectives and ideas about ADHD. Mothers and fathers showed different understandings of cultural perspectives in considering ADHD ‘naughty’ behaviour. While mothers used discourse related to naughty behaviour to explain the negative social aspects of ADHD behaviour, fathers considered naughty behaviour to be part of normal child behaviour. This difference indicates that not only social and cultural values, but also social groups (which in the current research was gender) influence perspectives and ideas about ADHD. The different and overlapping viewpoints regarding ADHD also have a lot of implications for parents’ lives, which are discussed below.

Overall, the current research results come from trying to explain parents’ ideas using disability models, which are not often used in the Kuwaiti context. The data indicates that parents had different ideas about ADHD, depending on the situation. The parents’ stories indicated that social and environmental barriers were difficulties that parents faced as much as the ambiguity of raising children with ADHD. The results suggest that ADHD is more than a learning difficulty or ‘disorder’ because the difficulties faced when raising a child with ADHD do not only come from the impairment, but also from the social environment, which needs to be considered to obtain support and services for children with ADHD and their families.

Moreover, parents’ stories of social interaction, such as in school or social meetings, contained negative perspectives on ADHD as deviant from social norms. However, when exploring personal and private perspectives on ADHD, parents were grateful for their children despite their ADHD diagnoses. Others consider ADHD to be a good condition that increases the child’s creative or academic ability. It seems that religious values impact parents’ positive perceptions of their children’s disability, and their appreciation for their children’s ability may acknowledge them as different from, but not less than, other children. ADHD should not be looked on as a problem, but as an opportunity for expanding understanding to enhance the abilities of children with ADHD, instead of just helping them through education. It is important to recognise both the social and medical aspects of impairment to provide adequate support for parents. Most importantly, it is crucial to consider that the private experience of parents with children with impairments may challenge the medical perspective on ADHD when determining the services and support needed for the families of children with ADHD.

This section focused on parents’ perspectives on ADHD, which have various implications for their experience of rearing a child with ADHD. These implications are discussed next.

## 8.1.2 Implications of parents’ perceptions of ADHD on their experiences

This section answers the research question: What are the implications of parents’ perceptions of ADHD on their experiences of raising a child with ADHD in the Kuwaiti context? Before answering the question, however, a discussion of the term ‘implications’ is important, because this concluding chapter has two sections whose headings include the term. The term implications, as used in answering the question, refers to the impact of parents’ perceptions regarding ADHD (which are illustrated in the previous section) in comparison with how society and social policies on disability understand the impact of ADHD on the experience of parents. By this, I mean that the parents’ varying and complex ideas about ADHD influence their expectations regarding services and support, as well as their response to society’s attitude to their children’s behaviour. This appears to lead parents to encounter challenges and barriers, which is the main focus of this section. Moreover, by attempting to understand how parents’ perceptions contrast with those of society and social policy regarding ADHD and the support needed, the parents’ stories highlighted social and cultural aspects that need to be considered in determining the support and services for the families of children with ADHD. Suggestions of ways to address the challenges and barriers encountered by families of children with ADHD are addressed below, and more generally address the implications of the current research.

While support and services mainly focus on children with ADHD impairment as a ‘disorder’ and learning difficulty, parents face many barriers in finding the support and information needed to facilitate their role as parents and to help their children. This section argues for the importance of recognising the impact of the cultural and social aspects on the services provided for children with ADHD. Furthermore, support for those with ADHD should not be limited to the children but should extend to the parents, who also need support, to facilitate their role and experience of raising a child with ADHD. Moreover, this section highlights the importance of including parents in determining the support needed for children with ADHD. Discussed below are the implications, based on the parents’ stories, which are categorised into three themes: (1) parents’ uncertainty regarding information and support for ADHD; (2) the implications of social and cultural factors on stigma; and (3) the implications for parents’ engagement with services and support.

### 8.1.2.1 Parents’ uncertainty regarding information and support for ADHD

The first implication of the differences between the parents’ perspectives and those of the social environment and social policy regarding ADHD relates to information and communication. In Chapter 6, I showed that parents’ descriptions of their experiences and understanding of ADHD and related support and services are uncertain and ambiguous due to a lack of information and effective communication. Parents described continuously searching for information as part of their experience of parenting a child with ADHD. I discovered that the information that parents need differs before and after ‘diagnosis’ and when accessing the disability support system. At the beginning of the parents’ experience, they require information that explains the ADHD condition. After receiving the ‘diagnosis’ and accessing the disability support system, parents need information about the support, services and intervention available for children with ADHD to help them throughout their experiences.

To explain the results of the lack of information experienced by parents, I will refer back to my discussion on disability practice underpinning the social policy on disability, that is, Disability Law No. 8. As discussed in Chapter 2, Disability Law No. 8 describes ADHD as a disorder and a learning difficulty, which is similar to the individual model of disability that focuses only on impairment (Haegele and Hodge, 2016). This approach is problematic because it depends on information from scientific studies and medical professionals. Such information often sees ADHD as a biological and neurological ‘disorder’ and ignores the idea that identifying ADHD ‘symptoms’ depends on the way culture understands hyperactivity, inattention and impulsivity, which means that ADHD has cultural and social aspects to it. In Chapter 5, I gave an example of the way parenting questions biomedical ideas of ADHD that seem to interact with cultural understandings of childhood and disability. Thus, information on ADHD and interventions for ADHD as a ‘disorder’ might not be enough, because the description of ADHD varies according to different explanations for it, and global strategies used to support people with ADHD (Conrad and Bergey, 2014).

Another explanation for the lack of information for parents, as the analysis described in Chapter 2 indicated, is the influence of the social model on the Disability Law No. 8; for example, the term ‘learning difficulty’ instead of ‘learning disability’ being used for children (full discussion in Chapter 2). However, social model studies have been criticised for failing to discuss impairment (Anastasiou and Kauffman, 2013), which means that the application of social model principles might not include all the difficulties faced by all disabled people, which vary according to impairment.

In line with this observation, the parents demonstrated that they encountered different challenges related to social practice, not only in the children’s behaviour in social activities or in school, but also related to difficulties in finding information about special needs schools, accessing support services or managing the psycho-emotional impact of stigma from society. The social model’s distinction between impairment and disability is useful for this discussion. Addressing the terminology in the Law of Disability, which identifies ADHD and similar child development issues as learning difficulties, instead of learning disabilities, could be a good start. I could argue that the law acknowledges the social model of disability, but that disability is not a product of impairment but of social practice. However, the implications of the social model should also include information for parents of children with ADHD, so that they can fully participate in supporting their children and facilitating their experiences (Swain et al., 2003). Some parents reported obtaining information, but only after a struggle and then using social groups; however, accessing information would be easier if the disability support system provided the information.

Some parents, after their experience with struggling to find information, mentioned different resources available to help them develop their knowledge about child behaviour and various ways to cope with their children’s differences. These resources included lectures on ADHD, online courses, private communication and play therapy. The issue with these resources is that they are not available to all parents. Moreover, most of these resources are not free, which places a financial burden on parents. Article 10 of Disability Law No. 8 explains the importance of educating academic professionals to meet the needs of children with learning difficulties, including ADHD ((Kuwait’s Constitution, 1962)). The parents’ stories suggest that the education of parents might be an important addition to this article, as parents also have a need for information. Doing so will facilitate faster access to information, while decreasing the financial costs of obtaining the information. Also, the education programme will help parents meet other parents in a similar situation, and they can benefit from each other’s experiences. Parents can also build relationships with professionals, which may reduce the gap regarding different opinions on ADHD and expectations of support.

### 8.1.2.2 Implications of social and cultural factors on stigma

The second implication from the parent stories is related to stigma, as psycho-emotional effects were described as a key part of the parents’ experience of bringing up a child with ADHD. In Chapter 6, I illustrated how parents shared the rejection and prejudice that their children with ADHD were exposed to in the social context, because parents are seen as responsible for the socialisation of their children. Consistent with previous studies, mothers were blamed more than fathers for their children’s behaviour, because of social expectations regarding the role of mothers in rearing children (Al-Azemi, 2010; Fargues, 1995). To explain the results, the parents’ stories were analysed using a sociological approach (Link and Phelan, 2001), which provided an extensive examination of the cultural, social and political factors that give people the power to stigmatise individuals with disabilities.

The current study found that parents’ stories were consistent with this position, as parents faced stigma before and after the ‘diagnosis’ of ADHD. This is because families exist in a society that negatively perceives the child’s behaviour as naughty or disrespectful or even perceives the child as a failure. This exposes the family to stigma. After the ‘diagnosis’, the parents found themselves facing two dilemmas. First, society’s misunderstanding of ADHD resulted in continued doubt and refusal to accept the label and the children’s behaviour. Parents, particularly mothers, were blamed for their children’s behaviour, as people considered the behaviour to be the result of an absent mother (Blum, 2007; Dalky, 2012). Second, the negative perception of the disability label forced parents to face blame for labelling their children. The results support Ciftci and Corrigan’s (2013) argument that parents of children with invisible impairments, such as ADHD, always fear exposing their children’s impairments. Moreover, Tyler and Slater (2018) explained that the very nature of the label connects the individual with ADHD, which is a stigmatised condition.

The stories of the parents highlight many implications for their lives due to stigma, which correlate with previous studies (Dalky, 2012; Koro-Lyjunberg, 2009; Mueller et al., 2012). The stigma of ADHD prevented parents from accessing social support and caused them to doubt their choice of obtaining an ADHD ‘diagnosis’. Stigma also affected the parents’ lives and health, as parents limited their social circles and depended only on themselves for emotional support to manage the stigma. Goffman (2006) argued that stigma is a relational process between the attitude of the individual and the deviant social characteristic, and by linking them together, the person is treated as unworthy and less valuable. This leads parents to exclude themselves socially and to ‘internalised oppression’ (Reeve, 2014; full explanation in Chapter 2, Section 2.3.2.3) because of their children’s behaviour or their failure to fulfil the parenting role.

The parents’ stories also highlight the social, cultural and structural circumstances that increase stigma and the psycho-emotional effect on the family. Link and Phelan (2001) explained that the stigma process occurs in interactional power situations that enable the stigmatiser to illustrate discriminatory attitudes towards the stigmatised. Power can take different forms, such as stigmatising stereotypes, political decisions or institutional practices which create disadvantages and foster a social environment that increases stigma towards people with disabilities (Link and Phelan, 2001). The analysis of the setting and context of the parents’ stories reveals many social factors in stigmatisation.

Parents and children are often stigmatised because the behaviour of the child fails to match the expectations of Arab society, and this failure causes society to view them as other and to devalue them. The parents’ stories indicate that cultural values affect and stigmatise boys and their mothers more than they affect other family members. Yang et al. (2013) explained that stigma towards people with a disability varies depending on how unacceptable behaviours affect the role that people with disabilities play, and their ability to achieve that role. The stigma occurs not only because of a negative perception of ADHD impairment, but also because people with an impairment fail to conform to cultural expectations (Yang et al., 2013). This provokes different kinds of stigma towards mothers and fathers or sons and daughters.

Parents also highlighted the cultural values and expectations for boys that parents relate to stigmatising attitudes. This is because Arab culture considers boys to be a source of social and economic support for the family (Hammad et al., 1999). According to the parents’ stories, the behaviour of boys with ADHD was seen as deviant because it challenged social expectations of boys to achieve academically or behave socially. This creates the incorrect assumption that boys with ADHD cannot fulfil the family role, which brings shame on the family. This principle is especially true in Arab culture, since the child is considered one part of a large entity, and children’s behaviour affects the social image and reputation of the entire extended family (Timimi, 2005). It is not surprising that parents were stigmatised the most by their extended families, who pressured them to force their children to conform to the social norms that affect the entire family.

The disability certificate also affects the stigma experienced by parents of children with ADHD. Parents must have a disability certificate to access the disability support system, because the reform movement implemented this requirement to protect the rights of people with disabilities against fraud. However, parents face difficulties accessing the support system because of the stigma attached to the certificate. These difficulties emphasise the usefulness of the social model in facilitating the decision to obtain a disability certificate. The social model advocates an exploration of the impact of society and culture on the lives of disabled people (Thomas, 2004), which can be made by understanding the relationship between disabled people and the social context that prevents them from enjoying the inclusion and equal opportunities that other people experience. The certificate of disability stigmatises people with learning disabilities through negative stereotypes in Arab society because it presents them as unable to fulfil their role in marriage and work.

Protecting disability rights by implementing a scientific test and the requirement of a certificate to establish eligibility for support services and disability rights ignores the difference between impairment and disability. Medical assessment and disability certificates are important steps in solving the problem of fraud that prevents many disabled people from using their right to support. However, there is more work to be done to benefit the minority of disabled people who have learning difficulties. In 2017, the applicable term changed from ‘people with learning disabilities’ to ‘people with learning difficulties’ (Kuwait’s Constitution, 1962). This was a positive step in recognising the impact of the term ‘disability’ on people with learning difficulties. Similarly, it may be useful to change the term used on the certificate to ‘learning difficulty’ to better represent the condition and to prevent confusion with assumptions related to disability. Some parents do not consider their children’s learning difficulty to be a disability, but think of it as an academic challenge for their children that requires support.

The stigma issue with disability certificates can also apply to psychological and social support services for parents. Some of the parents described challenges they encountered because of their children’s invisible impairment and normal appearance, echoing Thomas’ (1999) understanding of impairment. The parents explained that bringing up children with ADHD was a physical burden because they had to supervise the children most of the time. These parents, especially the mothers, are emotionally burdened because of negative social attitudes directed towards them and their children with ADHD. None of the parents used the free psychological or emotional support that was available to them because of its stigma. Rima (a mother of a child with ADHD) explained that accessing psychological and well-being support requires the opening of a file, which most parents consider problematic, and results in the parents not seeking support. This observation is consistent with previous studies that explained the stigma associated with a psychology file (Almazeedi and Alsuwaidan, 2014; Khullar and Coughlan, 2018; Scull et al., 2014).

Overall, it is crucial to understand that the experience of stigma is not solely a product of the child’s behaviour and impairment, but that other factors are influential. This information is useful in developing strategies to prevent stigma. These strategies should not only focus on the parents and children, but also reduce the influence of the social factors that affect stigmatisation. Implementing an awareness campaign is not enough to remove stigma, and focusing on the impairment of children as the source of stigma has negative consequences for families. Thus, the impact of the social environment on stigmatisation should be considered when creating interventions to decrease stigma.

Almazeedi and Alsuwaidan (2014) argued that although people in Kuwaiti society hesitate to seek psychological support because of public stigma, some people may ask for help from a local primary care physician. The parents’ stories reflected this practice, especially at the beginning of their experiences. Most parents used physicians to diagnose their children, while others used the private sector because of the stigma associated with public psychiatric services. However, physicians are not sufficiently trained to provide psychiatric services, so people are often not provided with the right support (Almazeedi and Alsuwaidan, 2014; Khullar and Coughlan, 2018). Taking the parents’ stories into consideration suggests that raising awareness about the importance of well-being services (Almazeedi and Alsuwaidan, 2014) should be recommended. In addition, facilitating group sessions may be helpful, considering the sensitivity of cultural norms and the values that work against psychological institutions. The parents indicated that social support was not only a way to emotionally support the family, but also a source of information to help manage the social barriers they face.

### 8.1.2.3 Implications for parents’ engagement with services and support

It was notable that parents’ experiences with support and services provided critical insight into the rights and support of children with learning difficulties. This insight was achieved by analysing the stories of parents describing a number of challenges when accessing support and services because of different expectations regarding the support. The parents explained that support and services, such as free medical services and paid educational services, were available to address the children’s impairment. These results were identified using the social material model of disability (Barnes and Oliver, 2012), which focuses on the process of service provision for children with ADHD. I found that despite the availability of these services, parents expected special needs schools to teach and interact with children with ADHD, but these services were not provided. In addition, appointments were not convenient for the parents, as it took a significant amount of time to receive support. Parents also identified problems with special needs schools, such as the low quality of teaching and the denial of admission to children with ADHD. Considering the parents’ problems with the services, it is suggested that the services address the parents’ opinions and feedback, and provide more flexible options for improvement.

To explain the stories, the parents’ challenges echo those of Swain et al. (2003) in their comparison of the *care of* disabled people and *caring for* disabled people. The care of disabled people involved using the opinions of professionals to provide support services to help them. In contrast, caring for disabled people involved providing parents with the agency to choose support that fitted their needs. Reflecting on the parents’ stories, the current care offered through services and support falls between these two categories. Parents provide support and use their opinions to choose the support that is covered financially. However, the practice of services misses the step of providing agency to parents by better communicating with them as experts to decide how to improve the services and what services they need to facilitate their lives (Swain et al., 2003). Thus, the participation of and communication with parents is crucial to the process and would result in better support and services that would benefit the children and remove some of the burdens of childcare from the parents.

In evaluating the available services, it is also important to understand that services, such as educational support and diagnostic services, relate to the impairment of the child. The services are usually based on a scientific or specialist opinion to help children with the impairment of ADHD. However, most of the parents’ challenges are related to social practices, such as finding good schools or obtaining emotional and well-being services. These services may not seem essential to children who have the impairment of ADHD, but they are important when considering the impact of the disability on the family in everyday practice. The current research suggests that adopting social models provides ways to support both children with ADHD and their parents because the model advocates listening to parents as experts and identifying ways to support them (Barnes and Oliver, 2012; Swain et al., 2003). This approach also helps to assess the impact of services provided to children with ADHD and their families. The model values the experience of parents as much as scientific knowledge related to ADHD. The parents’ stories demonstrate that ADHD poses not only learning difficulties, but also social challenges. Unfortunately, parents have often been alone in solving these challenges.

To sum up, similar to previous studies on the mothers of children with disabilities, the results of the current research show that parents experience stress (Karaca and Şener, 2021). However, the parents also highlighted the role of religious beliefs and values in providing them with emotional support and suggesting novel ways of looking at the differences in children with ADHD (Karaca and Şener, 2021). Barbara et al. (2009) explain this paradox by observing that most studies focus on the stress and mental health challenges shouldered by mothers, but do not create theories about the reasons and process leading to such challenges.

Understanding parents’ perceptions involves focusing on the complexity of their everyday parenting practice (Barbara et al., 2009). When applying previous ideas to the current research and talking to mothers and fathers about their everyday practice, they had a lot to say about the negative aspects of their experiences. However, this finding does not mean that either the parents' experiences were all negative or that negativity is strongly related to the child or the context of the family home. Ryan and Runswick-Cole (2008) argue that parents might choose to pathologise the child (or in the case of the current research, use negative language in their account of them) as a result of their tendencies to follow a set of disabling practices. While examining the set of practices coming forth from parents' perceptions, the negative discourse regarding the lives of families with disabilities and ADHD might influence the parents' orientation. Moreover, as shown in Chapter Six, the parents' negative perceptions could be a consequence of the social and structural disabling barriers that they face in their children’s’ schooling, while trying to access disability services, or through societal attitudes.

Additionally, Barbara et al. (2009), examining mothers' experiences of parenting a child with autism, demonstrated that the parenting experience presents both negative manifestations, such as stress and disability, and positive manifestations related to exploring a new meaning of life. This is similar to the discussion in Chapter 7, where I discussed the positive side of parents' experience to illustrate that there is much to understand about their experience. By assessing the personal and spiritual values held as part of the parents’ perspective, these values help parents overcome the emotional and physical challenges faced in society. Furthermore, they were able to express their own understanding of their children, which increased their acceptance of and love for their children.

From the current research previous results, I am able to draw the insight that parents' experiences are highly complex. One moment, parents may talk about the overwhelming effort they have to put into raising their child and the emotional stress it causes, but in the next moment, they celebrate and love their children's differences. The complexity of parents' perceptions of their experience reflects the mismatch and dynamics between the life they experience raising children with a disability and their belief in their children's abilities and hopes for a better future. Moreover, the results support the possibility that parents' experiences and perceptions are not static but are continually changing, which is often thrown into sharp relief by their complex emotions. The parents might feel ashamed, shocked, or sad on some occasions due to their experiences, but they still love their children.

## 8.2 Contributions

The intersectional nature of the current research addresses the complex experience of parents of children with ADHD. This study offers a number of original theoretical contributions to the literature on disability and ADHD, as follows:

1. The purpose of the research was to understand ADHD in Kuwait, despite there being few studies that address this, since it is often a topic left to the medical field in Arab and Middle East countries. The current research stands out because it addresses ADHD from the perspective of medical, sociological and disability studies to provide a cultural and social perspective of ADHD. This approach has not been used in studies on disability in Kuwait. Therefore, this is considered to be the main contribution to the literature.

2. The research findings in Chapter 5 contribute to studies on ADHD that use medicalisation theory to explore the influence of culture and society on parents’ adoption of biomedical ideas, by illustrating an example from the Middle East and Arab countries. The chapter provides a critical discussion of the ways that parents adopt the biomedical perspective and their reasons for doing so. It argues that Kuwait’s culture and social structure influences parents’ understanding of ADHD ‘diagnosis’ and ‘treatment’, rather than assuming that they will blindly follow the biomedical perspective. The ‘diagnosis’ and ‘treatment’ mean more for parents than simply advocating medicalisation and submitting to the power of medicine in their everyday life.

3. ADHD studies are often conducted in medical sociology studies, and few of these discuss the topic from the perspective of disabilities studies (social models of disability). The perspective usually focuses on impairment within children with ADHD. This limit on understanding benefits neither the children nor their parents, because of the way that impairment is seen to be situated between education, health and society. Nor does it deliver any benefit for the understanding of ADHD within the law of disability. By adopting social models of disability as lenses to demonstrate the complexity of the challenges and need for support and assistance to facilitate parents’ lives, the current research thus contributes to the few disability studies of ADHD.

4. The nature of the father’s role in parenting a child with ADHD challenges the understanding of the absence of the father’s role in the parenting process. Fathers are open to different perspectives on ADHD, especially when they are the primary caregiver. This offers a means of negotiation for marginalised groups such as fathers through an understanding of parenting in disability studies as well as addressing the normative cultural narrative of a father as having less of the parenting responsibility. The findings of this research indicate that fathers take their ideas of ADHD from a biomedical perspective. The study also highlights the social challenges that fathers encounter when parenting a child with ADHD. Although the research has gained a limited understanding of the father’s perspective, as it investigated few participants, it still used qualitative methods to contribute to the study of parenting children with a disability in the Kuwaiti literature.

## 8.3 Implications

The aim of the current research is to explore alternative ways of understanding ADHD. This aim assumes that a social understanding of ADHD has different implications for the lives of parents of children with the condition. The literature review and results indicate many implications that are relevant for parents of children with a different disability, as well as professionals, policy-makers and disability researchers with influence, who are involved with families of children with ADHD.

1. For policy-makers and disability activists, the discussion of parents’ experiences with ‘disability certification’, which is a requirement for accessing the disability support system, indicates the importance of changing the term. The negative influence of the current term is highlighted in Chapter 6 with an investigation of disability certificates within Arab culture using Arabic. The research found that the use of disability certification for children with an invisible impairment such as ADHD might portray them as ‘idiots’ or being ‘mad’, which increased stigma on the family.

However, as I explain in Chapter 2, there is a movement to reform disability certification in Kuwait and to protect the rights of people with disability from fraudulent people. Thus, the current research suggests changing the term used for the disability certificate of a child with ADHD or any other learning difficulty to ‘learning difficulty certification’. This would indicate an impairment without drawing a negative perception on the child. This may be an implication for the current research for policy-makers. The impact of language and terminology could also lead to future research to investigate the effect of such disability certification on other people with impairment.

2. For medical professionals and educators, as illustrated in Chapter 2, the use of a social model was not done to advocate support and assistance because of the availability of resources, but to investigate the process of service and providing support. The perspectives of parents and professionals echoed the importance of effective communication and the relationship between the parties involved in the lives of children with ADHD. The parents indicated a need for effective conversations with medical professionals that would go beyond talking about their child’s condition and ‘medical treatment’. Other parents’ stories indicated the importance and benefits of holding conversations with teachers about their child’s challenges and ways to support both the child and parents. The current study suggests improving services through collaboration and effective communication with professionals to ensure the best interests of the child are upheld.

3. The perspectives that demonstrated the structural and environmental impact of stigma could be useful for informing professionals and policy-makers with ideas about ways to decrease it. In Chapter 2, I showed that intervening in cases of stigma and its implication on the family usually takes the form of social awareness about ADHD or therapy sessions for families. By doing so with respect and without decreasing the importance and usefulness of making such an effort through social awareness, it may take longer to change social values. The parents might also hesitate to access therapy because of the social stigma associated with psychiatric placement. The analysis using the sociological and cultural approach to stigma provided some early ideas for consideration about how to change the social environment to decrease stigma, such as by creating social group therapy or changing the label from ‘disability’ to ‘learning difficulty’. As half of the mothers lived with their extended families, the children and mother encountered stigma from the extended family. The results also indicate the importance of helping families get a private home sooner, which decreases the stigma faced by extended families (Chapter 6). The suggestion provided by analysing the sociological approach focuses on the role of the social environment and not only on parents or children in decreasing the stigma.

4. The psycho-emotional effects and stigma faced by families of children with ADHD from professionals and society at large indicates the importance of awareness about the condition. In Chapter 2, I indicated the initiatives of public benefit associations for developing awareness campaigns about the condition. However, according to the results of the current research, awareness campaigns could be developed more in collaboration with those with disability and their parents instead of addressing ADHD more from the perspective of the professionals. The parents’ perspective could include awareness about the disability that they have encountered in their lives instead of just focusing on the impairment in relation to ADHD. The recollections also suggested empowering parents with information about ADHD as an intervention for stigma. This is because knowledge and experience of ADHD enables parents to resist stigma and psycho-emotional effects.

5. The final implication of the results for practice is the importance of using language that conceptualises ADHD in alternative ways which are less ‘othering’. This is because the biomedical language used to describe the children and their behaviour has negative consequences not only on the attitude and kind of support provided for families and children with different abilities, but also it reframes the parents’ and child’s perceptions of themselves and their abilities. Additionally, offensive and negative language can attack the child’s personality and agitates their response to other people.

However, positive language illustrates acceptance and compassion for a child’s differences. This type of language looks to the child themself and does not make comparisons with others. For example, a child is not a disruption to the class, but rather, they are having a hard time following the way the lesson is presented, which does not consider their needs. From this perspective, we do not assume that the child is breaking the rules intentionally, but that they are having a difficult time instead. With this approach, we have a framework of school expectations for the student which limits understanding of the diversity of children. We have to advocate a social culture that describes a child’s differences in affirmative instead of negative ways. It might not be an easy process and it might take a long time, but small changes in language matter and change the way we look at children with ADHD behaviour. We can start by asking parents or children about their preferences on the language that is used to address themselves and their children.

## 8.4 Limitations and suggestions for future research

This research explores various perspectives parents have on ADHD by focusing on parents’ experience of parenting a child with ADHD. The discussion of the parents’ stories of their experiences demonstrates the role of social practices, cultural values, and traditions in shaping the parents’ understanding of biomedical information on ADHD, as well as the disability and impairment concomitant with ADHD. In this research, I employed a narrative methodology, which requires reflection on the challenges and limitations of the research process. Hence, some of the limitations of the philosophical stances and the methodology are discussed in Chapter 3. After explaining each model, I also discussed the scope of the models of disability used to explore the experiences of the parents (see Chapter 3). In this section, the discussion of this research limitation could represent suggestions for other research in the future.

Starting with the research participants, the parents who participated in this study were selected using the snowball sampling method. Thus, the study sample might not be representative of all parents of children with ADHD, especially new parents who have yet to access the disability support system or a support group. This insight about new parents was obtained by analysing the stories shared by parents, which highlight the function of experience and information in the variation in experience between parents. This study may be an inspiration to parents who are new to the experience of rearing a child with ADHD. This research also highlights the need for future research on parents in different circumstances, e.g., parents of children with ADHD who have not been diagnosed and parents who have not accessed the disability support system.

Furthermore, because this study aims to explore the experiences of parents of children with ADHD, the discussion is based primarily on the reported experiences of mothers and fathers. However, the responsibility of rearing a child with ADHD may be shouldered by any member of the family (Bussing and Koro-Ljungberg, 2009). The responsibility for raising a child with ADHD may be shouldered by a grandmother, grandfather or even an aunt or uncle. Research on the ADHD perspectives focuses on the mother’s perspective, as she is assumed socially to be primarily responsible for her children (Singh, 2003), but this research also seeks to understand the father’s perspectives on ADHD. However, it would be interesting to explore the varied positions and experiences of other family members responsible for rearing a child with ADHD, which might reveal a broader perspective on the values and beliefs that parents may draw on to negotiate their understanding and experience with ADHD.

The sample of eight participants—despite helping explore the ADHD concept—is limited, as the dominant mother’s perspective cannot be generalised to the broader group, particularly fathers, because the sample contained only two fathers. It would be interesting for future research to focus on the perspective of fathers. As this study explores the stories of two fathers and a reflection on the challenges encountered while interviewing these fathers, I hope this research is beneficial to future researchers for designing a research concept that would interest fathers and facilitate fathers contributing to our understanding of ADHD.

The influence of my position (being inexperienced and female) shows in the interview process, despite my research and preparations to avoid the potential difficulties posed by conducting narratives with fathers from Western cultures (Denzin, 1989; Johnson, 2001). Because of my position, I encountered difficulties attempting to explore the perspectives and experiences of the fathers using the same approach that I used with the mothers. I may highlight some aspects of the fathers’ opinions on ADHD, disability and childhood (see Chapters 5 and 6). However, I learned a lot from my experience, such as being more direct and detailed with questions intended to encourage fathers to speak more about their perspectives. Furthermore, I recognise the importance of further investigation into how to effectively communicate with fathers within the Kuwaiti context. Hence, I recommend that future research acknowledges the sensitivity and different communication styles of Kuwaiti fathers and any cultural context. Such an approach would facilitate an in-depth exploration of the social and cultural aspects of masculinity that influence a father’s understanding of ADHD.

Notably, my understanding at the beginning of this study was that the social model of disability could challenge the dominant biomedical understanding of ADHD. However, as I analysed the stories, I developed an interest in understanding the influence of political, social and historical changes in the social environment in Kuwait on parents’ perspectives on biomedical ADHD concepts. I recognise the limits of my assumptions, as exploring the social context of biomedical ADHD concepts is as crucial as exploring how well the social model of disability highlights the voice of parents regarding disability practice in Kuwait surrounding their experiences.

## 8.5 Conclusion

The chapter starts by answering the research questions. Additionally, it states the contributions the research made to the literature. It also presents implications for the support systems for disability and ADHD in Kuwait, which arose from the parents' understanding of and experience with ADHD. Finally, I acknowledge that narrative research and disability studies are very complex. This means the current research has limitations, which I used to suggest recommendations for future studies.

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