The Inclusion of Disabled Children in Oral Health

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Abstract

Background: Existing guidance and research indicate that children need to be involved in matters relevant to them, including research. Medical and dental research frequently excludes disabled children. This thesis adopted a rights-based approach and explores the inclusion of disabled children in oral health.

Methods: Two studies form the thesis. Study 1 is a systematic review, which provides evidence for the ways in which disabled children have been included in oral health research.

The results from Study 1 provided justification for Study 2, which is an ethnography. This explores ways of including disabled children in oral health. A purposive sample of ten children between the ages of 9 and 15 years with a range of disabilities, ten mothers of disabled children and ten health and educational professionals in Riyadh, Saudi Arabia, participated. Data collection used pluralistic methods. Data analysis took place using inductive thematic analysis.

Results: *Study 1:* Out of the 153 studies retrieved, only 9 (5.9%) attempted to involve children in oral health research, but disabled children were mostly seen as the subjects of research. A total of 55 (35.9%) used mothers or carers as proxies and 89 studies (58.2%) treated children as objects of research. The disabling language used to describe the children frequently portrayed them as abnormal and deviant. The systematic review highlighted the routine exclusion of disabled children from oral health research.

Study 2: The creative and pluralistic methods; pictures, guided tours and games, enabled disabled children to participate in oral health research. It also increased their ability to chat informally and appeared to reduce the power imbalance compared to formal, structured interviews. Group interviews, symbols and drawings acted as a barrier to the children's participation. Children displayed oral health knowledge and discussed practices, acknowledging the supportive roles their mothers played. They felt excluded during dental appointments and feared the dentist, associating the profession with pain, not prevention. Mothers as sole agents for their children's oral health lacked support, information and inclusion, preventing them from including their children in oral health.

Inaccessible services added to the exclusion of mothers and children from oral health. Dental professionals displayed discriminatory attitudes towards disabled children and problematised mothers. They displayed poor communication skills, lacked education and insight about disability and the skills to treat disabled children without a general anaesthetic. Educational professionals tended to discuss disabled children in terms of inability, displaying a deficit approach to impairment.

Conclusions: Studies 1 and 2 provide evidence of disabled children's experiences of exclusion in oral health. The thesis also provides evidence that they can be included in research using appropriate methodological designs and innovative, pluralistic methods, drawn from different disciplines. This promotes a rights-based approach, one that recognises diversity and aims to reduce the discrimination and disempowerment of disabled children. Dental education, oral health policy and service provision in Saudi Arabia should consider ways of reducing oral health inequalities for this marginalised group via the provision of support and a focus on societal barriers rather than conceptualising disability as a problem within the individual.

Publications, presentations and awards

An up-to-date list of the research outputs arising from the research in this thesis is as follows.

Publications

- Alwadi, M. A., Baker, S. R. & Owens, J. (2018) The inclusion of children with disabilities in oral health research: A systematic review. *Community Dentistry and Oral Epidemiology*, 46(3), 238-244.

Presentations and other research outputs

- Alwadi MA, Baker SR, and Owens J. (2020). Disabled children's experiences and perceptions of oral health and services [Poster]. In: *IADR/AADR/CADR General Session, 18-21 March 2020, Washington, USA*.

- Alwadi MA, Baker SR, and Owens J. (2020). Oral health research involving children with disabilities. Participated in the Disability History Month, an annual event which aims to highlight the history and experiences of disabled people across the UK. Available online:
  https://www.sheffield.ac.uk/staff/news/disability-history-month-2020-1.928803
  [Accessed 23 June 2021].

- Alwadi MA, Baker SR, and Owens J. (2019). Including the voices of disabled children in oral health research [Oral Presentation]. In: *BSODR / British Society for Oral and Dental Research, 3-5 September 2019, Leeds, UK*.

- Alwadi MA, Baker SR, and Owens J. (2019). The inclusion of disabled children in oral health research [Oral Presentation]. In: *Sheffield Hallam University: Disability Research Forum, 22 February 2019, Sheffield, UK*.

- Alwadi MA, Baker SR, and Owens J. (2018). The experiences of disabled children: including their voices in oral health [Poster]. In: *The University of Sheffield, 25-26 April 2018, Sheffield, UK*.

- Alwadi MA, Baker SR, and Owens J. (2018). The oral health research evidence gap for disabled children [Poster]. In: *IADR/PER General Session & Exhibition, 25-28 July 2018, London, UK*.

- Alwadi MA, Baker SR, and Owens J. (2017). The inclusion of disabled children in oral health research [Oral Presentation]. In: *The University of Sheffield, 4 July 2017, Sheffield, UK.*

Awards

- **The MDH PGR Society:** Award for 1ˢᵗ Place in the Digital Poster Competition. August 2020.
- **British Society for Oral and Dental Research bursary:** Towards travel and accommodation costs for presenting at BSODR, Leeds. September 2019.
- **British Society for Oral and Dental Research bursary:** Towards travel and accommodation costs for presenting at IADR, London. July 2018.
- **The Saudi Arabian Cultural Bureau**: Six awards for excellence in each semester of the PhD.

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Preface

Different historical eras have viewed children differently. Historically, children were rarely considered as having the potential to be valid or competent research participants. They were conceptualised as "not-yet-being" (Verhellen, 2000 p. 16), and "adults in waiting" (Matthews & Limb, 1998 p. 67). In this example, children are viewed as passive receivers lacking the competencies of adults. Seeing children as lacking in competence justifies them not being offered chances in order to experience responsibility, for example, being excluded from aspects of society and indeed research (Such & Walker, 2005). However, with the emergence of the 'new social studies of childhood' (James et al, 1998) and the children's rights-based discourse (the United Nations Conventions on the Rights of the Child [UNCRC], 1989; the Children's Act, 2004), children are now seen as social actors who are 'experts' on their own lives (Fraser et al, 2004; Mauthner, 1997). The UNCRC affirms the rights of children to receive information and express their views on matters that affect them, including research. Of the UNCRC's 54 articles, article 13 draws attention to the need to provide appropriate means of communication to promote inclusion and participation.

Research in disciplines such as education discuss the varying ways children may be included in the research. This aims to get their voices heard and appropriately structure and provide services to meet their needs, whilst simultaneously providing adequate support. Scoping the literature around the involvement of disabled children in oral health research, however, reveals patchy evidence. Therefore, the main research question for this thesis is:

- **In what ways are disabled children included in oral health?**

Linked aims to the main research question are as follows:
- To review the current oral health literature to identify the ways in which disabled children are included in oral health research (Study 1).
- To explore ways of including disabled children in oral health (Study 2).

This thesis explores the inclusion of disabled children in oral health. It begins with a systematic review of the inclusion of disabled children in oral health research (Study 1). An extensive review of the literature in the area, exploration of methodologies and methods followed. This leads to an ethnographic empirical piece of work (Study 2), which explores children, parents, and professionals' voices to identify the ways of including disabled children in oral health and research. The results explore the whole environment for oral health and aim to create the fullest picture possible, thereby focusing on the inclusion of disabled children in oral health.

Thesis structure

Chapter 1 presents Study 1, setting out a systematic review of the current literature on the place of disabled children in oral health research. It identifies the routine exclusion of disabled children from oral health research, thus providing justification for Study 2.

Chapter 2 reviews the current academic literature. It highlights the legislative context that emphasises the importance of listening to children and explains the concept of disability. This chapter further provides an overview of oral health and related barriers for disabled children, and a review of research evidence on methods of inclusion, illustrating gaps in the current literature.

Chapter 3 introduces the Kingdom of Saudi Arabia (KSA), which is the context for the thesis. It describes the different contexts, for example, religious and cultural, and the structure of the Saudi family and society. This chapter also provides an outline of health services, the state of oral health in the KSA, and an overview of disability in Saudi Arabia.

Chapter 4 describes the methodological considerations and justifies ethnography as the methodological research design. The chapter also reviews inclusive research methods used with children in previous research to guide the methods employed during data collection.

Chapter 5 presents the methods used to collect and analyse the data. It focuses on the research setting, access, methods of sampling and recruitment, data collection and data analysis. Furthermore, it discusses issues of rigour and ethical considerations.

Chapter 6 provides ethnographic descriptions of the sites where the research occurred to give context for the reader about the physical and political environment of two schools for children with special needs in Saudi Arabia.

Chapter 7 presents the results of the children's interviews. Children displayed knowledge of oral health and practices but also feared and associated dentists with pain, not prevention. Their insights suggested discrimination and exclusion from oral health.

Chapter 8 presents the results of the mothers' interviews. Mothers revealed a lack of support when caring for their children's oral health, service-related barriers to care and poor professional attitudes. As agents for their children's oral health, they lacked agency, experiencing exclusion from information to support their child with their oral health and blame from professionals.

Chapter 9 provides results of the interviews of education and healthcare professionals. They all displayed a lack of insight and regard for mothers about the challenges of caring for children with a range of impairments. Moreover, educational and dental professionals took a deficit approach to impairment, which failed to support and include mothers and children in oral health.

Chapter 10 presents the main findings of Study 2, discusses the meanings and links them to the existing evidence base. It acknowledges that despite the study's limitations, it contributes new findings in this area, in terms of giving children a voice in the dental evidence and in the KSA. It also triangulates children's perspectives with those of parents and professionals. This chapter additionally presents the implication of the study.

Chapter 11 reflects on the discussion and presents recommendations for policy and future work. It suggests that there are challenges for the inclusion of disabled children in oral health, from professional, parental and children's perspectives.

Study 1: A systematic review of the current literature on the place of disabled children in oral health research

1.1   Introduction

The United Nations Convention on the Rights of the Child (UNCRC) was held in 1989 to promote support for the rights of children (UNICEF, 1989). This resulted in children with disabilities gradually beginning to claim their rights, both as children and as disabled individuals. Of the UNCRC's 54 articles, article 12 was arguably the most influential of the articles for research, because it argued that children should have the right to express their opinions and to have their perspectives taken seriously in matters that affect them, including health research (UNICEF, 1989). This was also significant for all children because their rights were upheld regardless of race, family, colour, religion, language, politics, sex, nationality, social origin, ethnicity, disability, birth and so on; they were seen as a diverse body. This is evident in Article 2 of the UNCRC, which established the principles for the promotion of all children's rights without discrimination; therefore, the convention also has a profound impact on how disabled children are perceived (UNICEF, 1989).

In the Western world, the majority of disabled children attend mainstream schools, live at home with their families, and have the same rights to treatment and inclusion as children without disabilities, as enshrined in International Convention:

> *"[...] shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right."*

(The United Nations Convention on the Rights of Persons with Disabilities [UNCRPD], 2006 Article 7)

Even though disabled children are children first, they are often left out from "generic children's research, from policy-making about children's services and, in their everyday lives, from inclusion in friendship groups and social and sporting activities" (Stalker et al, 2012, p.173). Disabled children may need additional support to conduct their everyday lives, but they have the same needs, hopes and wishes as any other young person.

In the field of childhood studies, the UNCRC has enhanced children's level of involvement in research by valuing their right to have a voice and have their opinions heard (James et al, 1998). This research perspective views children as experts on their own lives who can provide valued knowledge to validate, enrich and sometimes challenge the evidence base (Beazley et al, 2009). One aspect raised within the sociology of childhood is the tendency to omit social categories of significance such as ethnicity, social class and disability, which intersects with who they are; their social position and the necessity for researchers to incorporate these aspects into the research design thereby making research more appropriate and inclusive for children (Clavering & McLaughlin, 2010). This vision of the child as a diverse agent would appear important if research is to shift from portraying children in terms of a narrow range of social categories (Clark et al, 2005).

The concept of the voices of children in health related research appears to have emerged more slowly than in other fields, largely because of the entrenched protectionist and paternalistic perspectives that have historically pervaded disciplines such as medicine (Kellett, 2009). Although, there may also be an element of safeguarding involved, which could also be a reason for the exclusion of children from research.

With the emergence of the new sociology of childhood and disability studies, there has been a new approach to the study of disability in childhood with a shift from exploring impairment towards placing the child at the centre of the research process (Watson, 2012). Historically, research relied on adult perspectives to shape meaning rather than the views and experiences of disabled children (Stalker & Connors, 2003) or concentrated on children who are verbally articulate (Fabbretti et al, 1997). Nevertheless, an increasing number of social researchers are focusing on using qualitative methodologies to determine the views of disabled children in research to

improve understandings of what is important to them. These academics argue that it is not acceptable to exclude the voices of disabled children merely as they pose a challenge to traditional research approaches, for example if they privilege spoken words. Indeed, the responsibility is on academics to consider diversity more strongly when they design their research and develop skills to adopt inclusive research strategies that enable disabled children to become active participants in research that concerns them (Ash et al, 1997; Connors, 2003; Davis et al, 2000; Minkes et al, 1994; Morris, 2003).

Within the field of oral health research, two systematic reviews illustrate how dental research occurs with or on children. The first systematic review found that the majority of research (87%) of papers viewed children as the 'objects' on which to do research on, rather than with (Marshman et al, 2007). Another systematic review of the dental literature from 1997-2007 involving adults with intellectual disabilities was also conducted by Whelan et al. (2010) using the four main categories of Marshman et al. (2007) to synthesise the papers. Out of the 173 papers reviewed, most of the published dental research (82%) involving adults with intellectual disabilities treated them as research objects. Only 2.2% of the studies actively involved them; 9.3% involved them to some extent; and 5.2% used proxies to represent the views of adults with intellectual disabilities (Whelan et al, 2010). Marshman et al. (2015) then carried out an updated systematic review which identified that the proportion of research on children had decreased by 23% over that decade and moved more towards research with children rather than on them (Marshman et al, 2015). The systematic reviews led by Marshman and colleagues fail to identify that children are a diverse group or consider the inclusion of disabled children in oral health research. Therefore, this chapter systematically reviews the literature to identify the ways that disabled children are included in oral health research.

1.2   Methods

This systematic review was based on the former reviews of oral health research involving children (Marshman et al, 2007; Marshman et al, 2015). This study adapted the categories that were developed by Marshman and colleagues (2007), with some modification based on the wider social science literature around the inclusion of disabled children in research and collected published articles about the oral health of

disabled children from 2001-2017.

Categories

1. The first category included research *with* disabled children where children were seen as active participants sharing power and responsibility for the research design and process. Disabled children are included in all aspects of the research process from generating the questions through to the design as well as being involved in data collection and dissemination. Children are viewed as equals.

2. The second category, also classified as research *with* disabled children, where children are involved in the design and conduct of research. Children worked within pre-arranged focus and research questions and were involved in choices of methods and ways of carrying out research.

3. The third category included research *with* disabled children where their perspectives were taken into consideration around research design. The children would express their views around the research design and were involved in steering groups.

4. The fourth category also comprised research *with* disabled children and comprised studies where they were listened to and seen as subjects of research with adults deciding the research questions, design and methods. This category was subdivided into two subcategories. The first subcategory included studies where disabled children contributed by giving an account of their experiences in their own words (sub-category 4a), using methods for example qualitative interviews, in-depth, unstructured, and semi-structured. The second subcategory-contained studies where disabled children completed measures designed by adults (sub-category 4b) for example, structured interviews, questionnaires, and other scales.

5. The fifth category included studies that used others as proxies for disabled children - another person reporting on their oral health either parental/caregiver (category 5a) or clinician (category 5b). Using proxies was felt appropriate for children too young or sick or with a profound level of intellectual difficulty.

6. The final category included research *on* disabled children, where they were seen as the objects of research. For example, research included within this category might see them either as; a mouth or a set of teeth to be treated; source of a sample of plaque, saliva, or soft/hard tissues; recipient of an intervention such as oral health promotion; population group to be examined clinically; a particular group to be managed and finally a patient on whom a 'particular examination' was done.

The search strategy was undertaken to identify all published oral health studies on disabled children between 2001 and 2017 reflecting the conceptual model of the International Classification of Functioning, Disability and Health and '*Valuing People*' in the UK (Department of Health, 2001; WHO, 2001) using Child-related keywords, Disability-related keywords, and Dental-related keywords as research terms. The full search strategy is available in Appendix 1.

The search strategy was done using Scopus, Web of Science (which incorporates 12 online databases, alongside Medline® and the social sciences databases used by the previous Web of Knowledge) and Google Scholar which was used to search for any peer reviewed articles that may not be included in the databases. It was limited to dental journals and the English language. The resultant articles were exported to an Endnote library (ResearchSoft., 2005), and duplicates were removed at this stage. The titles and abstracts of each reference were screened by two trained reviewers independently based on the following exclusion criteria:

- Studies reported before 2001, because this was prior to the conceptual model of the International Classification of Functioning, Disability and Health and '*Valuing People*' in the UK.
- Studies with participants over 16 years of age.
- Studies that do not have disabled children and/or aspects of their oral health as their main topic.
- Studies with no primary data, case reports, conference proceedings and guidance documents.

Agreements about the application of exclusion criteria between the two reviewers occurred for 86% of the articles. Discussion between the reviewers or referral to a third reviewer settled disagreements. Full texts of papers that passed the initial title and abstract screening were retrieved to determine eligibility for inclusion in the review. At this stage, studies that did not meet the inclusion criteria were excluded and reasons for exclusion was noted.

Two researchers involved in the categorisation classified five papers together as a training exercise and an additional five papers for calibration purposes. Then, two reviewers classified each paper independently. If categorising the paper from the abstract was not possible, the full text of the article was reviewed. If the papers appeared to fit in more than one category, the category chosen assumed the greater involvement of disabled children. The agreement between the reviewers about categorisation occurred for 97% of the papers and disagreements solved by discussion between the reviewers or by recourse to a third reviewer if this proved difficult. The frequency distribution of the categories of articles is in Table 1.

Table 1: Percentage of papers in each of the six categories

Category	Properties	No. of articles (%)
1. 'With' disabled children – children seen as active participants sharing power and responsibility for research design and process.	Children included in all aspects of the research process from generating the question through to the design, involved in data collection and dissemination. Children viewed as equals.	0
2. 'With' disabled children – children involved in design and conduct of research.	Children work within pre-arranged research question and focus and involved in choices of method and ways of carrying out research.	0
3. 'With' disabled children – children's perspective taken into consideration around research design.	Children facilitated to express their views around research design. Children on steering groups.	0
4. 'With' disabled children – children seen as subjects with adults deciding research question, design and methods.	a) In their own words e.g., qualitative interviews, in-depth, unstructured, semi-structured.	1(0.9%)
	b) Children completing measures designed by adults e.g., structured interviews, questionnaires, other scales.	7 (6.1%)
5. Others as proxies for disabled children - another person reporting on their oral health.	a) Parental/caregiver used appropriately as a proxy e.g., child too young/sick or profound level of learning difficulty.	47 (41.2%)
	b) Clinician as proxy used appropriately as a proxy e.g., child too young/sick or profound level of learning difficulty.	0
6. 'On' disabled children.	Children 'seen' as the objects of research. Not consulted in any way. Incompetence presumed.	59 (51.8%)

Two reviewers extracted data independently, using an EXCEL spreadsheet to record the following: author name, publication year, type of study, the country where the study was conducted, sample size, the age of children and type of impairment. Discussion solved disagreements in data extraction and, if necessary, a third member of the review team was involved. Alongside the categorisation of papers, reviewing and synthesising papers utilised the social model of disability as a lens.

1.3   Results

The search strategy revealed 2418 articles. Titles and abstracts of 1604 papers were screened against the inclusion and exclusion criteria after removing of duplicates. In all, 135 full-text articles were obtained and screened against inclusion criteria, at which point a further 21 articles were excluded. In the final review, 114 papers were included (Figure 1).

Identification

Records identified through database searching
(n = 2417)

Additional records identified through other sources
(n = 1)

Screening

Records after duplicates removed
(n = 1604)

Records screened
(n = 1604)

Records excluded
(n = 1469)

Eligibility

Full-text articles assessed for eligibility
(n = 135)

Full-text articles excluded (n = 21), for the following reasons:

Age >16 (n=6)

Disabled children and aspects of their oral health not the main topic (n=11)

Not written in English (n=3)

Sample size not identified (n=1)

Included

Studies included in narrative synthesis
(n=114)

Research with disabled children (n=8)

Others as proxies (n=47)

Research on children with disabilities (n=59)

Figure 1: PRISMA flow chart

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From the 114 papers, the number of participants in the included studies ranged from 14 (Broadbent et al, 2004) to 1128 (Nelson et al, 2011) (see Appendix 2). The age of the children in the included studies ranged from birth (Alaki & Bakry, 2012) to 16 years of age (Al Habashneh et al, 2012). Different types of study designs were retrieved from the research. As can be seen from Appendix 2 and Table 2, most of the included studies were of a cross-sectional study design, which accounted for 32.5% of the total papers. Next came case-controlled studies 14.0%, comparative studies (13.2%), prospective studies (2.6%), observational studies (1.8%), interventional studies (0.9%), retrospective studies (0.9%), and qualitative studies (0.9%). However, 33.3% of papers appeared not to report the type of the study design and this has implications for the quality of the research.

Table 2. Number of studies by the type of study

Type of Study	Number of articles (% of total)
Cross sectional	37 (32.5%)
Case controlled	16 (14.0%)
Comparative	15 (13.2%)
Prospective	3 (2.6%)
Observational	2 (1.8%)
Interventional	1 (0.9%)
Retrospective	1 (0.9%)
Qualitative study	1(0.9%)
Unknown	38 (33.3%)

The studies of this systematic review were conducted in 31 different countries; the majority of the research was carried out in Brazil (21.1%) and India (20.2%) (Alaki & Bakry, 2012; Broadbent et al, 2004) (Figure 2). Although most of the research reporting oral health research and disabled children were from Brazil, the research studies which were with and actually involved them (category 4) were from India n=2, Sweden n=2, Saudi Arabia n=1, Turkey n=1, Hong Kong n=1 and United Kingdom n=1.
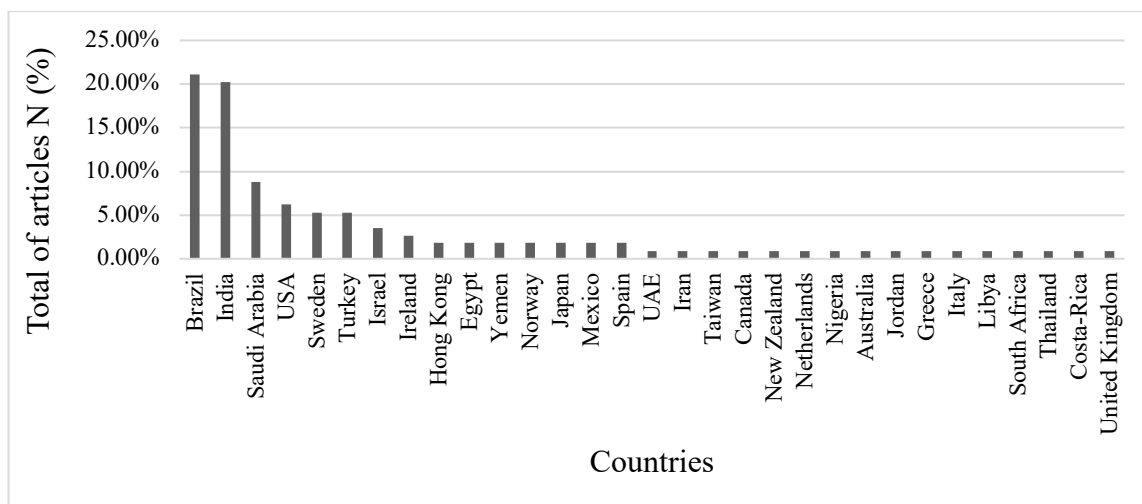
Figure 2: Percentage of papers according to country

This systematic review included a wide range of impairments. For example, intellectual disabilities (which encompass mental disability, developmental disabilities, learning disabilities, mental retardation and cognitive impairment), plus sensory disabilities were included as illustrated in Table 3. The majority of the studies (n=91, 79.8%) recruited children who had the same type of impairment, while (n=23, 20.2%) studies included children with multiple disabilities.

Table 3: Number of studies by type of disability

Type of impairment	Total of articles N (%)
Mixed	23 (20.2%)
Down syndrome	22 (19.3%)
Cerebral Palsy	19 (16.7%)
ADHD	15 (13.2%)
Autism	14 (12.3%)
Intellectual disability	12 (10.5%)
Visual impairment	5 (4.4 %)
Hearing impairment	2 (1.8%)
Foetal alcohol syndrome	1 (0.9%)
Poliomyelitis	1 (0.9%)

Of the 114 papers, 10.5 % used the word "retarded" to describe disabled children, 36.8% "healthy", and 30.7% "normal" to describe non-disabled peers when comparing them with disabled children. 1% used the word "disorder" to describe disabled children alongside language which medicalised children in terms of their impairment by placing

the condition first and the child last, for example cerebral palsy children, autistic spectrum disorder children, mentally disabled children, Down syndrome children, or handicapped children.

Research with Children

Of the 114 included articles, only 8 (7.02%) (Table 1) were categorised as research *with* children. However, none of them viewed disabled children as active participants sharing power and responsibility for the research design and process, in other words, they were not involved in the design and conduct of research nor was the child's perspective taken into consideration in the research design. These eight papers were categorised as the fourth category; research *with* children, where disabled children were the subjects of research. In these articles, disabled children were involved by completing measures wholly designed by adults without children's input into the format of the measures. In one of the included papers, disabled children contributed by describing their oral health and their experiences of dental health services in their own words using a qualitative approach (category 4a) (Yesudian et al, 2012). The remaining papers used a close-ended oral or written questionnaire answered by children regarding their oral health, dental hygiene habits or the dietary habits (category 4b) (Blomqvist et al, 2007; Chu & Lo, 2010).

Use of Proxies

Out of 114 included studies, forty-seven (41.2%) used proxies to gain the view of disabled children. These reports used parents/caregivers (category 5a), and none of them used clinicians as a proxy.

Research on Children

Finally, as can be seen in Table 1, over half of the included studies 59 (51.8%) were classified as research on disabled children, where children were not heard or listened to, but only seen (category 6). These articles express the idea of disabled children as the objects of research, without enabling their participation or inclusion of their perspectives or that of their parents.

1.4 Discussion

This systematic review presents a hierarchy of the participation of disabled children in oral health research ranging from full participation in the research process to no participation. When these classifications were applied to the identified and collected published articles about the oral health of disabled children from 2001-2017, most studies used disabled children as objects with no other participation. This review raises the importance of conducting more studies in the future with disabled children to capture their own experiences of oral health and service provision.

This compares with the results of the systematic review of adults with intellectual disabilities, which identified that the majority of articles (82%) viewed them as objects in oral health research (Whelan et al, 2010). It also contrasts with the results of the previous systematic reviews of children in dental research which suggest that children have become increasingly involved in oral health research (Marshman et al, 2007; Marshman et al, 2015). These studies found an increase of 17.4% in 2006 to 2014 compared with 7.3% from 2000 to 2005 and a decrease of 87.1% to 64.2% in the number of studies viewing children as objects in oral health research was also found (Marshman et al, 2007; Marshman et al, 2015). This indicates that since the first systematic review, oral health research has moved more towards research with children rather than on them. In contrast, our findings suggest the opposite concerning the position of disabled children in oral health research. This may be indicative of the way dental research considers disabled children as somehow different from their peers because the two groups of children appear not to be treated equally in research. It also suggests that disability may be a reason for their exclusion rather than their age. We can further argue that diversity amongst children appears to be neglected, and there is an assumption that they are all the same. If we consider children as a diverse body, it makes an important contribution towards the promotion of equality. By failing to include disabled children in oral health research, we are denying them a voice. This contradicts the values behind the social model of disability, which sees society as the cause of disability because it erects barriers to participation, a position supported by the aims of the UNCRC.

In terms of equality and diversity and with the introduction of the Equality Act (2010), it may be claimed that all research with children has a duty to treat disabled children equally and protect them from discrimination. Failing to include disabled children in consultations, planning, and research, along with their peers might be construed as discrimination as case law gradually becomes established. Indeed, assumptions about a child's competence or ability to take part in research can contribute to both their social and political vulnerability because we are justifying their exclusion from decision-making about their lives (Qvortrup, 1994). In terms of health, including oral health, failing to include children and young people in research about them means that we are also failing to recognise their diversity as well as denying them a voice, adding to their existing marginalisation in society.

The most striking finding is that none of the reports involved disabled children as active participants, sharing power and responsibility for the research process and design. Only 7.02% of the articles were categorised as research with children, but where disabled children were seen as the subjects of research (category 4). Children in these articles were not involved in the conduct of the research but were asked to complete measures, which were wholly designed by adults. The perspectives of disabled children had not been considered in the research design.

Two of the articles in this systematic review demonstrated that disabled children could participate in research through the use of inclusive research methods (Al-Sarheed et al, 2014; Prashanth et al, 2011). In the first study, self-perception and need for orthodontic treatment for children with visual (VI) and hearing (HI) impairments were determined by asking each child to rate his/her dental attractiveness. This was performed using the 10-point aesthetic component of the Index of Orthodontic Treatment Need (IOTN) for the control group and HI group, while four tactile graphics were used for the VI group. In the paper by Prashanth et al. (2011), a questionnaire regarding oral health practices and knowledge of children with visual impairments was conducted verbally. Although in these studies, there was a particular focus on children with sensory impairments which might be a common choice made by clinical researchers who possibly understand this as amongst the "easiest" disabled group to work with; they might also be examples of the importance of using inclusive methods in research. Moreover, one of the studies in this review suggested that using a qualitative approach and participatory activities,

enabled children with learning disabilities to describe their experiences of oral health and services (Yesudian et al, 2012). Despite the claims in this paper concerning participatory methods, inclusion and recognising children's abilities, the researchers without children's input or choice selected the methods.

We can discuss the exclusion of disabled children in research in different ways. Perhaps, they are simply ignored as potential contributors, which suggests that they are not viewed as possessing agency (Markham et al, 2009). They might be unseen in some societies because of their absence from community activities and schools, and therefore more difficult to recruit. Furthermore, the adult gatekeeper may suppose that disabled children are unable to express their views or have nothing to say. In this situation, children are being judged according to their disability, rather than their ability (Press et al, 2011). Finally, including disabled children in research might be considered as more time consuming, expensive and methodologically challenging because it also requires particular skill sets on the part of the researcher.

About 41.2% of the reviewed articles involved parents/carers as a proxy for disabled children (category 5 a) and none of them used clinicians. This increase in using proxies for disabled children suggests that dental researchers might still assume that they are unreliable contributors for oral health research. Although we cannot rely on adult proxy reports of the experiences of disabled children alone (Markham et al, 2009), it is significant to acknowledge that parents are skilled interpreters of their children's signals (Press et al, 2011) and as such researchers may be using the person that knows the child the best in order to elicit views. Previous research does indicate that the parent's interactional skills, combined with the use of inclusive research methods, influences successful communication with disabled children (McWilliam, 2010). We can suggest here that using parents as proxies should complement the views of disabled children rather than be used as a substitute. This is because using proxies might not reflect children's oral health experiences, which has already been acknowledged as a limitation in one of the articles included in this systematic review (Abanto et al, 2012). We can also suggest that parents might be addressing their own agendas and again we exclude children and lose the impact of their voices.

One of the included articles reported that oral hygiene data for children with autism was obtained from their parents/caregivers. In contrast, the data for children without autism was obtained from the children themselves (Namal et al, 2007). Researchers in this article may have assumed that children would be difficult to understand or unable to contribute and there is a generalised perception in some of the articles that children with autism have "difficulty interacting with people and understanding and following instructions" (Subramaniam & Gupta, 2011, p. 44). This discriminates against disabled children when compared to their peers in oral health research and is in tension with a rights-based approach to research. The rights of disabled children to be consulted and included are reinforced by the social model of disability which promotes participatory research (Oliver, 1996). Other researchers are critical of an approach that reifies the distinction between disabled and non-disabled children, suggesting that this division has merely worked to marginalise disabled children in research, practice, services, and policy (Davis & Watson, 2001).

Most of the included papers, 59 (51.8 %) presented research where disabled children were not heard or listened to but only seen (category 6). These papers were predominantly aimed at surveying dental health status, estimating treatment needs, and comparing disabled and non-disabled children's oral health status. In these papers, disabled children are mainly seen as passive objects rather than as active participants in the research process. An example of research on disabled children is observed in one study, which aimed to assess and compare the oral health status, and treatment needs of disabled and non-disabled children, this was achieved by conducting an oral clinical examination for the children (Purohit et al, 2010). These 59 papers indicate that disabled children were not consulted in any way, illustrating the importance of using inclusive research methods to enable participation in oral health research, simultaneously valuing their views.

The largest volume of research relating to the oral health of disabled children originated from Brazil followed by India. This might simply reflect a high number of active researchers and dental institutes within these countries. In contrast, there might be other facilitators encouraging the conduct of research studies such as lack of bureaucratic, ethical and governance processes and funding availability. There were also differences between the countries where the study involved disabled children in the research

process. These (category 4) were from India n=2, Sweden n=2, United Kingdom n=1, Saudi Arabia n=1, Turkey n=1 and Hong Kong n=1. The single most striking observation to emerge from comparing this finding with the previous systematic reviews (Marshman et al, 2015) was that none of the papers originated from the UK where children were actively involved throughout the research process. The reason might be that researchers in the UK have involved disabled children as a part of the category of child and not considered the diversity of the group, although we would expect to see a range of inclusive methods in the studies to ensure participation by all children. One suggestion here is that there appears to be enormous scope for international collaborative research within the field of oral health with disabled children.

The type of language used in many of the included articles to describe disabled and non-disabled children is unacceptable with comparisons between "retarded" and "normal" or "healthy" children. Referring to non-disabled children as "normal children" or "healthy children" implies that disabled children are abnormal, deviant, strange or unhealthy which reflects the medical model of disability, individualising disability and placing it within the person. Terms that medicalise children such as "the Down's syndrome child" or the "cerebral palsy child" are also unacceptable because they objectify and dehumanise children, undermining their worth. These terms and ways of viewing disabled children are also considered negative and offensive by disabled and non-disabled people alike. Using language that affords dignity and respect for disabled children, viewing them as active individuals with agency should be advocated in future oral health research.

1.5   Limitations of the study

It is acknowledged that the current systematic review has some limitations. The search was limited to the English language, three main electronic databases, and dental journals for practical reasons and because they mirror the designs of the previous systematic reviews. This means that some related studies might have been overlooked, particularly those written in languages other than English. Another limitation is the problematic use of the term "case-control" in the studies which is poorly defined. For example, studies where the oral health of disabled children is compared to those without

disabilities should not be defined as "case-control". This is because cases of disease are not identified and matched with controls that do not have the disease and then supposed risk factors for the disease explored. Instead, they are poorly designed cross-sectional studies. These study classifications are those of the original authors and not our own.

1.6   Summary

The results of this review suggest that in the majority of oral health research, disabled children are seen, but not heard or listened to. One recommendation is that future research should attempt to include disabled children in oral health research by designing studies using innovative methodologies, drawn from different disciplines, as far as possible. This aims towards a rights-based approach to avoid discrimination and disempowerment by including their voices in research that concerns them. Obtaining their perspectives through listening and acting upon their voices aims to improve the oral health outcomes of disabled children.

1.7   Implications for this thesis

The results of this systematic review highlight the gap in the current knowledge base. The review suggests the routine exclusion of disabled children, apart from one tokenistic paper, from oral health research. There is a dearth of research viewing disabled children as active participants sharing power and responsibility for the research design and process, in other words, they were not involved in the design and conduct of research nor was the child's perspective consistently taken into consideration. Most studies used proxies to gain the view of disabled children or used disabled children as objects with no other participation. This review raises the importance of conducting more studies in the future with disabled children to capture their own oral health experiences. Therefore, Study 2 in this thesis aims to address the current knowledge base gap by exploring ways of including disabled children in oral health.

1.8   Update to the systematic review

It is generally recognised that new evidence, even before the review is published, could replace the findings of systematic reviews (Beller et al, 2013). An update of this study was then carried out in January 2021 to determine if, since the completion of this PhD research, there had been some substantial change in the literature. As explained in the original systematic review (see Section 1.2), a repeated literature search was carried out, to find all relevant articles from 2017 onwards. The findings of this search are presented below.

1.8.1   Results from the updated search

An additional 745 papers were revealed in the search strategy. Titles and abstracts of 584 papers were screened against the inclusion and exclusion criteria following the removal of duplicates. In all, 62 full-text articles were obtained and screened against the inclusion criteria, at which point a further 23 articles were excluded. Thus, 39 extra records that qualified for inclusion were found in the repeated literature search.

From the 39 papers, the number of participants in the included studies ranged from 16 (Robertson et al, 2020) to 600 (Rajput et al, 2020) (see Appendix 2). The age of the children in the included studies ranged from birth to 16 years of age. Different types of study designs were retrieved from the research. As can be seen from Appendix 2, twelve of the included studies were cross-sectional studies, five prospective studies, three randomised clinical trials, two case-controlled studies, two experimental studies, one non-randomised clinical trials, one paired study, one interventional study, one qualitative study, with the rest not appearing to report the type of study.

The studies were conducted in 16 different countries; the majority of the research was carried out in Brazil (n= 10) and India (n= 6). This updated review included a wide range of impairments. For example, intellectual disabilities, physical disabilities and sensory disabilities were included, as illustrated in Appendix 2. The majority of the studies (n=33) recruited children who had the same type of impairment, while (n=6) studies included children with multiple disabilities.

Of the 39 papers, six used the word 'healthy', and two used the word 'normal' to describe non-disabled peers when comparing them with disabled children. Language used to describe disabled children was often disabling and portrayed them as abnormal and deviant.

Research with Children

Of the 39 included articles, only one study was categorised as research *with* children. This paper was categorised as the fourth category; research *with* children, where disabled children were the subjects of research. In this article, disabled children were involved by completing measures wholly designed by adults (category 4b) without children's input into the wording or format of the measures. This paper used a comprehensive questionnaire answered by children with or without attention deficit hyperactivity disorder (ADHD) regarding their oral hygiene and dietary habits; in cases with signs of dyslexia, their caregivers were available to assist (Ehlers et al, 2019). However, none of the included studies viewed disabled children as active participants sharing power and responsibility for the research design and process. In other words, they were not involved in the design and conduct of the research, nor was the child's perspective taken into consideration.

Use of Proxies

Eight of the 39 included studies used parents/caregivers as a proxy to gain the view of disabled children (category 5a).

Research on Children

The vast majority of papers (n = 30) involved research where disabled children were not listened to or heard, but only seen (category 6). These articles expressed the idea of disabled children as the objects of research, without enabling their participation or the inclusion of their perspectives or that of their parents.

1.8.2   Discussion

The results of the update were not dramatically different from those of the initial systematic review. The majority of the research used disabled children as objects with no other participation or used proxies to gain the views of disabled children. Significantly, since the original systematic review was published, only one study categorised as research with children, but where disabled children were seen as the research subjects.

Since the publication of the original review, the results of this updated review have served to demonstrate that the same gap in the knowledge base, which was addressed in this PhD thesis, has remained. By exploring ways of including disabled children in oral health, this thesis thus contributes to the body of work to date.

Literature review

1.9 Introduction

This chapter reviews the relevant literature around disabled children and oral health. It begins with the historical view of children inherited from the Victorian era and then moves to the recent rights-based approach that emphasises the importance of listening to children. Taking a rights-based approach means unpicking the concept of disability and the language used about disabled children and adults, which increases their exclusion from research and society. The chapter then moves to the oral health literature regarding research with disabled children, oral health, and related barriers. The chapter concludes with a review of research, including disabled children in research and methods of inclusion.

1.10 Policy context

Different historical eras have viewed children differently, from lacking the potential to be valid or competent research participants and conceptualised as 'not-yet-being' (Verhellen, 2000, p. 16) and 'adults in waiting' (Matthews & Limb, 1998, p. 67), viewing children as passive receivers lacking the competencies of adults. Seeing children as lacking in competence justifies them not being offered chances in order to experience responsibility (Such & Walker, 2005). In contrast, sociologists of childhood have highlighted the need to understand children as social actors who are experts on their own experiences and who have a fundamental right to be heard (James et al, 1998). This significant shift in thinking about children has been facilitated by policies and legislation to support the rights of children in all matters that affect them (Roulstone et al, 2011). This section clarifies how the inclusion of disabled and non-disabled children in decision-making, research and services has been developed and adopted within policy.

1.10.1 The United Nations Convention on the Rights of the Child (UNCRC)

The Convention on the Rights of the Child (CRC) was adopted by the United Nations in 1989 and almost every country in the world has been ratified it (UNICEF, 1989). This convention emphasised children and their rights in research agendas and policy making (Kallio, 2012). Of the UNCRC's 54 articles, article 12 was arguably the most influential of the articles for research, because it argued that children should have the right to express their views and to have their perspectives taken seriously in all matters that have an effect on them, including health research (UNICEF, 1989). In interpreting this article, UNICEF recognised the need to empower and enable children to consult, express their opinions and influence decisions through creating space and promoting planning for them. The evolving capacity of the child represents just one side of the equation, while the other side is the evolving capacity of the adults and their willingness to learn from and listen to children, consider, and understand their viewpoint, to re-evaluate children's views and to see solutions that adopt children's perceptions (www.unicef.org/crc). This illustrates that adult should support children to enable them to express their views in all matters related to them. Guidance from the UNCRC creates a driver to increase inclusion of children in policy as well as in research.

The UNCRC was also important for all children, regardless of their race, family, colour, religion, language, politics, sex, nationality, social origin, ethnicity, disability, birth or other source of difference. This is evident in Article 2 of the UNCRC, which established the principle for the promotion of all children's rights without discrimination; therefore, the convention also has a profound impact on perceptions of disabled children (UNICEF, 1989).

Article 13 in this convention promotes the effective inclusion of children, mainly disabled children who might need a variety of communication approaches in order to support their views, enabling them to be heard and valued.

> *"The child shall have the right to freedom of expression: this right shall include the freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice"* (Article 13, UNICEF, 1989).

Article 13 indicates that children have the right to express their opinions and to request, receive and disseminate all types of ideas and information using a range of methods. The article emphasises that human communication takes a variety of forms and it is not only limited to language alone (Willow, 2002). This policy means that all children (including children with disabilities) should have the right to be treated as active members with their own interests, concerns and points of view in societies, communities and families (CRC, 2005). Furthermore, it implies that children's views, understandings and experiences should inform all decision-making, practices, research and planning concerning them.

The UNCRC has profiled the significance of children's views and this has meant that people have started to listen to children seriously throughout the world. The following table (Table 4) includes some international policies that reflect this policy through promoting children's rights in matters that affect them.

Table 4: Historical progression of policies that reflect the UNCRC

Policy	Country of origin	Emphasis
Children's Act 2004 (Office of Public Sector Information, 2004)	UK	Requiring welfare agencies to consider the best interests of children, their needs and desires.
National Service Framework for Children, Young People and Maternity Services (NSF) (Department of Health and Department for Education and Skills, 2004)	UK	Raising the quality of social care and health services that children receive by soliciting their consultation and involvement.
Commissioner for Children and Young People (Vardon Report Implementation Team, 2005)	Australia	Advocating and promoting the rights, wellbeing and interest of all children in Australia through considering their views.
Children's Act 2005, South Africa (Parliament of Sauth Africa, 2005)	South Africa	Supporting the rights of all children (including disabled children) in all matters related to them through considering their perspectives.

Valuing People (2001) and Valuing People Now, (2008)	UK	Emphasises the principals of choice, independence, civil rights and inclusion, facilitating the use of both person-centred approaches and advocacy for planning with individuals with intellectual disabilities
The Working Together, Listening to the Voices of Children and Young People (2008) (Department for Children, 2008)	UK	Promoting inclusion of children's views and young people in school decision-making.
Healthy lives, Brighter Futures (2009) and You're Welcome Quality Criteria (2006) (Department of Health and Department for Children, Schools and Families, 2009).	UK	Outlines plans to strengthen the involvement of children, young people and their parents in shaping services.
New Zealand's Youth Parliament (Ministry of Youth development, 2010)	New Zealand	Promoting inclusion, the children's views
Law on Child Care (Kragh-Müller & Isbell, 2011)	Denmark	Requires that children's perceptions of their own childcare should be collected annually and posted for parents and other people to be used when they make a decision about which childcare centres to attend.
The Council of Europe's 'Guidelines on Child-Friendly Health' (COE, 2011)	European countries	Advocating the rights of children to healthcare. It also emphasises the need for the protection and recognition of children's rights in healthcare.
Youth Participation in Decision Making and Policy Implementation (2011-2015) (UNDP, 2011).	Azerbaijan	Empowering young people to participate in decision making through participating in policy planning and policy outcomes

Western guidance developed most of these policies for different sectors such as health and education, while there is limited knowledge about listening to children outside of western backgrounds. What is clear from the emphasis within this guidance is that these policies place the onus on researchers and services in order to ensure children's views on matters that affect them are taken into account.

1.10.2 The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The United Nations Convention ratified the Rights of Persons with Disabilities in 2006. The convention sets out what human rights mean in the context of disability and aims to protect the rights and dignity of disabled children. UNCRPD parties are obliged to ensure that disabled children enjoy human rights and full equality under the law. The convention represents a significant movement from seeing disabled children as an object of medical care, social protection and charity toward viewing them as an equal and full member of society with human rights. This is apparent particularly in Article 7 of the UNCRPD, which states that

> *"[...] Children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right."* (UNCRPD, 2006 Article 7).

Both the UNCRC and the UNCRPD promote the rights of disabled and non-disabled children to have their views taken seriously in all matters related to them.

1.10.3 Summary

There has been a significant awareness within policies over the last 20 years of the significance of children's involvement in all matters that affect them; this has triggered a global change towards improving children's rights. This positive step forwards also recognises the rights of disabled and non-disabled children to be included in research and in decisions relating to children's concerns, of course, this may depend on how society views disability and in turn disabled children, this is something I will now consider in the next section.

1.11 The concept of disability

1.11.1 Introduction

Disability is an umbrella term that has been defined in many different ways over the years, with explanations influenced by various social, historical, and ideological practices (Connors, 2003). Despite this diversity of understanding, the medical and social models have been the two most prominent models of disability discourse for over the past 50 years. These disability models provide a framework for understanding the ways in which disabled people perceive and experience disability and how society perceives them. These theoretical models offer a reference for society in which social structures, and laws are developed (Oliver, 1996). This section briefly outlines the literature concerning the medical and social models of disability and the biopsychosocial model of disability. The primary objective here is to understand how the different models of disability have an effect on our understanding and approach towards disabled people, the application in research, the law and services that concern disabled people.

1.11.2 The individual/ medical model of disability

By the early nineteenth century, the individual approach to disability saw medicine as the solution through diagnosis and amelioration (Barnes, 2010). Although it had no name at the time, the primary focus of this model is on physical abnormality, deficiency or disorder due to damage or a disease process and the way in which this, in turn, produces functional limitations or some degree of disability. For example, a person who has quadriplegia cannot use their arms and as a result may experience difficulty dressing or washing. Nevertheless, this functional incapacity is the foundation for categorisation of the person. The lack of function becomes the defining characteristic of disabled people and generalised to all areas of their lives. This forms the base for a 'personal tragedy approach', where a person is the victim of some tragic occurrence or circumstance. It also views the individual in need of attention, care and dependent on others; this view has become translated into social policies (for example, welfare policies) which aim to help disabled people cope with their disability and is not always a supportive perception (Finkelstein, 1993; Oliver, 1996).

The recommended solution from the medical model perspective lies in rehabilitative and therapeutic intervention, with a rising participation of associated health practitioners, psychologists, occupational therapists and educationalists. This illustrates that a person becomes an object of professional attention from diagnosis. In this case, the expert is the one who defines the individual's needs and decides solutions to minimise or overcome the consequences of disability. The rehabilitative emphasis has supported an increasing range of policy initiatives proposed by numerous qualified experts in order to tackle the personal difficulties and 'special needs' of disabled people (Barnes, 1999). Diagnosis of the intellectual or physical impairment and advising on proper treatment is the fundamental medical concern. Within some countries, there is a policy interest and associated administration in interpreting the person's disability for particular needs for services and welfare benefits (Albrecht, 1976). In the UK, this has stimulated a debate concerning what constitutes the most appropriate description and measure of disability.

Initially, the person's 'abnormality or loss' was a particular level of incapacity. To illustrate, the British National Insurance Benefit Regulations in the 1960s advised that the amputation of a foot and the loss of three fingers or the loss of an eye was given a 30 percent score, while losing fingers and a leg amputated under the knee afforded a 50 percent disability (Sainsbury, 1973). This mechanistic approach has been heavily criticised by social researchers and policymakers. There was also a widening of the description of disability to include:

1. Psychological, physiological or anatomical loss or abnormality, for example as an individual without an arm or a leg, paralysed or blind.
2. Chronic illnesses that interfere with psychological or physiological processes, like epilepsy, schizophrenia and arthritis (Townsend, 1979).

Reinterpretation of physical incapacity became the inability to do essential activities of daily life. This approach was the basis for the first national survey of 'disability' in Britain, which was done by the Office of Population Censuses and Surveys (OPCS-renamed the Office for National Statistics in 1997) in 1968-9 (Harris et al, 1971) and in the 1980s (Martin et al, 1988).

The focus of this debate was on measurement and technical issues regarding the best predictor of the service needs of the individual. For example, the range of activities involved; whether all activities must be similarly weighted; whether allowance must be made for changing ability over time and between social contexts and within social groups (Sainsbury, 1973; Townsend, 1979). The trend has been to extend the range of activity limits beyond immediate self-care, for example, washing to involve a variety of other daily activities (Charlton et al, 1983). This led to the WHO's provision of the International Classification of Disease (ICD) (WHO, 1976). The structure of the ICD describes the consequences of disease, which was the most important intervention in these debates. These discussions stemmed in a threefold distinction in the development of the new International Classification of Impairments, Disabilities and Handicaps (ICIDH), in 1981. The key terms defined in the explanatory document (WHO, 1980) are as follows:

- Impairment: any abnormality or loss of physiological, psychological or anatomical function or structure.
- Disability: any limitation or lack of capacity for a human being to do normal activity due to impairment.
- Handicap: a disadvantage to a person arising from an impairment or disability that restricts or prevents the fulfilment of a normal role (subject on gender, age, cultural and social factors) for that person (WHO, 1980).

This definition of impairment includes the parts of the body that limit the individual, and disability focuses on restriction from participation in activities because of their impairment. However, most of the novelty of the WHO schema lies in the meaning of handicap. This extends the concept of 'consequences' to difficulties in the accomplishment of a social role, through acknowledging these differences within cultural contexts and social groups.

The definitions and measurement of disability in both the ICIDH approach and OPCS have generated significant critical debate. One of the critical points is that this approach relies mainly on medical definitions and the way in which disabled people are seen as unable to contribute to society without considering the impact of the community in

disabling their life (UPIAS, 1976; Oliver, 1996). In both the ICIDH approach and the OPCS studies, disability and handicap create impairment and the way to overcome disability is through rehabilitative and therapeutic interventions, while ignoring the disabling barriers created by society. Further critique of the medical model is that it places individuals with impairments in a reliant position, medicalising impairment and confirming the dependence of disabled people on professional experts to deliver treatment and social support, with little weight given to their experiences (Barnes, 1999).

Finally, this model also presumes that disabled people can make every effort to adjust to the mainstream social system. This is linked to Wolfersberger's proposal around normalisation and the closure of long stay institutions, which were viewed as preventing disabled people from living a 'normal' life, albeit with support (Wolfensberger, 1972). This approach is limited since it perceives disabled people to be adaptable, placing the responsibility for change on them, rather than on society. Using the social model of disability suggests that any meaningful solution focuses on societal change rather than personal rehabilitation and adjustment, so the responsibility lies within society to adapt it rather than excluding disabled people.

1.11.3 The social model of disability

Disabled activists and their organisations expressed criticism about the medical paradigm of disability during the 1970s and 1980s. In the publication of the Fundamental Principles of Disability, the Union of the Physically Impaired Against Segregation (UPIAS) redefined disability by emphasising that environmental factors contribute towards disability, thus shifting the focus of disability discourse from individual to society (UPIAS, 1976).

> *"In our view, it is the society, which disables physically impaired people. Disability is something imposed on top of our impairment by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society."* (UPIAS, 1976, p. 14).

Based on this reconstructed understanding, UPIAS rejected linking disability, impairment, and handicap. While the medical definition of impairment is broadly accepted, a radical reinterpretation of the definition of disability occurred.

> *"Thus, we define impairment as lacking part or all of a limb, organ or mechanism of the body and disability as the disadvantage or restrictions of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities"* (UPIAS, 1976, p. 14).

The definition of disability in this document was a starting point for the social model of disability (Oliver, 1981; 1990). The social model breaks the traditional causal relation between disability and impairment. It does not reject the reality of impairment, but impairment is not essentially an adequate condition of disability. The social model emphasises the environmental, cultural and economic barriers, which prevent disabled people from performing at the same level as non-disabled people, and not on the mind or body functions (Oliver, 1996). Consequently, Oliver (1996) argues that redesigning society to meet the requirements of disabled people is needed. Shakespeare (2006) also talks about society's 'moral responsibility' to remove social barriers to create an inclusive environment where disabled people can participate in all aspects of social life. Oliver (1996) argues that overcoming disabling barriers involves challenging marginalising and discriminatory conditions.

On the other hand, the social model has been criticised because it may overlook the experience of impairment and reduces identification of physical differences (Crow, 1992; French, 1993; Morris, 1991). However, Oliver (1996) argues that the 'social model' has been adapted and does not deny the importance of impairment in the lives of disabled people but focuses on those social barriers built 'on top of' impairment. This research uses this position because it appreciates both physical differences and social disablement, are important factors that have an impact on the inclusion of disabled children in oral health.

1.11.4 The biopsychosocial model of disability

The criticism of the ICIDH, advanced mainly by policy makers, mainstream researchers and organisations of disabled people, has led to the production of a revised version of WHO which is the "International Classification of Functioning, Disability, and Health" (ICIDH-2) that was officially authorised in 2001 (WHO, 2001). One of the resolutions involved the alteration of the acronym ICIHD-2 from the previous revised version to ICF, with the name remaining "International Classification of Functioning, Disability and Health" (WHO, 2001).

The ICF adopts a 'biopsychosocial model', which attempts to synthesise the medical and social model to disablement. In the ICF, disability and functioning are an outcome of the interaction between the individual with the health condition and contextual factors. The WHO used disability in the ICF as the umbrella term for impairment, activity limitation and restriction of participation, referring to the negative aspects of the person's interface with their environment. However, functioning is an umbrella term for all the positive aspects at all three levels (WHO, 2001).
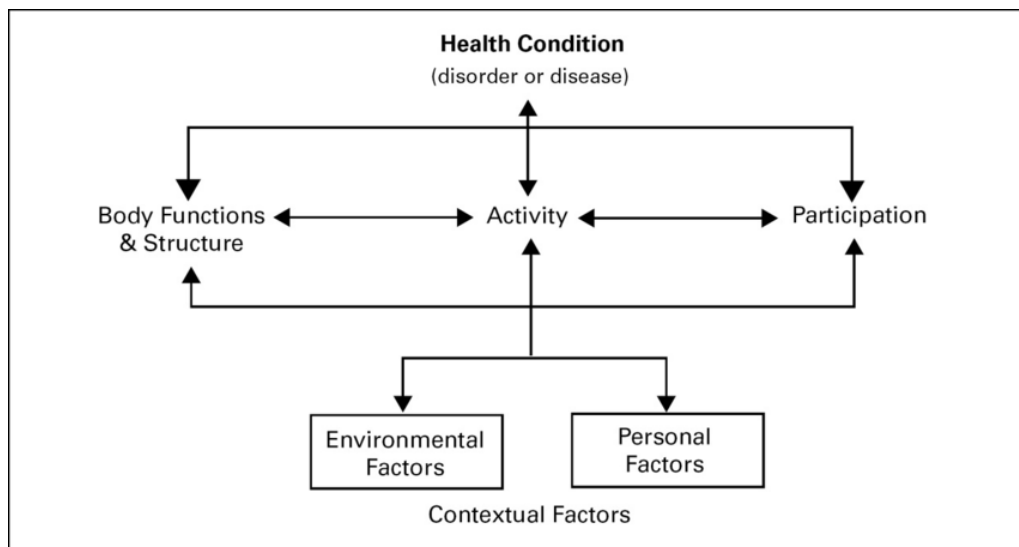
Figure 3: Graphic presentation of the ICF (WHO, 2001)

Figure 3 illustrates the ICF model where the health condition of the individual relates to the contextual factors to result in disability or function at one or more of the three levels. The health status in this model is an umbrella term for disorders, disease, injury or trauma that can be permanent or temporary and will include mental and/or physical

problems; the contextual factors are environmental and personal factors. The arrows are bi-directional linking the components of health (WHO, 2001). The three levels of functioning are further explained in Table 5.

Table 5: Three levels of functioning (ICF)

Term	Description
Body functions and structure. Body level	This indicates to the psychological and physiological functioning of the body system and the body structure, i.e., the anatomic parts such as the limbs, organs and their components. This term is similar to the impairment level used in the ICIDH.
Activities. Individual level	This indicates to the implementation of tasks or activities by a person. This is comparable to the disability level employed in the ICIDH.
Participation. Society level	This means the involvement of the individual in a life situation. It is considerably different from the handicap level used in the ICIDH.

The ICF model underlines the significance of environmental aspects, which refer to the social and physical environments where people are living, and personal factors, which are features of the individual that might affect the experience of disability, that influence functioning (Bickenbach et al, 1999).

The ICIDH and ICF models are similar in conceptualising the concept of disability as occurring at three levels of functioning and that this is the outcome of the interaction between individuals with the health disorder and their environment. However, there are some significant differences between ICIDH and ICF. Each model uses the term disability differently. In the ICIDH, disability refers to difficulties at a personal level. In the ICF, disability refers to a negative result of the interaction between a person who has a disorder and external environment and not merely a label applied to an individual (Bickenbach et al, 1999; Bornman, 2004). Therefore, it would appear that ICIDH aligns with the medical model, which views the individual as a tragic victim in need of treatment.

In contrast, the ICF illustrates the attempts to synthesise the social and medical model as more aligned to the social model of disability since the focus of the intervention in the ICF is situated not solely with the individual, but also within society. However,

although, the ICF tries to transcend the medical model of disability, it struggles to escape from its relationship with it. A systematic review reviewed the ICF from 2001 to 2009. Its use, operationalisation and implementation revealed that most papers, which are related to public health research, were around the rehabilitative and clinical use, which reflects the medical model of disability (Cerniauskaite et al, 2011).

1.11.5 Summary

In summary, the main thrust of the medical model is to present disability as a personal tragedy. It mainly focuses on an individual's functional limitations that in return cause social restrictions. Therefore, the primary policy response relies on personal rehabilitation and treatment. This model was consequently revised, with the introduction of the ICIDH (WHO, 1980), to allow for social conditions as a limitation to participation, while the primary causal connection to impairment remained intact.

Disabled people embarked on active movements against their marginalisation and exclusion from mainstream society and proposed the social model of disability as an alternative approach. This directed attention to the environmental and social barriers to inclusion. It illustrated an essential distinction between 'impairment', which is defined in medical terms and 'disability', which is identified as a social problem. More recently, the WHO constructed a biopsychosocial approach that is a synthesis of the medical and social model and removed the term handicap.

1.12 Change and usage of terminology

Understanding the concept of disability by changing from a medical model to a social model has played an important role in the development of language that is used for disabled people. The medical model, by definition, focused on what people 'cannot-do' because of their impairment. This led to the negative view that considered people only by their impairment. This view was amended by the social model of disability, which presented disability as a socially constructed problem and not a product of individual characteristics through the distinction between impairment and disability (Oliver, 1996). Oliver (1996) highlights the necessity of modifying the language used when referring to disability concerns and provides illustrations to exemplify the relationship to variations

in the current terminology. One example Oliver provides is changing the term 'care' to rights, and medicalisation to self-help.

In addition, a significant amount of terminology regarding disability has developed to refer to disabled people, which denies the social barriers that create disability. The British disabled people's civil rights movement considers terms such as 'spastic', 'cripple', and 'Mongol' for referring to disabled people as offensive because they have lost their original technical meaning, becoming discriminatory languages in the English-speaking world. However, this might be not equivalent in other languages since different cultures have different expressions for disabled people. The term 'handicap' was also linked to oppressive meanings in English speaking countries because of its historical connection with charity and begging or reduced capacity, while this is not always the situation in other languages (Barnes, 2010).

Some countries and organisations reject the term 'people with disabilities' because it suggests that the disabling effect rests within the person rather than caused by society. Using the term 'disabilities' in this context refers to a personal medical condition and, therefore, blurs the crucial conceptual dissimilarity between disability and impairment as in the social model of disability. Instead, the term 'disabled people' is more appropriate. This is because it illustrates the recognition that people are disabled by social barriers (Barnes et al, 2010). Terms that medicalise children for example the 'cerebral palsy child', 'the Down's syndrome child' or the 'mentally disabled children', through labelling them with these particular conditions, are also unacceptable because it is reductionist, dehumanises children and undermines their worth.

Therefore, the terms that imply a shift from traditional perspectives concerning disability from a medical capacity towards a more social understanding of disability should be advocated. The language that people use reflects and reinforces thinking and can affect how people are perceived and dealt with. If we regard the problem as being within the environment, systems, and cultures that create disabling barriers, the assumption is that more effort will be made to take different approaches than if we perceive that the problem is with the person. Using appropriate terminology (Table 6)

when referring to disabled people is an expression of respect because it constructs them as citizens with agency.

Table 6: Inclusive language: words to use and avoid when writing about disability (GOV.UK, 2017).

Avoid	Use
(The) disabled, (the) handicapped	Disabled (people)
Wheelchair-bound, confined to a wheelchair	Wheelchair user
Suffers from, victim of, afflicted by	Has [name of condition or impairment]
Spastic	Person with cerebral palsy
Cripple, invalid	Disabled person
Mentally defective, mentally handicapped retarded, subnormal	With a learning disability (singular) with learning disabilities (plural)
Mental patient, insane, mad	Individual with a mental health condition
Able-bodied, normal	Non-disabled
Fits, spells, attacks	Seizures
Dwarf; midget	Someone with restricted growth or short stature
An epileptic, diabetic, depressive, and so on	Individual with epilepsy, diabetes, depression
The blind	People with visual impairments
Deaf and dumb; deaf mute	User of British Sign Language (BSL), person with a hearing impairment

1.13 Epidemiology of disability (Worldwide)

It is difficult to provide a reliable estimation of the prevalence of disability based on the difficulty of defining the concept of disability and the variety of methods used in gathering data across countries. Based on the available data, the WHO uses two data sources to estimate the prevalence of disability: the WHO World Health Survey of 2002-2004, from 59 countries, and the WHO Global Burden of Disease study for 2004. The data from these sources are not equivalent since they use different methods for disability measurement and estimation. According to 2010 population estimates (6.9 billion with 1.86 billion under 15 years old), the available data shows that there are about 785 (15.6% consistent with the World Health Survey) to 975 (19.4% consistent with the Global Burden of Disease) million people 15 years and older living with a disability (WHO, 2011). Of these, the World Health Survey estimates that 110 (2.2%)

to 190 (3.8% according to the Global Burden of Disease) million have very significant difficulties in functioning. When children are included (about 15% of the world's population) over a billion individuals were assessed as living with a disability (WHO, 2011).

In terms of the estimated prevalence of disabled children, 13 million (0.7%) children aged 0–14 years experienced severe difficulties, and the number of children experiencing 'moderate or severe disability' was 93 million (5.1%) children, estimated by the Global Burden of Disease estimates (WHO, 2011). In 2005, estimations are 150 million disabled children below age 18 (UNICEF, 2005). It was also reported in a latest review of the literature in low and middle-income countries that the prevalence of disabled children was from 0.4% to 12.7% based on the assessment tool and the study (Maulik & Darmstadt, 2007). A review in low-income countries argued that the obstacles in recognising and defining the number of disabled people is because of the deficiency of national and language-specific instruments for measurement (Hartley & Newton, 2009). This might be the reason for the disparity in prevalence figures. It means that disabled children are not recognised or receive the services needed. The prevalence estimates of disabled people worldwide presented is not a definitive estimate but reflects present knowledge and available data. Knowing the number of disabled people and their circumstances is important because it might help to improve efforts to tackle the disabling barriers which in turn help to offer services to disabled people that enable inclusion in society (WHO, 2011).

In reviewing disability models, it appears that there is diversity in understanding the concept of disability, which differs between cultures and the characteristics of each society in various countries. The terms used in this research will follow current UK guidance. For example, employing the term 'disabled children' instead of 'children with disabilities', unless quoting from other works. This research will also employ the social model of disability meanings of the term's 'impairment' and 'disability', utilising the term 'impairment' to define the biological limitations. The understanding of disability as a form of social oppression rather than belonging to the child is acknowledged in this thesis. The next section will provide an overview of oral health and related barriers for disabled children.

1.14 Oral health and related barriers

1.14.1 Introduction

This section defines the concept of oral health and explains the significance of oral health. It provides a brief overview of published research on the oral health status of disabled children. It also provides a brief overview of the factors leading to poor oral health care for disabled children and highlights the obstacles to access to oral health faced by disabled patients.

1.14.2 Oral health

The WHO has made great efforts over the last ten years to highlight the value of oral health status as an important and integral part of general health (Petersen, 2003). Different descriptions have explained the notion of oral health. However, the "standard of health of the oral and related tissues which enables an individual to eat, speak and socialise without active disease, discomfort or embarrassment and which contributes to general well-being" was the broadened meaning of oral health that was stated by the Department of Health in England (1994, p. 2). This universal description mirrors the bio-psychosocial concepts of health. It combines the individual's ability to cope with their daily and social activities that lead to their well-being overall.

There is a growing body of literature recognising that influence of oral health on overall health, well-being and quality of life. Clusters of evidence highlight the impact of poor oral health on general physical health comprising important associations with major chronic diseases for example diabetes, cardiovascular disease, stroke and respiratory illness (Aida et al, 2011; Genco et al, 2001; Joshipura et al, 2003; Jung et al, 2011; Tada & Miura, 2012). Oral health of an individual not only effects general health but also has major effects on the quality of life, the psychological and social health of the individual. For example, poor oral health can cause dental pain and associated anxiety, difficulty in doing everyday tasks, impaired social interactions and reducing dietary intake (Alves et al, 2016; Couto et al, 2018; Hillebrecht et al, 2019; Locker & Slade, 1997; McGrath et al, 2019; Zhou et al, 2017). This highlights the importance of identifying appropriate interventions that can improve the oral health for disabled people and addressing contributing factors.

1.14.3 Oral health of disabled children

The existence of health disparities between disabled and non-people has been highlighted by recent evidence (Allerton et al, 2011; Emerson & Baines, 2011; Merrick & Merrick, 2007). Of particular concern is oral health for disabled people, as research has shown that this population suffers from poor oral health compared to non-disabled people, with dental problems ranging from tooth decay and gingivitis to severe periodontal disease (Wilson et al, 2019).

Individuals with intellectual disabilities have greater severity and a higher prevalence of periodontal disease compared with the general population (Anders & Davis, 2010; Campanaro et al, 2014). Dental caries prevalence in children with an intellectual disability is comparable to those of the general population (Robertson et al, 2019; Whelton et al, 2009). Nevertheless, their oral health deteriorates at a faster rate as they move into adulthood. More missing teeth, more untreated dental decay, and fewer restorations are found in adults with an intellectual disability compared with the general population (Anders & Davis, 2010; Catteau et al, 2011; Crowley et al, 2005; De Jongh et al, 2008; Hennequin et al, 2008; Morgan et al, 2012; Oliveira et al, 2013).

Disabled people, in particular, have also more complex oral health care needs compared to non-disabled people (Horwitz et al, 2000). Numerous studies have examined the clinical oral health condition of disabled children and have found significant dental care needs in comparison with the general population (Desai et al, 2001; Ivančić Jokić et al, 2007; O'Leary et al, 2007). This disparity is because of a myriad of risk factors that disabled people may face. These include obstacles to accessing quality oral health care, the need for assistance in basic tasks such as oral hygiene, communication problems, behavioural issues, elevated high intestinal nutrient prevalence, and a higher possibility of having lower education and income levels when compared to non-disabled (Kavanagh et al, 2012; Pradhan et al, 2009; Slack-Smith et al, 2010). It is well documented that people with low income and education levels rarely receive dental care facilities, and consequently, have higher rates of tooth loss and tooth decay (Chrisopoulos et al, 2016). People, especially those with challenges accessing dental services, should be invited to express their needs and expectations from dental encounters (Noushi & Bedos, 2020). Therefore, to achieve optimal oral health for

disabled children and to meet children's needs and preferences regarding dental care, the care system must place the person and their social well-being at the centre of decision-making and understand the factors that are spent outside the clinical settings, including individual behaviour, context and lifestyle (Ekman et al, 2011). Person-centred care emphasises communication during clinical encounters and the significance of dental professionals understanding patients' perspectives, expectations, and needs. They also state that the dentist and their patients should share the authority to choose the best treatment options (Noushi & Bedos, 2020). The systematic review undertaken here suggests that the voices of disabled children in the field of oral health have not been adequately considered and addressed yet and most studies have attempted to explore the views and experiences of parents/caregivers in oral health and dental care for disabled children (Al Wadi et al, 2018). This indicates that children are given less opportunities to be included as active participants with parent and clinician (triadic interactions) in the evaluation and planning of their oral health care. We, therefore, lack information on children's preferences about dental care. Failure to obtain the views and perspectives of disabled children and acting upon their voices impact the oral health outcomes of disabled children.

1.14.4 Barriers to oral health care and accessing dental services for disabled children

1.14.4.1 Barriers to oral health care

Factors that lead to poor oral hygiene practices among disabled persons comprise insufficient brushing techniques and a lack of training for caregivers (Anders & Davis, 2010). Disabled children may depend on family caregivers or paid carers for support with self and oral care. Insufficient training for caregivers can hinder quality oral care (Phadraig et al, 2014; Wilson et al, 2019). Other issues can be understaffing, a lack of time or low prioritisation of oral health   (Mac Giolla Phadraig et al, 2013; Wilson et al, 2019). There may be challenges with effective toothbrushing because of limited cooperation (Mac Giolla Phadraig et al, 2013); or carer concerns that tooth brushing is painful for a person (Chadwick et al, 2018). Other research reports that staff finding toothbrushing an unpleasant and invasive task (Mac Giolla Phadraig et al, 2013).

Studies also revealed that reduced oral health education for caregivers was correlated with a greater burden on caregivers and reduced preventive dental care use (Chi et al, 2014). The attitude of caregivers towards oral health was found to be relatively unsatisfactory even though their knowledge was sufficient, and this may constitute an obstacle to achieving good oral health care for disabled children (Shah et al, 2017). These pieces of evidence appear to indicate that caregivers may have a role in including or excluding disabled children in oral health care.

Barriers to accessing preventive oral care can also be individual, social, or cultural, such as fear of perceived need, educational level, and health literacy level (Hilton et al, 2007). Culturally influencing factors in oral health care include beliefs, behaviours, values, and attitudes for example, dental knowledge, concern for oral health, care of primary teeth, diet and infant feeding practices. To illustrate, belonging to a group in which a condition such as dental caries is endemic and may not be defined as a disease or belonging to a group where preventive dental care is not the norm (Scrimshaw, 2003) are ways in which cultural concerns can influence dental care. In a report on the status of oral health in the United States, residents indicate that people from specific ethnic minorities often have a poor oral health (Hunt et al, 1995; Sheiham & Watt, 1999) (US Department of Health and Human Services, 2000, cited in (Butani et al, 2008). Being part of an ethnic minority group does not necessarily refer to an individual with poor oral health. However, it does suggest that there may be some cultural practices and beliefs common to individuals in these groups that affect their oral health status. Therefore, cultural factors can have significant implications for the health of an individual and others for those who provide care, such as older people and children (Hilton et al, 2007; Loesche, 1985; Milnes, 1996; Riedy et al, 2001).

Moreover, educators can play an active role in promoting and preventing oral health as they interact with children daily, as well as have close contacts with families of children. Nevertheless, the lack of training and support for school educators in this regard creates a major obstacle to the successful implementation of programs for oral health education in schools (St Leger, 2000). Consequently, encouraging schoolteachers to play a main role in developing students' oral health habits is essential. In short, the knowledge and behaviour of caregivers about oral health, as well as the culture of

caregivers, can serve as barriers to include children in oral healthcare. Furthermore, disabled children face other barriers in accessing dental care.

1.14.4.2 Barriers to accessing dental care services

Research suggests that disabled individuals are more likely to have dental problems and untreated dental diseases (Steinberg, 2005; Waldman et al, 2010). Disabled people appear to have limited access to oral health care services, in addition to the poorer oral health outcomes, which may lead to oral health inequalities. Several studies conducted in different parts of the world have found that disabled people are more likely to experience inequalities in accessing dental care services (Al Agili et al, 2004; Koneru & Sigal, 2009; Prabhu et al, 2010). These studies explored the views of parents/caregivers of disabled adults and children in accessing dental care services, highlighting barriers, which include problems in finding dentists willing to treat their children (Al Agili et al, 2004), extended waiting times, difficulty with travel and access to clinics (Prabhu et al, 2010).

Some studies suggest that disabled people have limited access to dental care because of their mental or physical impairments, cost of treatment and insufficient funding of services (Adyanthaya et al, 2017; Fenton et al, 2003; Steinberg, 2005). Furthermore, the willingness and preparedness of dental care professionals to treat disabled patients may be a barrier to access (Ahmad et al, 2014; Dao et al, 2005; Matt et al, 2009). Dentists' attitudes towards and treatment of disabled adults and children were negative, but dentists did not receive special training, exposure or education around disabled adults and children and this could account for the negativity and obstacles to care provision (Campbell & McCaslin, 1983; Kleinert et al, 2007; Steinberg, 2005).

Studies conducted in Saudi Arabia identified similar barriers with the most common obstacles to accessing dental care being fear of the dentist, inability to sit on the dental chair, geographic location and transport difficulties, cost of treatment, dentist's unwillingness to treat disabled people, and a shortage of dentists who have advanced training in the management of disabled patients (Al-Shehri, 2012). A cross-sectional study conducted in Saudi Arabia illustrated parents' answers to the distributed questionnaire that more than half of the children (53.7%) had no previous experience of dental care. For 41.1% with access, no treatment was provided because of a lack of

cooperation, with only 4.9% of them successfully treated in regular sessions. Almost a third (33%) of children were treated under general anaesthesia (Murshid, 2011). Only 13.3% of caregivers reported that the lack of visits was due to the limited availability of dental clinics specialising in treating disabled children (Murshid, 2011). This appears to indicate oral health inequalities exist for disabled children.

Many previous studies have attempted to explore the views and experiences of parents/caregivers in oral health and dental care for disabled children. To date, there is a lack of research that have directly explored the views of disabled children about their oral health (Al Wadi et al, 2018).

1.14.5 Summary

In summary, this section has defined the concepts of oral health and provided a brief overview of published research on the oral health status of disabled children. It has also provided a brief overview of the factors contributing to poor oral health care for disabled children and highlighted the barriers and challenges facing disabled patients in accessing oral health care. It has identified that many studies involve parents and carers, but none directly solicit or include the views of disabled children, leaving their voices ignored.

1.15 Defining inclusion

1.15.1 Introduction

This section illustrates the importance of including the perspectives of all children in matters that have an effect on them and the definition of inclusive research. It describes ways to include disabled children in research. It also explains the possible reasons for their exclusion and presents some of the available evidence on the inclusion of disabled children in research.

1.15.2 Importance of including the perspectives of disabled children

Since the increased acknowledgement of children's rights over the last decade within legislation (UNICEF, 1989), the importance of children's inclusion has been recognised

which is often grouped into legal, political, and social reasons (Sinclair and Franklin, 2000; Willow, 2002).

Sinclair and Franklin (2000) have outlined the reasons for including the perspectives of children in various ways: to fulfil legal responsibilities as in the UN Convention on the Rights of the Child (UNICEF, 1989), to support children's rights, to improve decision making, to improve services that provided for children, to promote children's protection, and to enhance democratic processes and children's skills. One argument is that listening to children's views is a way of including and respecting those who were previously marginalised, leading to the improvement of children's relationships with adults and chances for contributors to increase their learning, knowledge and to develop their communication and social skills (Willow, 2002).

A considerable amount of literature has also been published on the benefits for organisations and children themselves from children's participation in all matters related to them (Badham & Wade, 2005; Lansdown, 2011; Willow & Neale, 2004). The academic literature suggests children's participation improves the quality of services and enables resources to be aimed more efficiently, which might have a positive impact on the economy. Children's inclusion also contributes to their personal development as it is argued that including children helps them to positively influence and support each other, develops their self-esteem, social skills and competence, increases responsibility and empathy, and provides opportunities to gain experience, skills and knowledge and extend their aspirations (Badham & Wade, 2005; Lansdown, 2011; Willow & Neale, 2004). Although many of the previously mentioned benefits were based on the insights of those contributed and was not formally documented (Kirby et al, 2003), it might deliver substantial support for the interests of children's participation for services and children themselves.

The benefits of including children in research can be seen in four key areas, including; the benefits of research itself; for evaluation and dissemination; for young contributors; and adult researchers (McLaughlin, 2006). Involving children in developing a research project can help prioritise topic areas, ensure age-appropriate material development, and can assist in recruitment strategies (McLaughlin, 2006). Research dissemination can be improved by engaging young researchers involved and ensuring future publications (For instance, patient information leaflets, participant research reports, etc.) are published in

a format that other young individuals are more likely to reach and easy to use. Effective participation in research can help develop thinking, discussion, and decision-making skills for young participants (Sinclair and Franklin, 2000). Additionally, there are benefits to adult researchers, for example, gaining a better understanding of the views of children and young individuals, learning new skills to ease communication and take advantage of youthful enthusiasm (McLaughlin, 2006).

Disabled children have the same rights as non-disabled children, and it is argued that it is important to consult them about the support and the services that are provided for them because this group is more subject to medical treatment and assessment compared with their peers (Dickens, 2008). Priestley (2000) suggests that many disabled children are subject to increased surveillance in their daily lives, which might lead to their disempowerment and strengthen adult control over their lives. Children have different perspectives compared to their parents (Lansdown, 2011) and place significance on the services and the support they receive. Therefore, decisions that are made by disabled children may improve the quality of a service if it is designed for them (Mitchell & Sloper, 2001; Morris, 1999).

However, Willow (2002) argues that focusing on the positive consequences of children's participation might sometimes obscure the fact that including children's voices is a human right. Therefore, children's inclusion in all matters related to them is a fundamental right, as stated in the UNCRC, more than a reason for gaining benefits for services, research, or children themselves.

In summary, many of the previous studies used a variety of participatory research approaches, to clarify the importance of children's participation in health services, research and on improving personal skills, it aimed to reflect the importance of supporting children's views in matters that affect them.

1.15.3 Defining inclusive research

The term inclusive research is not widely used but found notably in the field of learning difficulty research (Johnson & Walmsley, 2003; Walmsley, 2001). Inclusive research is itself "an umbrella term for people with learning difficulties involved in research as more than just respondents or subjects" (Walmsley, 2001, p. 188). This term has been

used to embrace a variety of research approaches that traditionally have been termed as 'emancipatory' or 'participatory' research (p. 10). Walmsley (2001) argued the need for a concept for this kind of research to be used across disciplines and fields since inclusive research, allows for the unclear and shifting boundaries between the traditional research approaches. It also has the benefit of being more readily clarified and less cumbersome for people who are unfamiliar with the academic debate around each concept and allows for the continuity and reciprocity between them. Emancipatory and participatory research approaches have a strong history gained from disability studies.

Table 7: Characteristics of participatory, emancipatory, and inclusive research. Source: adapted from (Johnson & Walmsley, 2003).

Participatory research	Emancipatory research	Inclusive research
- The research problem recognised either by non-disabled researchers or disabled people who then create it for the attention of non-disabled individuals - Disabled individuals work together with researchers in order to achieve the collective analysis of the research concerned - Agreements are formed between researchers, other experts and disabled people while these alliances should be under the control and mainly in the interest of disabled people (Chappell, 2000).	- Research must be used as a tool to improve the life of disabled people - It must be an opportunity for disabled people to be researchers - Funders and commissioners of research should be acted by the democratic organisations - Researchers must be responsible to the democratic administrations of disabled people (Oliver, 1996).	- Disabled people must be the ones who own the research problem and not necessarily initiated by them - Researchers must be on the side of disabled people, treat them with respect, and research must further the interests of disabled people - Research must be collaborative, meaning disabled individuals should be included in the research - Disabled people must be capable of employing some control over the outcome and process - The research process, reports and questions should be accessible to disabled individuals (Walmsley, 2001).

It can be summarised from Table 7, that when the emphasis is on participatory research, it should involve disabled people in conducting the study. Including them in planning the project, research design, collecting and analysing the data of the project, or/and the application and the distribution of the research results as well as research decision-making (Bourke, 2009). This definition highlights the participation of disabled people in conducting the research process instead of merely providing data for analysis (Nind, 2014). Although participatory research can express a transfer of power from researchers to research participants (Boyden & Ennew, 1997), disabled activists have argued that this kind of research should still be conducted under the control of non-disabled people. Stressing the emancipatory condition means research becomes part of the 'struggle for civil rights' in which disabled individuals should control rather than just participate in the research process (Walmsley, 2001, p. 195). Oliver (1996) endorsed emancipatory research with disabled people because it was about tackling social oppression. However, inclusive research, which covers the previous traditional types of research approaches, describes research according to the principals that research must follow which includes, that research should matter to disabled people, treat them with respect by the research community, and access and represent their experiences and views. This thesis will employ the term inclusive research because it is more appropriate for the research aim and the group of people with whom the research was conducted.

1.15.4 *How to include the perspectives of disabled children in research*

Despite the evidence revealing the effectiveness of a range of modalities for studying with non-disabled children, it is less frequent to see disabled children included in the research. In particular, young disabled children have been under represented in research and therefore, their perspectives usually become replaced by the views of the adults in their lives (Underwood et al, 2015). There are two significant aspects of supporting disabled children if they are to be successfully included in the research process (Rabiee et al, 2005). Firstly, understanding that communication is a two-way process (Rabiee et al. ibid.). This means that researchers should learn how disabled children communicate and reveal their views rather than forcing adults to form a communication method that requires speech of the disabled children. The additional aspect is designing communication-based approaches for disabled children to enable them to express their views and experiences.

Methods need to be adaptable and take into consideration the abilities of a range of individuals to support the diversity of disabled children to be included in the research. To illustrate, the inclusion of more non-verbal communication methods can diminish the influence of the language, speech, and communication needs. As Malchiodi (1998) suggested, drawing could help disabled children to express their views in ways that language cannot. Other modifications include spending more extended periods with disabled children when undertaking the task, listening, and emphasising ways that messages are given and received.

In the case of disabled children with severe intellectual disabilities or communication impairments, their inclusion in research frequently does not happen and there have been calls for more effort to include them in research (Morris, 2003). Several attempts have been made to draw together inclusive research with disabled children and describe the research methods used to seek their perspectives and views. A systematic review of 22 papers revealed that different techniques such as photography, cue cards, Talking Mats®, tape recordings and drawing could be used to include disabled children who employ non-verbal forms of communication (Bailey et al, 2015). Additional methods have been identified from the report that described the themes from five seminars in the United Kingdom (Carpenter & McConkey, 2012), comprising large-scale questionnaire surveys. Clover and colleagues believe (2010 cited in (Carpenter & McConkey, 2012) that children can express their views on paper by using large-scale questionnaire surveys; although this might not always be the case for disabled children. In contrast, Clarke and Wilkinson (2009) described the use of conversational analysis to evaluate the details of a video recording of the interaction between 'non-speaking' children. This approach is significant since very few studies have attempted to give an account of the views of children who cannot answer questions. However, analysis of non-verbal conversations relies mainly on the interpretations of the researchers, which might be not accurate, and it might represent the voice of adult over the voice of children (Clarke & Wilkinson, 2009).

Focusing on the voice over other forms of communication appears problematic because it can silence disabled children who do not use speech as a primary form of communication (Tisdall, 2012). Tisdall further suggests other approaches to

communication for example role-play, photography, drawing and observation. Added to these approaches are Talking Mats® effectiveness of which is described in two studies (Germain, 2004; Rabiee et al, 2005). This method is a visual framework that uses picture symbols that represent specific topics, emotions, and options used in sequences to identify the children's views about their lives. Results from these two studies showed the simplicity of these methods and suggested that these provide help for children who do not use verbal communication to be able to express their views with ease and in an enjoyable way.

Using flexible, non-rigid approaches to data collection permits places for creative and reactive methodological approaches to consult disabled children (Beresford, 1997). Based on qualitative researchers' experiences, different methodological approaches have been established (Davis et al, 2000; Marchant et al, 2001; Morris, 2003). An example of this is the ethnographic study carried out by Davis et al, (2000) in which they used a variety of qualitative methods comprising participant observation and interviewing to explore the experiences of disabled children. In terms of observing disabled children, different situations over time can expose the particular aspects of children's experience. Morris (2003) named this 'being with' (p. 345) a child as a means of knowing their experience. This might be valuable if the researchers observe the child in various settings in order to accrue knowledge of the child in each setting. Conversely, there is a risk that academics might impose their interpretation and views over the actions of the child. In general, these findings suggest the importance of using creative methods selected on what is suitable for disabled children to facilitate their communication, resulting in including them effectively in research that concerns them. Chapter 4 discusses other methods used with children in previous studies.

1.15.5 Including disabled children in research

In the field of childhood studies, the UNCRC has enhanced children's level of involvement in research by valuing children's rights to have a voice and have their opinions heard (James et al, 1998). James and colleagues (1998) explain how most studies until the 1990s gave little attention to children and viewed children as developmentally incomplete adults rather than as active contributors in research. This illustrates that research was conducted on children according to cultural attitudes

towards them. However, children's voices in research have become increasingly recognised (Barron, 2000) with the concurrent rise in emphasis on the views and rights of children. Social researchers shifted from viewing children as objects to promoting children to contribute actively in research (Christensen & James, 2008).

Despite the inclusion of disabled children in the two UN conventions; UNCRC, and UNCRPD, disabled children have been less commonly included in research (Beresford, 2012; Morris, 2003). This has ethical implications because excluding disabled children from research means that the diversity of children fails to be recognised and this leads us open to accusations of ableism. Historically, research on childhood and disability has either relied on adult's perspectives rather than the views and experiences of disabled children (Stalker & Connors, 2003) or has focused on children who were mostly verbally articulate (Fabbretti et al, 1997). Although we cannot rely on adult proxy reports of the experiences of disabled children alone (Markham et al, 2009), it is significant to acknowledge that parents/ carers are a good source for information about how their children already communicate (Dickins, 2004) and skilled interpreters of their children's signals (Press et al, 2011). Therefore, we can suggest here that using parents, as proxies should only be used to complement the views of disabled children rather than as a substitute.

Including children who are verbally articulate is possible because of perceived struggles with communication, access and negative assumptions about their abilities (Allsop et al, 2010; Beresford, 2012; Clavering & McLaughlin, 2010). Fundamental to achieving the overall aim of including disabled children in research is developing communication approaches, which enable disabled children to express their views and address the barriers that prevent their inclusion. This is emphasised in article 13 in the UNCRC that grants children the right to express, receive and information in any medium they desire (UNICEF, 1989) as mentioned earlier in this chapter. Including disabled children in research is significant; they are ideally employed to inform about what is beneficial for them and their families.

Nevertheless, a growing number of social researchers are focusing on using qualitative approaches in order to address the views of disabled children in research to improve

understandings of what is important to them. These scholars argue that it is not acceptable to exclude the voices of disabled children merely since they pose a challenge to traditional research approaches. Indeed, the onus is on academics to consider diversity more strongly when they design their research and adopt inclusive research strategies to enable disabled children to be active members in research (Ash et al, 1997; Connors, 2003; Davis et al, 2000; Minkes et al, 1994; Morris, 2003). These efforts in changing research methods may reflect shifts in the understanding of disability through applying the social model of disability instead of the medical model in researching disabled children. This knowledge, based on the social model of disability, may enable researchers to realise that the traditional research method, and not children's impairments, is one of the barriers that has prevented the involvement of disabled children in research.

There is some evidence that different disciplines include the voice of disabled children in different ways. Some of them include disabled children in studying children's views, generally without discrimination between disabled children and their peers (Thomas & O'Kane, 1999). Some academics include young people and disabled children in advising or doing the research (Ash et al, 1997). Others focus mainly on disabled children, identifying how research approaches should be adapted to enable them to be included in research about them (Beresford, 1997; Davis & Watson, 2000; Davis et al, 2000; Stalker & Connors, 2003).

Bailey and colleagues (2015) conducted a systematic review reviewing papers from 1946 to 2013 on how disabled children have been included in the research, challenges of recruitment, inclusion, overcoming barriers and the outcomes of involvement for research, and disabled children and young people. The researcher found nine examples where young people and disabled children have contributed as part of the research team. They were involved in activities at different stages of the research, included in designing the research project, interviewing, data analysis, and creating policies, reports, and presentations. Using a wide range of methods, such as photography, drawing and cue cards, talking mats, tape recordings and pictures enabled disabled children and young people to contribute, especially for those with non-verbal communication. Furthermore, involvement had a positive impact and increased self-

esteem, confidence and independence for disabled children and young people (Bailey et al, 2015). Communication can also be facilitated by familiar communicators or a trusted adult (Beresford, 2012). Overall, studies argue that researchers need sufficient time, training, skills and resources to enable successful interactions with disabled people (Cavet & Sloper, 2004; Delman, 2012; Sloper & Lightfoot, 2003). Therefore, pluralistic methods, which can be adapted according to the individual's need, are recommended for overcoming challenges of involvement (Cavet & Sloper, 2004; Delman, 2012). Most of the effects of involvement were the writers' opinions rather than data. Simultaneously, one of the included studies interviewed disabled children and young people about the impacts of their inclusion for them (Lightfoot & Sloper, 2003). However, although this review identified few examples of involving disabled children and the quality of evidence is low, it illustrates the importance of using a range of flexible methods to support disabled children to be included in research that concerns them. Study 1 Chapter 1 has already identified the routine exclusion of disabled children from oral health research (Alwadi et al, 2018). By failing to include disabled children in oral health research, we also deny those children a voice, which contradicts the values behind the social model of disability as well as the aim of the UNCRC.

1.16 Summary

It would appear that there are many factors preventing the inclusion of disabled children in oral health and research. These range from the perceptions around disabled children in a particular society, which can restrict their participation and fail to provide basic services. Then there are professional attitudes, which are often the result of a lack of education, exposure, and skill development. Then there are researcher skills, which research often points to a lack of effort with inclusive methods. Inclusive methods need to be adaptable and supportive of the abilities of disabled children to enable them to participate in issues that concern them. Moreover, global guidance from the UNCRC suggests that inclusion in research is a right for disabled children, and researchers should be thinking of creative ways to engender their involvement.

Introduction and background of the context: Kingdom of Saudi Arabia

1.17 Introduction

The Kingdom of Saudi Arabia (KSA) is the geographical context of the study. Therefore, this chapter presents the Kingdom, Saudi people's lives and the context for disabled children. The chapter also presents the Kingdom of Saudi Arabia as a Muslim country. It provides an overview of family life for disabled children in the Kingdom, through an outline of the structure of and explaining the significance of Saudi family relationships. This chapter also provides background information on the importance of Islam to the organisation of daily life, an outline of health services and oral health status in the Kingdom. Finally, there is a discussion about the meaning of disability and the rights of disabled people in the context of the KSA, providing the reader with background information about the cultural and social milieu.

1.18 Overview of Saudi Arabia

The Kingdom of Saudi Arabia became a country in 1932. It lies to the south part of the Asian continent, and it borders the Arabian Gulf and the Red Sea. KSA is the largest country in the Middle East, accounting for approximately 80 percent of the Arabian Peninsula. The total population in KSA is around 34,813,871 based on the latest United Nations estimates (UN 2020 estimate), and its capital city is Riyadh. The Saudi geography is diverse with mountain ranges, desert, grasslands and forests. This country holds the largest reserves of petroleum in the world and the industrial sector that is mostly gas and oil is the main source of wealth in KSA (Al-Rasheed, 2010).

The new 2030 vision for Saudi Arabia plans to reduce reliance on oil, grow its economy, and improve public service sectors such as health, education, leisure, tourism, and infrastructure (KSA, 2017). Targets comprise increasing trade between countries in the non-oil sector through goods and consumer products, encouraging economic and investment activities and increasing government expenditure on military, ammunition

and manufacturing equipment. This new plan includes 80 projects, each costing between $3.7 million and $20 million. The Council of Ministers has tasked the Council of Economic and Development Affairs to identify and monitor the basic mechanisms and procedures for implementing the "Saudi Arabia's Vision 2030" (KSA, 2017).

KSA is the leading heart of the Muslim faith in the world. This is because Islam began in Mecca, which is a city in the Kingdom, and Saudi Arabia is the guardian of two main holy mosques. Islam plays a main role in the political structure of KSA, and millions of Muslims go each year to the sites of the holy mosques to perform Hajj and Umrah (Farsy, 1990). This is what distinguishes this country from other developing Muslim countries (Khalifa, 2001).

1.19 The structure of family within Saudi culture

Over the centuries, the main feature of Saudi society remains religious, patriarchal and traditional (Yousuf Danish & Lawton Smith, 2012). The traditional extended family with dominant gender-roles is the basic unit of the society (Altamimi, 2015). Saudi society constructs the male role as the head of the family and in charge of responsibilities that are usually located outside the household, while female roles are homemakers, responsible for child-rearing and domestic matters within the home (Hamdan, 2005; Zamberi Ahmad, 2011). Husbands are responsible for supporting their children and wife financially (Künzler et al, 2001), although gender roles are changing with rapid modernisation. Currently, there seems to be male acceptance of expanding female participation outside the household in professional jobs, which is partly happening through the changing economy. There is some resistance at the same time, from males to play a more active role in managing the household and child-rearing. Adult children in Saudi Arabia remain in their families' home until they marry, although the period of time young adults continue to stay with their families has extended because over the past 30 years the age of marriage has increased (Long, 2005). Disabled children are also cared for by their families, rather than in an institution. Nevertheless, many family members do not have the knowledge or expertise in order to deliver appropriate or adequate care for a disabled child even though this kind of duty is part of Islamic tradition and law (Alsaif, 1992). A close relationship exists among

families and relatives, who make extensive efforts to sustain stable relations in the Kingdom.

The leading cause for the conventional extended family system's resilience in Saudi Arabia is the exceptional strength of traditional Islamic social, political and economic values. While behavioural patterns have changed over time, these fundamental values are hundreds of years old and held in high regard; therefore, any change will occur slowly (Long, 2003). Long (2003) argues that people in Saudi Arabia depend on the extended family for obtaining help, emotional and financial support. Family members usually respect the social principles of dignity and integrity. For example, parents might ask the grandparents about important matters such as marriage, respecting and valuing older family members for their wisdom. Understanding the Saudi family structure is important for this research because family relationships may have a significant impact on children's and mother's perspectives and experiences of oral health and dental care.

1.20 The structure of Islam and moderate daily life

In KSA, Islam offers guidance to individuals' lives as well as extending to the government's function and the policies. The Holy Qur'an is the constitution of Saudi Arabia and Islamic law, or 'Shari'ah', the legal system. 'Shari'ah' is the basis of law, built on the Qu'ran and Sunnah (Campbell, 2007). Islam dictates the general way of living. Religion regulates individuals, family relationships, societal organisation, business, nutrition, hygiene, etiquette, ways of dressing and much more.

Additionally, it covers the economic, social, political, public and private life of Saudi citizens. Saudi Nationals (recognised citizens) in KSA start studying the rules of Islam at an early stage in school as well as in the home. This means that Islam constructs and moderates the daily life of Saudi people. An example of this is while performing prayer five times a day (Salat), all businesses stop work, and all-male customers and workers pray together in an allocated area (North & Tripp, 2009). Women and children usually pray at home, while males pray with a group of males at allocated areas or mosques.

Another example, which illustrates how Islam regulates public life in KSA, is the religious holidays following the two religious' occasions of the year. Hajj (pilgrimage) season and the holy month of Ramadan. The Hajj season is where millions of Muslim pilgrims come to Makkah to perform Hajj. Eid Al-Adha is the end of this season in which it is conventional for families to slaughter a sheep. After they slaughter the sheep, they distribute meat to the poor people, friends, and relatives. During Ramadan, Muslims fast from dawn to sunset for a lunar month, which culminates with Eid-Al-Fitr. During this Eid, people usually wear new outfits, buy presents for children and visit relatives and friends (Cartwright-Jones, 2001).

In family life, Islamic duties to parents, particularly older people, are powerfully emphasised in Saudi culture. Thus, older Saudi individuals continue to stay with their families, and there are no residences, such as care homes for older people. This highlights the level of respect the culture has for older people and it also reflects a chance to seek the blessing of God (Trzaskowski et al, 2014). These examples illustrate how Islam moderates most matters in Saudi Arabia and not surprisingly, plays a significant role in oral health care.

1.21 Islam and oral health

Oral health in Islamic societies was initially dependent on dental knowledge that originates from the Quran and Hadiths (sayings of the Prophet Mohammed PBUH). Advice exists within the Quran for mouth cleansing by rinsing with water before prayer time five times a day. It is also emphasised in Hadiths by the Prophet Mohammed of using Miswak to maintain oral health (see Figure 4). Miswak is a small traditional stick with anti-bacterial properties and made from the twigs or roots of the Arak, Eucalyptus, and other trees used daily before each prayer time to keep oral health (Owens & Saeed, 2008). Older adults, a few children or younger people from rural areas mostly use Miswak to clean their teeth. Most young people use it as an extra aid with the toothbrush; however, older people believe that using Miswak is enough for cleaning their teeth (Scully & Wilson, 2006). Cultural values shape the interpretation and understanding of health and illness and thus, the behaviour of health care (Scully & Wilson, 2006).

Figure 4: The Miswak

Nowadays, people still tend to rinse their mouth with water daily, using a toothbrush rather than Miswak. Usually, Miswak is used in the holy month of Ramadan and during fasting since toothpaste and mouthwash are considered an offensive performance - makruh (Sirois et al, 2013). We can suggest here that some dental health practices seem to have become acceptable and included part of Islamic cultural practice. However, though, it is essential for people in Saudi Arabia to follow the rules of Islam, Islam encourages Muslim people to learn new sciences and adapt to improve their oral health

1.22   A brief overview of health and oral health system in Saudi Arabia

The Kingdom of SA established the services of health care in the first quarter of the 20th century. It then promulgated establishing The Ministry of Health (MOH) in 1954, providing free public health services at three levels: primary, secondary, and tertiary care for all Saudi people. The primary health care approach concentrates on prevention within primary health care service; these services help decrease the specialist and general hospital load. Even though the MOH in KSA take many steps in order to reform the health system, there are still some challenges in delivering health services, such as inaccessibility of some health care facilities, inadequate number of health care providers, and the shifting pattern of various diseases (Al-Yousuf et al, 2002; Almalki et al, 2011). The MOH also provides oral health services. Although, the Kingdom of SA has shown steady growth in the dental workforce over the last 20 years, demand still outstrips the number of qualified dentists (Saudi Ministry of Health, 2018).

1.23 Understanding disability in Saudi Arabia

Disability in the KSA is understood through cultural norms, legislation, and also through the lens of Islamic Sharia (Al-Jadid, 2013). Islam teaches people to treat disabled people equally and with respect. As per the Labour and Workmen Law of SA, a "person with a disability" is defined as "any person whose capacity to achieve and continue a suitable job has diminished as a result of a physical or mental infirmity" (KSA, 2002, p. 7). Disabled people refer to persons who have one or more of the following disabilities: hearing disability, visual disability, motor disability, cognitive disability, speech and language impairments, learning disabilities, pervasive developmental delay, behavioural problems, and multi-disabilities (KSA, 2002). This definition illustrates that Saudi Arabia tends to understand disability through the medical model of disability, rather than the social model of disability because it considers the primary cause of disability as impairment, not social barriers. Notwithstanding medical statistics gathered by the MOH for its annual reports, there are no reliable and regular disability reports, including the prevalence and incidence of disability and socio-demographic properties of disabled people, kinds of disabilities, or geographical distribution of disabilities in the Kingdom of SA (Al-Jadid, 2013).

1.23.1 The rights of disabled people in Saudi Arabia

Islamic laws contained within the Sharia regulate the KSA. Sharia stresses human rights, especially disabled people's right to live with dignity and benefit from welfare. The KSA had concentrated on disabled people since the introduction of its economic and social development strategies two decades ago (KSA, 2002). In 1987, the legislation of disability (LD) was approved as the first KSA legislation for disabled people. This legislation includes significant provisions that assure disabled people's rights are equal to those of their non-disabled peers in society. In 2000, the KSA government passed the disability code to pledge that disabled people have access to appropriate and free psychological, social, medical, rehabilitation and educational facilities throughout public agencies (Al-Jadid, 2013). In 2008, the KSA acceded to the Convention on the Rights of Persons with Disabilities, working diligently to merge the Convention into the local framework to become completely compliant. For this reason,

KSA created a committee under the Saudi Arabian Human Rights Commission in order to evaluate the situation of disabled people and advocate practical approaches to applying the Convention to produce a legitimate supportive infrastructure. In addition, the committee works with other countries to support global collaboration in overcoming challenges related to the application of a convention and offering financial support to other countries (Alsaif, 2017).

1.23.1.1 The right for healthcare

The MOH is concerned with therapeutic care, preventative methods to prevent disability, and medical rehabilitation. The MOH has established several rehabilitative services for disabled individuals and other citizens in the Kingdom. Most of these programs offer occupational, physical, orthotic and prosthetic services as well as hearing and speech therapies. Disabled people, in general, attend hospitals of the MOH because healthcare is free and includes rehabilitation. Secondary and tertiary hospitals all employ rehabilitation therapists (i.e., occupational therapists, physiotherapists, dieticians and speech therapists), if there is no therapist at the district hospital, children are referred to the nearest hospital that has a therapist (KSA, 2002).

1.23.1.2 The right to education

In KSA, offering free and proper education for all students, including disabled students, is the responsibility of the Ministry of Education (MOE). There are two main educational settings in the kingdom: inclusion where disabled students study in mainstream schools with their non-disabled peers and segregation, where disabled students are segregated and study in separate schools. Before 1957, disabled children in KSA did not receive any education, apart from religious instruction. It was the responsibility of their parents to teach them. The first special education services were provided for students with vision impairments since some educational agencies were encouraged to open evening classes to teach braille. Consequently, scientific institutes approved their application and opened these classes in 1957 (Battal, 2016).

In 1960, the MOE established a new school for pupils with vision impairments and then they established a new Special Education Department. The aim of this department was to provide academic, vocational, and social education for students with visual and hearing impairments and pupils with learning difficulties (Al-Mousa, 2010). In 1990, The Department of Special Education started to include disabled students in mainstream schooling (Al-Mousa, 2010). This shift towards inclusive education mirrors a real change in understanding disability and attitudes, from a caring viewpoint towards a perception that encompasses human rights and development.

In KSA, two kinds of inclusion exist. The first one is full inclusion, in which disabled students participate at least 50% of the time in a mainstream education classroom. However, they only receive special education services from special education teachers in subjects where they need additional help (Al-Mousa, 2010). Students with mild needs, for example, physical impairments, low vision, behavioural and emotional disturbances, and communication disorders are the targets of this type of inclusion (Al-Mousa, 2010). The other type of inclusion is partial inclusion. This type of inclusion is devoted to students with significant and moderate needs, for example, deaf, blind people and students with intellectual disabilities, autism, or multiple disabilities. Disabled students experience segregation, educated in self-contained classes in general schools. However, they may participate with non-disabled students in non-curricula activities (i.e. physical and art education) (Al-Mousa, 2010).

While there is an improvement in including disabled children within mainstream schooling, segregation still occurs for disabled students in special schools. However, although the Saudi government is making an effort to support equality of learning, the educational level for disabled people appears poor. This may be because of the lack of skilled special teachers in most schools, and the undesirable attitudes of students in schools about disabled children which are critical barriers to the success of inclusion programs (Alsaif, 2009).

1.23.1.3 The right to work

In the Kingdom of SA, the labour law emphasises the right to work, for disabled individuals. The law requires private sector employers who have 50 or more workforces to employ disabled people to make up at least 2% of the total staff. This has offered disabled individuals the chance to find a job and to contribute to society. The Ministry of Civil Services also offers specific consideration to employment applications from disabled Saudi citizens and offers them established jobs once they graduate or complete their training (KSA, 2002).

1.23.1.4 Social services

Currently, disabled people in KSA receive the following benefits:

- Artificial limbs.
- A 50% airfare discount for oneself and a companion.
- Occupation support on an equal basis with non-disabled people.
- Access to public roads, parks, and gardens.
- Special parking places at various institutions.
- Under the supervision of the Ministry of Education, educational opportunities for people with hearing, visual, or speech impairments and intellectual disability at specialised institutions (special schools) (KSA, 2002).

1.24 Summary

This chapter offered a brief overview of KSA, the structure of the family and insight into the ways Islam moderates daily life. It has also provided a brief overview of health and the oral health system in KSA. Although disabled adults and children have rights in the Kingdom, many of the policies seem to take a medical model position, problematising disabled adults and children.

Methodology

1.25 Introduction

This chapter presents the rationale for the research study and explains the methodological considerations and research design. At the end of this chapter is a review of inclusive research methods used with children in previous research, which informs the next chapter on research methods, or the tools of research.

1.26 Rationale, aim and objectives

1.26.1 Rationale

As highlighted in the preceding chapters, the construction of the child as a competent actor has its roots in the Convention on the Rights of the Child (UNICEF, 1989). Some of the academic literature has been influenced by the convention and taken a rights-based approach, arguing that children need to be included in research that is about them (Christensen & James, 2000; Clark & Moss, 2001; Cunningham, 2005; James et al, 1998; James & Prout, 1990; Johnson et al, 1995; Punch, 2002). This position contrasts with previous research, which viewed children as lacking in competence to participate fully in research, possibly led by the medicalised discourses around safeguarding. This reduced the child to the position of an object who required protection, constructed as passive and lacking the competence of adults. Using this perception of children means that they have previously been viewed as 'not-yet-being' (Verhellen, 2000, p. 16), and 'adults in waiting' (Matthews & Limb, 1998, p. 67). Which not only marginalises and invalidates children as human beings capable of making choices and decisions about issues that concern them, but it also takes a rigid developmental approach to the construction of children and childhood.

Despite the inclusion of disabled children in children's rights policy, disabled children have been less commonly included in research (Beresford, 2012; Morris, 2003). This has ethical implications because excluding them from research means that the diversity of children fails to be recognised and this leads research open to accusations of ableism.

The systematic review of the current literature on the place of disabled children in oral health research, presented in Chapter 1, Study 1, revealed that disabled children have been routinely excluded from oral health research (Alwadi et al, 2018). This justifies the need for research that attempts to use methods, which include disabled children as fully as possible to ensure that their perspectives are obtained, and their voices are heard. The lack of inclusion of the views and perspectives of disabled children has an impact on service provision and policy because without them we are unable to identify areas for improvements in oral health promotion initiatives and dental care services.

Study 2 aims to explore ways of including disabled children in oral health. It explores children's perspectives and experiences in the field of oral health to represent their voices and include them in oral health and research. In order to do this, innovative and inclusive methods needed devising. The study also explores the voices of parents and professionals to identify the ways that disabled children are included in oral health.

1.26.2 Aim and objectives

The aim of Study 2 is to explore ways of including disabled children in oral health. The specific objectives of the study are to:

- Devise and utilise a range of methods to enable the inclusion of disabled children in oral health research.
- Represent children's perspectives and experiences, giving them a voice in oral health research.
- Explore the ways in which mothers support and include their disabled children with their oral health.
- Explore the ways in which professionals support and include mothers and disabled children with oral health.

1.27 Methodology - Design

1.27.1 Overview

The overarching purpose of this study is to explore ways of including disabled children in oral health by exploring participants' experiences in the field of oral health. Exploring experiences means using a qualitative research design and because I wanted to make sense of disabled children's meanings and understand their subjective social reality, I will therefore explore the natural setting where children live their everyday lives (Denzin & Lincoln, 1994). Enabling disabled children's voices to be heard in research means the process will rely on my interactions with them and my involvement will form a part of the data. To aid transparency, I will include a section on reflexivity in Chapter 5. In contrast, quantitative research is more fact-based, assumes an objective fixed reality which exists separately to the researcher, is measurable and reported using statistical analyses (Creswell, 2009).

There are numerous approaches to qualitative research, for example, narrative, phenomenology, case study, grounded theory, and ethnography.

Narrative

Narrative research focuses on exploring the life of one or more individuals through the medium of stories (Polkinghorne, 1995). It may also be said to be both a method and a phenomenon because it interprets the stories that people tell about their lives (Riessman, 2008). Whilst the aim of the narrative is to release marginalised voices, Riessman also suggests, *"Narratives invite us as listeners, readers, and viewers to enter the perspective of the narrator"* (2008: 9). Furthermore, narrative relies on the details of individual lives collected through in-depth interviews. Although my research aimed to enable the voices of disabled children, it was not to obtain their individual stories; therefore, I felt it was unsuitable as a methodology for my research aims.

Phenomenology

A phenomenological study focuses on understanding the essence of the experiences, or how things appear and the meaning things have in our experience; it studies conscious experience from a first person perspective (Creswell & Clark, 2007). Whilst narrative

and phenomenology may be said to be about experiences and therefore overlap; phenomenology takes more of an ontological position in that it attempts to identify, isolate, formalise and to produce an analysis of the phenomenon in question (Hollway & Jefferson, 2000). This study is interested in exploring ways of including disabled children in oral health rather than studying the meanings they attach, and therefore, phenomenology as a methodology would not fit my research aims.

Case study

Case study approach places emphasis on developing an in-depth description and analysis of a case or several cases within a bounded system (i.e., a setting, a context) (Creswell, 2018). This approach is suited for a study requiring an in-depth understanding of a case or several cases. The study aims to explore experiences and as such is not suitable for a case approach.

Grounded theory

Grounded theory places emphasis on developing an emergent theory, which is grounded in the participant's views (Creswell & Clark, 2007). The development of the theory could provide a framework for further research or help describe the practice. This approach would not fit the purpose of this research, because this research does not aim to develop a new theory.

Ethnography

Ethnography focuses on describing and interpreting the shared and learned patterns of behaviours, values, language, and beliefs of a culture sharing group (Harris, 2001). This approach draws from the field of anthropology; therefore, the notion of culture is of primary importance. Ethnography is a process that includes extensive observations of a group in their natural context. The ethnographer is immersed in the day-to-day lives of the individuals, remaining with them in their setting over time and uses mainly participant observations, field notes and interviews for collecting data (Hammersley, 2007). The purpose is to understand the specific culture or group with observer involvement. This approach is the best fit for my research because it studies or explores a group of people in their familiar environments in Saudi Arabia. Furthermore, ethnographers investigate language, behaviour, and the interactions between

participants of the culture-sharing group. This is relevant to the aim of the study. Researchers using ethnography advocate using a range of data collection methods as long as they sit comfortably with the environment (Brewer, 2000), which is an additional benefit.

Ethnography is the most appropriate methodology to enable exploration of ways to include a diverse group of children in oral health; Conducted over six months in their usual school setting enabled insight into the ways in which we may be able to include children in oral health.

1.27.2 Ethnography

1.27.3 Ethnography and its features

Ethnography as a methodology is a specific qualitative research design comprising of field notes (Jackson, 1990), fieldwork in the shape of documentary analysis, participant diaries, interviews, focus groups, or a combination of all of these (Brewer, 2000) and participant observation (Hammersley, 1995). Ethnography has evolved as a methodology and is derived from the field of anthropology (Laughame, 1995; Mackenzie, 1994). Within the nineteenth century ethnography developed from cultural anthropology (used by anthropologists such as Malinowski, Boas, Mead, and Radcliffe-Brown) as a means of understanding and describing tribal cultures (Hammersley & Atkinson, 2007). Traditionally, anthropologists lived among these 'other' cultures for years in order to document their everyday lives, languages and traditions. Sociologists (such as Dewey, Park, and Mead) at the University of Chicago followed anthropological traditions in the 1920s to 1930s to research the city's social lifestyles (Hammersley & Atkinson, 2007). Recently, ethnography has expanded in and across many disciplines (Bluebond-Langner, 2000), for example, education (Siraj-Blatchford, 2010), sociology (Emond, 2005), nursing (Tinney, 2008), midwifery (Hung et al, 1995), and medicine (Zaman, 2008). As a consequence of this diversity, ethnography has become re-contextualised in different ways (Creswell & Clark, 2007). Table 8 demonstrates some of the different definitions of ethnography from diverse perspectives, adapted from (Lambert et al, 2011).

Table 8: Different definitions of ethnography

Definition	Author
For some, ethnography means a philosophical model to which a scholar is fully committed. For others, it determines the method used by the person when appropriate. Obviously, there are positions along these two extremes.	(Hammersley & Atkinson, 1994)
Ethnography is work that defines culture. The key goal of ethnography is to learn another way of life from the original point of view.	(Spradley, 1980)
Ethnography always recognises the concept of culture. It focuses on a group of individuals who have something in common.	(Boyle, 1994)
The basic purpose of ethnography, which literally means "image of a people", is to understand the way of life of a cultural group from the "native's" perspective. Ethnography is used to explain and describe the regularity and variability of social behaviours.	(Lipson, 1991)
Ethnographic research includes the use of different methods to collect data on human values, beliefs and practices.	(Hume & Mulcock, 2004)
Ethnography is not one specific approach of collecting data; it is a research style characterised by its purposes, which are to know the social meanings and ordinary behaviours of individuals in a specified field or setting, and an approach, which includes close association with, and frequently participation in, this field.	(Brewer, 2000)

Although there are many different descriptions of ethnography, these interpretations all emphasise that it is mainly about people's shared understandings of culture from their perspective.

Ethnography usually involves the researcher's participation in the daily lives of people for a prolonged period of time, observing what happens, listening to what is being said, and/or questioning questions through formal and informal interviews, gathering artefacts and records – collecting all available data in order to inform the emerging focus of study (Hammersley & Atkinson, 2007). In contrast to quantitative research design which may be said to possess a rigid structure, ethnographers usually use a

relatively open approach which may involve using pluralistic data collection methods in order to access a wide range of experiences (Maxwell, 2004). They may begin with an interest in a particular area of social life. Though they often take into account what the anthropologist Malinowski, suggests that their orientation is explanatory. This means that the researcher attempts to explain the everyday lives of the participants in the research to the audience and this relies heavily on representation (Geertz, 1973; Hammersley & Atkinson, 2007). This infers that the researcher is a part of the study and how they choose to represent the data in turns affects how the audience receives and interprets it.

1.27.4 Issues associated with ethnography

Ethnography can be challenging to use for several reasons. The time required for data collection is sometimes extensive because of the fieldwork involved. It requires a great deal of commitment and effort on the part of the researcher to obtain extensive and valuable data for analysis (Denzin & Lincoln, 2011; Green & Thorogood, 2018). There is a chance that the scholar will "go native" and identify too strongly with participants, which can create inherent bias within the study because the views represented may be more partisan. These are only a few of the issues in the complex set of fieldwork problems facing ethnographers who move into an unknown cultural community. In this situation, sensitivity to the needs of individual studies is particularly significant; in addition, the ethnographers must admit to their influence on the places and individuals being researched, alongside their own preconceived notions through the process of reflexivity (Creswell & Clark, 2007; Lincoln & Guba, 1985; Malterud, 2001).

One recommendation for researchers to help identify feelings of negativity towards participants is the use of a personal diary, recording emotions and feelings to check against bias, this can sometimes also be called field notes (Agar, 1986; Field & Morse, 1985).

To ensure a good quality piece of research, data triangulation may occur through using multiple methods for data collection and different sources of data. Triangulation or multiple methods extends the range of data and is normally a feature of ethnographic studies (Denzin & Lincoln, 2011). Chapter 5 discusses these strategies after outlining qualitative rigour.

1.27.5 Methods of collecting data in ethnography

1.27.5.1 Observation

Observation as defined by Marshall and Rossman (1995) as the systematic noting and recording in a social setting of behaviours, objects, and events. This is essential in ethnographic research. Ethnography includes two particular research tools: non-participatory observation and participant observation (Brewer, 2000). In non-participant observation, the researcher observes participants "from a distance" without interacting with them. Researchers who use this strategy are not interested in examining symbolic meanings and are careful not to interfere in a person's actions so as not to affect their behaviours. Participant observation includes collecting data by sharing the daily lives of informants in their regular environment: seeing, observing and speaking to them to uncover their explanations, social meanings and activities (Brewer, 2000). According to Silverman (2011), participant observation has the following characteristics in that the researcher:

1. Assesses a direct association with the social actors;
2. Remains with them in their normal setting;
3. Observes and describes their social activities;
4. Interacts with them and contributes to their daily celebrations and rituals; and
5. Learns their code (or at least parts of it) to know the meaning of their activities (Silverman, 2011)

Participant observation appears to be the best fit to achieve the objectives of this study. Although I would not be able to observe the participants in their homes as a natural place for them, because this is socially unacceptable and invades their privacy. The privacy of the family is important and protected in Saudi society. I would be able to observe the interactions of the participants in the schools, where they usually spend half of their day. Doing this would help me understand their attitudes, views, and values , at least in this site. I will now discuss the advantages and disadvantages of using this method.

1.27.5.1.1 Participant observation for collecting data

Participant observation is helpful for researchers because it provides a means to verify the nonverbal expression of emotions; identifies whom they are interacting with; enables understanding of how participants communicate with one another; and verifies how much time is spent on different activities (Schmuck, 1997). Observing participants helps researchers to check their meanings of terms used in interviews, to observe activities in which participants may be unwilling or unable to participate, and to observe issues described in interviews, this makes researchers aware of inaccuracies or distortions in explanations provided by participants (Marshall & Rossman, 1995).

Dewalt and Dewalt (2011) believe that the purpose of designing a study using participant observation as a technique is to develop a comprehensive understanding of the phenomenon under study. They suggest that participant observation is a method to ensure the genuineness of the research because it enables the researcher to gain more insight into the context and phenomenon described. The study's credibility is more substantial with using additional approaches with observation, such as document analysis, interviewing, or other quantitative methods (Dewalt & Dewalt, 2011).

De Munck and Sobo (1998) mention many strengths for using participant observation in anthropological data collection. These involve the fact that it allows for an intimately and richly detailed description, and it offers the anthropologist a chance to view or participate in events that are not scheduled. Dewalt and DeWalt (2002) also suggest that it enhances the quality of data that has been collected and facilitates the interpretation of the researcher. Observing participants is also useful in understanding the social, physical, economic and cultural environments in which the contributors live; the relationships between individuals, norms, contexts, ideas, and events; people's actions and behaviours - what they do, how often, and with whom (Hammersley, 1989).

The use of participant observation has several drawbacks. The main drawback is that it is time-consuming. Traditionally, ethnographic researchers spend at least one year at the field site in order to collect data by using participant observation and other research methods of study. For most applied research studies, which essentially need a shorter time for collecting data, this is impractical. This limitation is partly addressed by having

researchers from the same cultural background who already have a solid base of cultural awareness and more capable of focusing on the study question itself (Mack, 2005).

The second drawback is the difficulty of recording the data; when the researcher is interacting and observing, it is difficult to write down everything that is significant. Hence, the scholar should rely on his/her personal discipline, management, and memory to write and expand his/ her notes as soon as possible and as much as possible. Since memory fades fast, delaying the expansion of the notes may result in data loss or inaccuracy. Thus, data quality depends on the researcher's diligence, not on technology, such as recording devices (Hammersley, 2007).

The third drawback of participant observation is that it is a naturally subjective practice. Transparency over the ways individual biases are addressed is therefore of importance and these need to be included in the research data because it influences interpretations and representations (Mack, 2005). Further disadvantages are that the researcher may be seen as intrusive, and some participants (such as children) may have special problems in achieving rapport (Creswell, 2018). The presence of the researcher also inevitably influences the interactions and behaviours of those under observation. This can lead to what has been termed the Hawthorne effect, derived from factory studies in the Hawthorne Works of the Western Electrical Company in the 1920s and 1930s, when workers changed their work behaviour and performance because they were aware that they were being observed (Roethlisberger & Dickson, 2003). Other studies suggest that when the researcher becomes a "familiar face" and part of the environment, then behaviours adjust as the researcher becomes accepted and that this might address the problem to some extent (Barnes, 1992; Fetterman, 2009; Oswald et al, 2014).

1.27.5.2 Field notes

Field notes are used during participant observation and are one of the most widely used basic tools of collecting data in ethnographic research (Emerson, 2011; Speziale et al, 2011). When in the field, the researcher needs to take notes for recording the collected data from the field site. These notes could include everything discussed, questioned and heard in the field, involving the researcher's experiences, feelings, thoughts, and comments. Field notes could also include an account of events, and of how individuals

acted and responded, where individuals are placed in relationship with each other, physical gestures, and many other information and observations required in order to make the participant observation experience comprehensive (Creswell, 2009). Advice and suggestions regarding the use of field notes are well-documented, including:

- Always take a pen and diary;
- Write down the time, day, location and names;
- Create an instant note of everything you find interesting for the research;
- Write a short note and expand it directly if possible before the detail memory fades;
- Write your experiences, thoughts, and feelings about the actions;
- Do not jump to interpretations or conclusions immediately;
- Search for additional evidence about what you saw and heard;
- Question individuals to approve things by further observation, formal and informal interviews

(Hennink et al, 2010; Silverman, 2006; Speziale et al, 2011; Spradley, 1980).

I used these suggestions as a guide to structure and consider my field notes whilst carrying out my study.

1.27.5.3 Interviews

The interview is a conversation between an interviewer and an interviewee, where questions are asked, and answers are given (Robson, 2011). Interviews are a common way to collect qualitative data (King, 2010), and there are many different types of interviews. The commonly used classification distinguishes between structured, semi-structured and unstructured interviews. This can be somewhat related to the "depth" of the response required (Robson, 2011).

The interviewer controls a structured interview by asking a specific set of predetermined questions and the interviewee just responds to this set of questions, all participants are asked the same questions in the same order (Saunders, 2009). Structured interviews are sometimes meant as "quantitative research interviews" (Saunders, 2009) and can produce numerical values which can be presented in tables (Byrne, 2001).

The semi-structured interviews allow the participant to have more flexibility when responding; an extreme version is the "depth interview" where the respondent is largely free to say what he/she likes in the broad subject of the interview, with the researcher's minimal prompting (Robson, 2011). In this kind of interview, the interviewer has an "interview guide" or aide memoire which aids as a checklist of subjects to be covered in the interview and a default wording and ranking of questions (Bryman, 2004; Saunders, 2009). However, the wording and arrangement are often largely modified according to the flow of the interview and further probes to elicit meaning at a deeper level (Rosalind & Janet, 2013).

In unstructured interviews, the interviewer has a general area of concern and interest but the participant leads the conversation and is facilitated to talk about the research area (Bryman, 2004; King et al, 2018).

Semi-structured and unstructured interviews are widely used in flexible designs. A range of other terms also define the types of interview used in such designs, involving qualitative interviews, depth interviews (sometimes referred to as *in-depth interviews*), which may be described as a conversation with a purpose, and *focused interviews* (where open-ended questions are asked about a specific topic or issue) (Hennink et al, 2010; Robson, 2011).

In my research, I conducted in-depth semi-structured interviews with research participants in order to investigate their views and experiences regarding oral health. I chose interviews because my study focused on individual perspective and experience. This type of interview facilitates extensive data collection from participants and assists in probing features of their experiences in more ways, when compared to a structured interview. Using this method helped the participants to say whatever they liked, with minimal prompting from me. Semi-structured interviews also tend to enable the researcher to explore participants' culture, values, beliefs and norms, since the researcher is interested in the content of the interview and the way participants expresses themselves – through the words they use (Robson, 2011). I developed interview guides to keep me focused, drawing on topics from the literature review which had increased my knowledge of the subject coupled with the experience of the supervisors in this area. I used the guides flexibly, using my judgement as to when to

deviate and follow an area, which I felt may yield important data and produce new or related questions to ask other participants.

There are strengths and limitations of in-depth semi-structured interviews, which are summarised in Table 9.

Table 9: Strengths and limitations of in-depth semi-structured interviews

Strengths	Limitations
• Gain information on individual personal experiences, feeling, ideas, opinion and life stories (Berg, 2012) • Gain in-depth information of a studied phenomenon (King et al, 2018) • Useful for sensitive topics (Hennink et al, 2010)	• One-to-one interview, no feedback from others (Hennink et al, 2010) • Time-consuming (Robson, 2011) and a lot of transcription is needed (Hennink et al, 2010) • Needs skills in order to develop relationships, use motivational probes, listen and respond to interviewees (Hennink et al, 2010)

I felt that it was important to understand the balance of strengths and constraints for in-depth semi-structured interviews and use them as a tool to complement participant observation.

1.28   Techniques for research with children

Effective participation in research can be a challenge for all children; however, disabled children can face further barriers. This is due to researchers' inadequacies in designing accessible methods and communication techniques, as well as societal attitudes towards disability and rights of participation. If researchers fail to provide a supportive structure, disabled children's voices could remain unheard and they can be further marginalised (Davis & Watson, 2000). Exclusion of disabled children from child research could perhaps be justified by the methodological 'difficulties' (Kembhavi-Tam & Wickenden, 2014). We could further argue that the researcher needs to be motivated to use 'child-friendly' approaches (Punch, 2002), it may also be assumed that research with disabled children certainly needs significantly different approaches than those used with non-disabled children or adults. I argue that such an assumption derives from a normative discourse that positions disabled children as 'different' children, who are not competent

to share their views. Instead, they should be seen as individuals with competence and agency and we should look beyond their impairments (Connors & Stalker, 2007). Previous research argues that disabled children (even those with severe impairments) were able to participate in research by carefully considering methodology and methods (Gray & Winter, 2011; Lewis et al, 2007; Mortier et al, 2011; Nutbrown & Clough, 2009; Wright, 2008).

Different methods for use in children's research include play-based techniques such as role-play and dressing up in order to obtain children's views (Kellett, 2011). Dressing up allows children to communicate through an invented identity and is fun. This illustrates that if a researcher joins in the fun and becomes an improvised character too, this might result in supporting children to be more willing to share their views and feelings. Storytelling and using puppets can also be a way to convey information to children in an engaging and non-threatening way, particularly if a dialogue is significant to the engagement. Preferred toys and dolls can be a voice of the children and adult and can distance children from a subject area, particularly if it is difficult (Kellett, 2011).

The Mosaic Method, which was developed by Clark & Moss (2001), helps young children to open up their world to the researchers. This approach aims to be inclusive because it enables children with different abilities to be included in the research. The Mosaic Method offers various tools, including informal child group interviews, familiar methods of observation, tours, mapping, photography and bookmaking. The art-based techniques besides the mosaic approach can deliver numerous diverse activities through which children can use their diverse skills and communicate their views. In addition, guided tours, wishing trees, listening posts and cultural circles, filmmaking and photography, map-making, storytelling, focused observations and Video Stimulated Dialogue [VSD] are a variety of different strategies utilised in the Children Crossing Borders project to help all children to express their views (Pascal & Bertram, 2009).

Other academics have acknowledged specific strengths in artistic approaches, which comprise performance, poetry, music, narrative and visual arts, because these kinds of methods add meaning to the life of children and their daily activities and methods can diminish the intensity of the process of the interview (Carter & Ford, 2013). However, personal interviews, including structured, semi-structured and unstructured as well as

focus groups, which are considered traditional research approaches, become more acceptable with older children (Kellett, 2011). Pascal & Bertram (2009) suggested using videotapes within focus groups to encourage dialogue with children and promote inclusive methods, although this may be difficult in Saudi Arabia, which is a very private society, and it could have ethical limitations.

Rabiee and colleagues (2005) adopted the idea of 'Talking Mats'® after the first stage, which was an interview with children who were able to speak and their parents to develop the themes that would be used in the second stage. Talking Mats® were used with children with an intellectual or physical impairment and who did not use speech as a primary mode of communication. Rabiee et al.'s study suggests that Talking Mats® were a useful way of exploring children's feelings and choices about services provided for them. This finding illustrates that disabled children are able to contribute through the removal of disabling barriers.

Several studies use photography as a method of research, usually reinforced by other approaches. For example, Goodley and Runswick-Cole (2011) applied 'photovoice' in research with disabled children to support children in taking photographs and expressing their stories to the researchers. They argued from this study that photographs are a powerful tool for communication with disabled children. One issue is that of representation because we are never quite sure what the individual meant when creating an image on film, similar to Clarke's analysis of non-verbal conversations (See Chapter 2 for more detail) which argues that using photos might run the risk of recognising the voice of the academic over the children's voices (Clarke & Wilkinson, 2009).

Germain (2004) also used photographs alongside Talking Mats® as research tools in her research with disabled young people. In this study, she asked young people to sort their pictures using Talking Mats® symbols to access their views about their social activities, which was the focus of the research. Interviewing their parents enabled triangulation of their stories. Germain suggests that giving a camera to the children is a way to empower them because it puts children in control of expressing themselves and paints a picture of their world. Moreover, photos help children remember specific events and memories that supported the research process. Taking photographs was additionally explained by

Ajodhia-Andrews (2016) as a helpful approach to help children define themselves, and suggest it works even better if this method is paired with the child's explanations.

Photography was frequently included in the mosaic approach. This is evident in the study done by Gray and Winter (2011), where a camera was part of a toolbox, which also included various methods like drawings, stickers, "Molly the ragdoll" and tape recordings. This research utilises a variety of creative and innovative approaches, selected according to the communication abilities of each child (Gray & Winter, 2011). Some research suggests that using multi-methods with disabled children support the research to be more inclusive and allows children to play to their varying strengths (Ajodhia-Andrews, 2016). The multi-methods including drama, music, digital media and specialist IT was also used in the Disabled Children and Young Peoples Participation Project (DCYPPP) that was founded to discover the means to include disabled children and young people in decision making in health services provided to them (Murray, 2012).

Research with children frequently uses photographs and pictures as a means of facilitating interviews because they provide visual references to the subject covered in an interview (e.g., (Backett & Alexander, 1991; Curry & Russ, 1985; Eiser et al, 1990). Customised photographs can be particularly useful. One of the researchers who used images when talking to children about their experiences with respite care believed that the images of the actual facilities used by the child had proved to be more productive (Robinson, 1995 cited in (Beresford, 1997). Games or tasks that form part of the research interview may use photographs or pictures. For example, work on children's concepts of healthy and unhealthy food and activities, children in this research were asked to post pictures of food and activities into one of two boxes (Backett & Alexander, 1991). Backett and Alexander asked children to arrange a series of seven pictures of activities from the healthiest to the unhealthiest. They then asked them to explain the order they had selected. It seems that the use of these methods may encourage communication with children, enabling them to access the questions and participate more effectively rather than relying solely on speech.

Levin (1994, cited in (Beresford, 1997) used drawings to facilitate her interviews with child members about their perceptions of family and step-family members. Drawings have previously been used to explore health-related problems (Oakley et al, 1995; Williams et al, 1989), although relatively little has been published in the dental research (Marshman & Hall, 2008). Backett and Alexander (1991) sent children a drawing board before the research visit and asked them to draw food and activities that were unhealthy and healthy. Asking the children to talk about their drawings was an excellent way to start the interview. It created a relationship and gave children a basic framework for explaining how to maintain health (Backett & Alexander, 1991).

Using graphics with younger children can mean that they can be included in studies, despite their limited verbal skills, and appear to be useful for disabled children who do not use speech as a way to communicate. However, there are some restrictions to using drawings. Particular research topics may not fit this technique, especially if they relate to abstract concepts. In addition, the drawing ability of the child may lead to certain elements being drawn over others (Backett & Alexander, 1991).

Other tools for eliciting information are 'face scales' or visual analogues in order to gain knowledge about experiences or feelings, such as pain, that are difficult for children to describe (Gaffney et al, 2003; Lebaron & Zelter, 1984; Ross et al, 1993; West & Sammons, 1991). Research on the quality of life for young children with asthma involved asking them to colour in histograms (Christie et al, 1993). These techniques do not provide any in-depth information, although they increase the interactive nature of the research interview and can be used as way to facilitate discussion (Lebaron & Zelter, 1984).

Some researchers use interviewing alone as a research method to elicit children's views (Marchant et al, 2001; Morris, 2003). Former researchers conducted successful interviews with children and indicated that children are able to participate in research (Docherty & Sandelowski, 1999). Children have contributed to studies that used interviews and focus groups on a number of facets of their lives, including diseases and experiences related to health and oral health (Alderson, 1990; Beaune et al, 2004; Bennett et al, 2001; Fitzgerald et al, 2004; May & Waterhouse, 2003; Ostberg, 2002).

It would appear that children's interviews can be a useful method to ascertain their experiences if employed sensitively and adequately. The challenge is tailoring these conversations to every child and their specific level of ability (Morris, 2003). Flexible methods, including one-to-one interviews are useful for children who prefer one-to-one interaction, although non-verbal forms of interaction can expose whether the child has finished or needs to say more and whether they feel negatively or positively about the questions (Morris, 2003).

Using their extensive research experiences with disabled children, some researchers have published guides (Lewis, 2004; Morris 2003). For example, in her 2003 Gulliford Lecture, Lewis suggested amending interviews and complying with children's requests to rephrase a question and accept 'do not know' replies. Interviewing children with intellectual disabilities may mean using general questions rather than specific ones and avoiding yes /no questions because children have an "affirmative bias" (Lewis, 2004, p. 5) and tendency to reply "yes". Lewis further recommends avoiding repeating questions since this might send a sign to children that their answer was incorrect. Apparently, this does not occur when pictorial methods are used and consequently, cameras and tools similar to Talking Mats® have a lot of potential in the questioning process (Lewis, 2004).

Using pronouns, referents such as "those", "they", and "there", and modifying terms are some small concerns to do with interviewing children with intellectual disabilities because they frequently misinterpret them. Modifiers are adverbs or adjectives, and children might find it more challenging to understand the concept of a limited modifier for example "slow", while they might grasp modifiers that are unlimited for example "fast". Using cue cards without comments is suggested as one method to advance an "uninterrupted narrative" and prevent continually having to prompt the child (Lewis, 2004, p. 6).

Other authors recommend waiting and permitting the child time to end stating their thoughts, and not trying to fill every silent moment with talking (Morris, 2003). Eye contact might need moderating because some children may find this invasive. Children with autistic spectrum disorders or with hearing impairments may have difficulty picking up details in voice tone to decipher meaning in comments or questions.

Challenges for children with visual impairments may occur with interpreting facial expressions or body language. The recommendations of previous researchers illustrate that it is essential to consider each child as an individual (Morris, 2003; Lewis 2004).

The bulk of the evidence highlights the importance of using pluralistic methods in order to ensure all children can express their views. The suggestions from the previous studies may have limitations because scholars drew their conclusions using different theoretical stances and specific research contexts. Therefore, it is the responsibility of the researcher to build a proper research context for disabled children through guaranteeing their rights to make informed decisions, taking time to build rapport, adopting specific techniques to support their communication, making a range of research methods available, consulting children about research arrangements, and recognising their competence and agency.

In my study, I considered it essential to use multiple research methods in order to facilitate the participation of disabled children. These included interviews, which employed pictures and games as facilitators, guided tours, use of symbols and drawing with the children. Further explanations of these methods are in the next chapter.

1.29 Summary

I chose ethnography as my research methodology because it best fitted the aims of the research. I present the different methods employed by previous researchers to facilitate the inclusion of disabled children in the research encounter, identifying which ones I felt would be useful based on previous research. The next chapter explains and gives examples of the methods employed in collecting the data.

Methods

1.30 Introduction

The previous chapter discussed the methodological considerations of this study and introduced ethnography as the research design. This chapter presents the methods used to collect and analyse the data. It focuses on the research setting, sampling methods, recruitment, data collection, challenges faced and efforts to overcome them and analysis. Furthermore, it discusses issues of rigour and ethical considerations.

1.31 Settings for the project

The context for this study is Riyadh, the capital city of the KSA (see Chapter 3 for further information about Riyadh and the KSA). I recruited participants from two sites in Riyadh. Site 1 was a Center for Disabled Children and site 2 was a school for students with intellectual disabilities. I selected these two sites because they are both significant providers of free education and healthcare for disabled children and are more likely to present a diverse section of the population.

1.32 Gaining access

Whilst resident in the UK, I sent an email to both sites asking about the possibility of conducting the study. The email included an overview of the research and enquired about local ethical requirements for access. I attached a supporting letter from the research supervisors. I received written approval from both sites to conduct the study (see Appendices 3 and 4). I then sent a letter to King Saud University, my sponsor, through the Saudi Cultural Bureau in London to obtain official permission to conduct my study and field trip. When I arrived in Riyadh, I sent reminder messages to both places and a reminder telephone call to confirm permission to start my fieldwork.

The following excerpt from the field notes describes my feeling toward gaining access to the research sites:

> *On the first day of my fieldwork at the school for students with intellectual disabilities, I received my welcome from the staff, and they served me Arabic*

coffee. After discussion, they were ready to help me with anything I needed. Initially, they gave me an overview of the school and its system, and then they offered me a private room as a place for conducting interviews with teachers and children who agreed to participate. Similarly, the secretary at the Centre for Disabled Children offered me an empty room in the centre that was private, quiet, and ideal for interviewing mothers, while the interviews with healthcare providers were conducted in their offices.

Regarding entry to the Centre for Disabled Children, it was difficult at first to obtain official approval from them, but after several phone calls, they answered my e-mail, and finally, I got the official approval via e-mail. This may be because I was calling the head of the clinics. However, when I met her, she introduced me to her secretary and communication improved because she gave me her phone number and went out of her way to help me. She told me: "I am happy to do my best to get benefits for our children". She then introduced the place and its system. She also asked me to wear a badge so people would know who I was and that I was a visitor.

Once I attended the clinics, I felt welcomed, but it took a few weeks before people began to accept me and treat me as if I belonged. This may have also been because it took me a few weeks to become familiar with the situation and how the clinics worked. After that, I felt they were used to my presence, and if I was not around, they even started asking me questions like "Where have you been?" and "Why did not you come yesterday?" and "How is your data collection?" Even mothers who knew me, they usually asked about my research, and one of them said: "If you need more mothers to participate in your research, tell me, and I will call my friends to meet you if you want to because it is easy to find them since we have a group in WhatsApp". Much care has always been given to children, and I have heard from most staff that "children are primary in this place", and that is our goal and our slogan. (Research Diary Note, April 2018)

Below is a description of sampling the participants in this research, recruitment, data collection and data analysis.

1.33 Sampling

Purposive sampling was employed to identify and select children, mothers and professionals as the participants who best fitted the aims of the study. This is because purposive sampling is a non-probability sample designated according to the objective of the study and characteristics of a population (Daniel, 2011) as it does not randomly select elements from a designated population. In probability sampling techniques, the researcher draws samples from large populations with the purpose of making general decisions that represent the people of interest. Therefore, I used purposive sampling because representational generalisation is not the aim of qualitative research; theoretical generalisation, on the other hand, can be achieved which is where the sample exhibits the diversity of dimensions and constituencies that are central to explanation (Lincoln & Guba, 1985).

By adopting purposive sampling for this study, I aimed to talk to a range of disabled children, from various age groups and with different kinds of impairments, about their oral health. I also aimed to interview different teachers from different educational stages, healthcare providers who provide different medical services for disabled children, and mothers of disabled children. This is because I planned to maximise the heterogeneity and the diversity of the participants' characteristics in order to achieve the aim of the research study.

In total, I recruited 30 participants, self-selected to take part comprising a mixture of health professionals, mothers, educational professionals, and disabled children. Anonymisation, using pseudonyms and redacting identifiable data protected the identity of all participants.

The sample: Five healthcare providers were self-selected to participate. Only one of them was from Saudi Arabia, and two of them spoke English. The professions of the health professionals were not identified to maintain anonymity. Five teachers participating in the study were all from Saudi Arabia. Further, they were female and had undergraduate degrees in education, specialising in intellectual disability. The

characteristics of healthcare providers and teachers (anonymised) participating in the study are presented in Table 10.

Table 10: Summary of healthcare providers and educators' characteristics

Participants	Sex	Role	Education level
Hind	Female	Medical professional	Bachelor's degree
Samar	Female	Medical professional	Master's degree
Maha	Female	Medical professional	Bachelor's degree
Louisa	Female	Medical professional	Bachelor's degree
Jessica	Female	Medical professional	Bachelor's degree
Majdh	Female	Educational professional	Bachelor's degree
Arwa	Female	Educational professional	Bachelor's degree
Salma	Female	Educational professional	Bachelor's degree
Wafa	Female	Educational professional	Bachelor's degree
Nada	Female	Educational professional	Bachelor's degree

The ten mothers of the disabled children participating in this research were all from Saudi Arabia. Their children ranged in age from 3 to 10 years. These were not the mothers of the child participants in this research study. They were all married and homemakers. Two mothers were illiterate and had never attended school. One mother had completed primary education, and one had graduated from high school. One of them had a diploma, and five had bachelor's degrees. All mothers had middle-class socio-economic backgrounds except for one who was in a higher socio-economic category because of her husband's work. Socioeconomic backgrounds were determined by information on family income and education provided by mothers.

Ten children participated, all girls, due to the segregated school system, and thus complying with Saudi societal rules. Four of them had a mild intellectual disability. Two had multiple disabilities: one had hearing impairment and epilepsy, and the other had a physical disability along with an intellectual disability. Four of them had moderate intellectual disabilities. Two had cerebral palsy. The age range was 9–15 years and they were studying in primary school (Table 11). The children in this study all

lived in Riyadh, but originally came from all over Saudi Arabia. They were all able to communicate verbally, but with varying degrees of fluency.

Table 11: Summary of children

Children	Age	Gender
Lina	9	Female
Renad	10	Female
Danah	10	Female
Basmah	11	Female
Haneen	11	Female
Haya	11	Female
Gala	12	Female
Deema	13	Female
Joud	14	Female
Yara	15	Female

1.34 Process of recruitment

This section describes the process of recruiting participants for this study and highlights the challenges encountered.

I approached healthcare providers and mothers of disabled children at the Centre for Disabled Children, teaching staff and disabled children from the school for disabled children. I have described the two contexts in Chapter 6.

To recruit health professionals, I asked the secretary at the Centre for Disabled Children about the specialities of healthcare providers. With this information, I recruited healthcare providers who provide different medical services. I approached them personally with help from the clinic secretary who followed Saudi protocols, accompanying me to their offices and introducing me. They were given an envelope containing a letter of invitation (see Appendix 5), information sheet (see Appendix 6), and consent form (see Appendix 7) (All translated into Arabic). I also placed an invitation letter and an information sheet on the clinic board to be available for all staff to read.

I contacted each mother face-to-face when she attended the centre with her child. I gave them an invitation letter (see Appendix 5), an information sheet about the study (see Appendix 6), and a consent form (see Appendix 7) (All translated into Arabic), which I asked them to read while they waited for their children. I contacted mothers who were interested in participating by telephone to arrange an appointment and attend one-to-one interviews in a private room at the centre at a mutually convenient time. I also specified that the length of time required for the interview would be an hour and a half.

To recruit teachers, I gave a short presentation to the staff at the school in which I explained the aim of the study in detail. I gave an envelope containing an invitation letter (see Appendix 5), an information sheet (see Appendix 6), and a consent form (see Appendix 7) (All translated into Arabic) to the staff. I then made appointments with interested teachers for interviews at the school at mutually convenient times, indicating that the interview could last for an hour and a half.

For recruiting disabled children, Initially, I observed the school for a month in order for the children to become used to my presence before any other form of interaction occurred. Teachers, who knew children the best, provided knowledge about who would be least distressed by interacting with me, this guided recruitment. I gave children an information sheet appropriate to their age and level of ability. They took the information sheet to their home and discussed with their families whether they would like to participate (see Appendix 8). An assent form was constructed for children, and because not all children could write, the adult in charge of the classroom countersigned the forms (see Appendices 9 and 10). I also provided a separate adult information sheet and consent form for mothers (see Appendices 11 and 12). I gave children interested in participating in the study an appointment for individual or group interviews, according to preference. I held the interviews in the room the school had provided for me at a time convenient to both parties. I also indicated that the time required for the interview would be 45 minutes, which is the usual length of each lesson. I decided this period after discussion with their teachers; they also recommended that I interview children before their break because they usually felt tired or would be unable to concentrate afterwards.

I assured everyone involved that participation was not compulsory, that they could withdraw at any time they wished, and that withdrawal would not upset anybody in any way. In total, five healthcare providers, ten mothers, five teachers and ten children participated.

1.34.1 Strengths and limitations of the recruitment process

Recruiting health and educational professionals occurred with the help of a headteacher at the school and the secretary at the Centre for Disabled Children. The process was not complicated at either site. This was because teachers were recruited at the end of the semester when they had finished their teaching requirements and were not as busy; therefore, they were available most of the time.

Initially, I planned to recruit mothers and carers of disabled children but had to change to interviewing only mothers. This was because I found it challenging to get agreement from mothers to allow nannies to participate in the study because of concerns about protecting the family's privacy.

The recruitment of mothers was one of the challenges at this stage. In Saudi Arabia, people are reluctant to participate in research, especially when it involves talking about their families and their experiences. Family matters are private, and disability is frequently a taboo subject. I was pleasantly surprised at the readiness of some mothers to participate in this study. Only two mothers refused, for different reasons, to take part in the study. One of the mothers refused to participate, saying, *"[…] if you are going to treat my teeth, that's fine, but I do not have time for chatting"*. The other said politely *"Oh I am sorry, I'm busy, I do not have time for the interview, but if you go upstairs, you will find a special meeting room for mothers, they always sit in this room when they are waiting for their children, so you'll find someone else."* (Research Diary Note, May 2018).

A further challenge when recruiting mothers was that two mothers did not give me their real names because they were afraid and thought that this would have a negative impact on the care of their children. I assured them that this would not happen. One participant politely ended the interview when her husband came to collect her from the school: *"I*

cannot stay more because my husband is waiting outside" (Research Diary Note, May 2018). Although this was frustrating, I understood that her actions reflected Saudi norms and expectations, I, therefore, had to respect her situation. Instead, I managed to arrange another meeting with her.

Recruiting disabled children for this study was much easier than I had expected. I assumed that this was a new and exciting opportunity for them. This became evident during interviews, when Deema said, *"Thanks doctor, you made me talk, I feel comfortable now because I said all that in my heart. I really needed to talk".* At the beginning of the interview, when I introduced myself to her, she said, *"Oh, I thought you were another teacher, not a dentist because the dentist always asks me why you do not take care of your teeth. I do not want you to tell me that as well".*

When recruiting children, one of the difficulties was the student attendance rate. The proportion of absentee students was high, and this was generally because of their health conditions. However, this issue was resolved because I remained in the field for an extended period.

1.35 Data collection

In keeping with ethnography, I used pluralistic research methods to collect data. These primarily involved participant observation, in-depth semi-structured interviews and inclusive activities.

I collected data in two visits. During the first visit, which occurred from April 2018 and lasted for three months, I interviewed 20 participants (ten mothers of disabled children, five healthcare providers and five teachers). I also wrote field notes about my feelings and observations and attended some classes to observe how teachers communicated with disabled children. The experiences of teachers guided the development of inclusive methods to enable children's participation. For example, if teachers used pictures most of the time, incorporating this as a method appeared pragmatic because children were familiar with this approach and unlikely to find it stressful. However, I was prepared to

adapt or change my methods in the field to be as ethical and inclusive as possible and describe this further in Section 5.6.3.

The second visit began in September 2018 and lasted for three months. I continued to recruit children to the study and finalised my methods. Where possible, I worked with the children to elicit their views and experiences about oral health and services. I also observed their everyday practices and routines at the schools. I decided on two visits to collect children's data due to the two-month school leave, and I felt it would give me more time to discuss methods and ways of approaching the children with staff used to regularly working with them. The gap allowed me to consider their advice and design appropriate inclusive methods that considered the children's range of abilities.

1.35.1 Participant observation

Participant observation is crucial to ethnographic research. In this study, participant observation began with the commencement of the fieldwork, but this method also continued during data collection. Although there are a number of disadvantages to this method – for example, the researcher may be seen as intrusive, and certain participants, such as children, may present particular challenges with gaining rapport (Creswell, 2009) – using this approach has been one of the strengths of this inquiry and has offered many advantages. Some studies have argued that using participant observation helps significantly expand the depth and breadth of children's data (Darbyshire et al, 2005). Participant observation complements the limitations of interviewing (Lewis & Porter, 2004). The children in this research, like all children, sometimes had trouble articulating their views and feelings in the interviews. Participant observation allowed me to explore children's interactions in their environment and their understanding of oral health without directly asking them.

As a result of my observations, I was able to individualise the techniques used with the children and improve other methods, such as interviews. For example, it helped me to ensure the cultural relevance and suitability of the interview questions. Participant observation also facilitated and developed positive relationships with stakeholders, key informants and gatekeepers whose assistance was required to conduct this study.

Further, trying to immerse myself in participants' lives might have made it easier for contributors to be open and honest with me.

I visited the research sites and observed for three hours, every day, five days a week, for three months at each site. In total, this accounted for six months at both sites, in order to gain more familiarity with the layout of the place, the structure, the routines, and the daily events of the institutions. I organised a classroom observation schedule in order to observe the social interactions of disabled children with other children and other school members, and the communication methods used. During the classes, I sat at the back of the classroom without interrupting the teachers, although this did not guarantee that teachers or students would not act differently because of my presence. Outside the classroom, I moved around the site and talked with disabled children and staff informally.

Guides for observations at the school and the Centre for Disabled Children are in Appendices 13 and 14. I tried to keep my eyes open to anything happening in this area, including unexpected events. Indeed, an ethnographic researcher's primary objective must be to have an open mind about the phenomenon or group being studied rather than trying to impose his or her interpretations on phenomena (Brewer, 2000; Murchison, 2010). However, an open mind should not mean that the ethnographic researcher must have a blank head when conducting the study (Hammersley, 2007). Ethnography can help both the researcher and the respondents to interact, discuss, learn, and explain any ambiguity. Giving participants the freedom to express what they think while observing them in their environment provides more depth and richness to the collected data. For example, during the break time, children had the freedom to interact with their friends, say whatever they wanted, eat what they liked and participate in activities of their choice, which added more meaning to what they said during the interviews.

Field notes recorded the observation data. This process was less intrusive, compared to other methods and readily accepted by research participants. Unstructured notes meant writing as much as I could of what I had observed. I tried to describe the events just as they were (Clark & Leat, 1998), and addressed nine dimensions of the social situations suggested by Spradley (1980): space, activity, actor, act, object, time, goal, event, and

feeling. At the same time, I also had the research purpose and the observational guide in my mind so that I could study the objectives of the current study quickly. I was aware that what I observed was formed by a focus on research, as well as by my assumptions and implicit knowledge (Foster, 1996). I also incorporated myself into the observations, for example recording data about my sensory feelings, actions or emotional reactions (Murchison, 2010).

Writing detailed notes on classroom observations was straightforward. However, in other cases, I had to find opportunities for taking notes as soon as possible before my memory became blurred (Bernard & Handwerker, 2006). The participating research sites provided me with office space so I could work on my notes. I transcribed my handwritten notes into electronic form out of the field, and I filled them with more details. Furthermore, I saved a diary for recording more individual experiences (Bernard & Handwerker, 2006; Punch, 2012). Photographs of the places were also taken, but not of children unless their families agreed. For ethical reasons, I only got a limited number of images after obtaining verbal approval from the officials.

1.35.2 Semi- structured interviews

I conducted in-depth semi-structured interviews with mothers, teachers, and health care providers to investigate their views and experiences and gain deeper insights into the ways in which children are included in oral health. Interviews allow participants to answer questions in their own words, thereby providing a personal view (Braun & Clarke, 2013). A semi-structured approach was chosen in order to ensure that all participants were given the same list of questions (and to help me compare the answers); however, this approach also allowed participants to raise concerns that I did not expect before the interview, and it enabled me to follow them up in the interview (King, 2010).

Interview guides were prepared before the interviews with mothers, health and educational professionals (see Appendix 15). The interview guides provide some focus that allows a degree of adaptability and freedom to obtain information from the interviewee. At the beginning of each interview, I reminded participants of their right to withdraw from the conversation at any time they wished. Anonymisation protected

identities. Each individual interview lasted between 45-60 minutes. Individual participant interviews enabled mothers to feel more comfortable when sharing their views and protected their privacy. Mothers in Saudi culture usually do not like to talk about their personal or family matters in front of others in order to maintain confidentiality. This method was also suitable for educational and healthcare professionals because they had different time schedules for their work. I asked them to select a suitable time and place. During the interviews, I felt that the research participants were open and honest with me and conveyed that they were genuinely concerned and sympathetic about disabled children and their future. They shared many individual stories and tended to be reflective about their experiences.

I digitally recorded the interviews with mothers and professionals, taking handwritten notes if they refused. This is an acceptable approach, which Norman Denzin calls the journalistic method (Denzin, 2001). I transcribed the interview verbatim in Arabic and then translated into English. In this study, all interviews were audio-recorded except for one conducted with a social worker who refused. I respected her request and agreed because I wanted to know her point of view. She waited patiently for me to complete writing notes during the interview, and I was confident that I had accurately documented her words. One mother also said: *"Please do not record my voice because my husband does not like that"*. Then she said, *"It's ok to use the recorder if you're the only person who will listen to it and please make sure you delete it as promised"*. After I reassured her, she trusted me and allowed me to record the interview.

1.35.3 Inclusive activities with disabled children

The social model of disability and a sociological understanding of childhood both acknowledge the abilities of disabled children as competent participants in research. In order to gain insight into their lives and views, I felt that it was important to use varied methods that enabled them to display their knowledge and abilities — collecting data involved using pluralistic methods with each child to explore their perspectives and experiences on oral health (see Appendix 16 for aspects considered in the interviews).

When I first visited the field for the initial data collection, I discussed with teachers how to help children talk about aspects considered in the interviews. They made some

suggestions such as simplifying the question format or using different methods, such as images, to explain the questions. Table 12 describes these suggestions.

Table 12: Teachers' suggestions

Research aspects with children	Teachers' suggestions
What does disability mean to children?	*"It is difficult to ask a direct question, but you could ask them. Do you usually eat by yourself or is there anyone help you? Do you want your father or mother to help you? Are you like your brothers in everything? Or you can show them some pictures of disabled people ..."*
What does oral health mean to them?	*"Try to use some educational models for teeth, or mouth as their teachers did in their teaching"*
What do they know about teeth?	*"By using pictures or cards"*
What is their favourite food? What do they feel is good or bad for their teeth?	*"If you can bring some healthy and unhealthy foods, then let the child to choose what is her favourite food and which one does she feel is good or bad for her teeth"*
What do they use to clean their teeth?	*"Using images for tools used to clean teeth or using cards to illustrate these tools"*
What is important about having a clean mouth?	*"Using an image (e.g., a girl complaining of pain in her teeth)"*
Does anyone help them in cleaning their teeth?	*"There is nothing wrong with asking them a direct question"*
What do they know about the dentist and the dental clinic? Why do children go to the dentist? Why do grown-ups go to the dentist? What do they think helps them when they go to the dentist? Is there anything you want to tell me about going to the dentist? Is there anything you want to tell me about your teeth?	*"By using photos or videos to help them talk"* OR *"If you also want to know if they want to go to dentists, you may need to ask this in different ways to get a response, for example, is your dentist talking to you? Is he/she kind? Do you like visiting him/her? In general, you should use some interactive techniques with them to help them express their views. If you do not this means that you are unfair to them."*

Previous suggestion enabled the development of the following research methods used with the children. Furthermore, as I mentioned earlier, in the first phase of my data collection, I attended some classes to observe the communication methods that teachers employed. I also reviewed the literature of other inclusive approaches used by children generally and disabled children (see more detail in Chapter 4). A note was made of the research tools academics had observed as working well with disabled children in different contexts.

By using pluralistic methods, I created a space for the children to express their views and to say whatever they wanted. Before starting the data collection, I checked whether the child would like to take part in the research and obtained their assent to record the data. The next section discusses the different methods employed.

1.35.3.1 Interviews with disabled children

The study sought to explore children's experiences; therefore, semi-structured interviews were appropriate. Interviews took place at school; social conventions meant the researcher could not visit children's homes. At the early stages of data collection with children, I spent some time with them in multiple sessions to introduce myself. These sessions were informal and relaxed, intended to break the ice between me and them and to build rapport and balance potential power relationships. During these sessions, I also contributed to their daily activities, so they became more familiar with me as a researcher. Before conducting the interviews with children, children's assent to participate in this study was obtained. Whilst gaining assent, I assured them that participation in this research was not mandatory and that it was not schoolwork. This demonstrated to children that my role was different from that of a teacher. At the outset of the interviews, I explained to each child what we might do together, and they were given time to talk about anything they liked. This aimed at maximising children's confidence in expressing themselves and increased my confidence and understanding of their communication methods. Existing research guided me on developing skills working with children, understanding children's communication methods and work on the relationship between the children and myself. Disability activists view this an

essential part of the research process before conducting research activities (Abbott, 2013).

Using guidance from the disability research (Kroll et al, 2007) about focus groups being facilitative for people with communication impairments, I then decided to interview children in two groups, with five children in each. Previous research suggests group interviews achieve goals, because they may be less difficult than individual interviews for young children, and because they can diffuse the balance of power between adult interviewer and child interviewees (Brooker, 2001; Carr, 2000; Mauthner, 1997). However, after I met with the first group, I noticed that this method did not work very well, partly because I lacked experience in managing a group of five disabled children with differing needs and abilities. The children appeared to find being a group distracting and found it difficult to focus. I also noticed that some children talked more than others did, so not all children got an opportunity to speak. I felt at this stage that I was actually disabling some of the children and preventing their participation by using a focus group and decided to change my approach.

I then interviewed the children in pairs as recommended by many authors (Graue et al, 1998; Greig, 1999; Mayall, 2008). This worked much better, with the interviews taking place in a small, quiet, room lacking in distractions. At the end of these sessions, individual interviews with four children occurred at their request because they did not like speaking in front of their friends. After interviewing individually or in groups of two, children became more familiar with me, allowing more specific questioning, this helped children provide descriptions and justifications for their experiences and views. Conducting the interviews for each child occurred over five or six sessions. Each session took 45 minutes on different days, which considered tiredness and the limits for each individual. Digital recording and verbatim transcription occurred for all interviews.

During the interviews, a set of creative methods were developed and used to stimulate children's responses. The choice and presentation of these methods varied (along with more traditional interviewing question-and-answer discussion) in accordance with each child's self-presentation, preferences, demonstrated abilities, and comfort. Methods

differed for each child. The following is a discussion of creative methods used with children.

1.35.3.2 Pictures as facilitators

Pictures are often used in research with children as a means of providing visual references to the areas covered in an interview (Backett & Alexander, 1991; Curry & Russ, 1985; Eiser et al, 1990), and as a means to stimulate conversation (Hurworth, 2003). Visual techniques provide an innovative way to reduce power dynamics when adults conduct interviews (Bagnoli, 2012; Cappello, 2005; Einarsdottir, 2005). They can make research participation more interesting for children and young people (Bagnoli, 2012; Darbyshire et al, 2005). Some studies have argued that these approaches should or can replace existing methods, such as interviews and observation when designing work with children and young people (McLaughlin & Coleman-Fountain, 2019).

I followed some practical suggestions when setting up pictures that were used with disabled children; for example, the pictures had to be substantial, simple, realistic and of high quality (Stewig, 1994). The materials used had to be durable. This was so that children could handle them freely; for example, I found it helpful to laminate the pictures (Beresford, 1997). Finally, using pictures in interviews with care so children can accurately recognise and interpret the images (Beresford, 1997).

I used groups of pictures directly related to the research questions to stimulate conversation with the children. I asked some questions about each image, such as 'what is in the picture?' and 'what is known about it?' Table 13 presents the pictures used in this study as well as a sample of the questions used with each image.

Table 13: Pictures used in the study

Oral health
✓   What do you see in this picture? What do they know about teeth? What caused the pain? What do we get from our teeth? Why are teeth important to us? Is there anything you want to tell me about your teeth?
Oral health practices
✓   What do you see in this picture and what do you know about it? What do they use to clean their teeth? How many times, for example, do children clean their teeth, who will help them, and how? Does someone help them clean their teeth (such as a father, mother, brother or sister), or do they clean their teeth by themselves? Can you tell me the differences between the two pictures? (Such as healthy and unhealthy food)

Dental clinic
✓ What do they know about the dentist and the dental clinic? Why do children go to the dentist? Why do grown-ups go to the dentist? What do they think helps them when they go to the dentist? How they were feeling in the dental clinic, what did they like best, what they did not like, what did they find difficult, and what did they find not difficult? Does the dentist talk to you? Is she/he kind? Do you like visiting him/her.
Concept of disability
✓ What do you see in this picture? What does disability mean to children? Who uses a wheelchair or a walker?
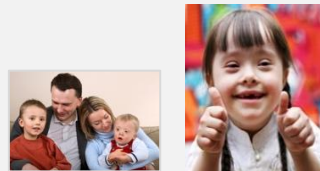
Five pictures were used to reflect oral health and there were 11 pictures of oral health practices (e.g., toothbrush, toothpaste, toothpick, healthy and unhealthy food). There were also nine images of the dental clinic (such as a dental chair, dental instruments, and a picture showing dental treatment) and six pictures illustrating societal representations of the concept of disability. Printing and laminating large and high quality for all images meant that the children could handle and talk about them freely. The interview questions were semi-structured, and, in many cases, they looked like conversations more than interviews. I recorded and transcribed children's interviews with permission. Table 14 presents two practical examples of using this method with research participants.

Table 14: Practical examples of using pictures

Example 1:

Danah is 10 years old and has a moderate intellectual disability.

The picture helped Danah express her point of view when she saw a picture on the table, although I had not shown her that particular picture.

> Danah said: *"I took a picture of a mother with her children* [the selected photo below]. *I love this family because the mother is with her daughter, it is the mother's duty to stay with her daughter and to show her love and care ..."*

Basmah is 11 years old and has a moderate intellectual disability.

> Basmah: "*In this picture* [pictured below] *pointing to non-disabled children: they can play and walk alone, but this* (the disabled child) *he must go with his mother, so that she helps him. These two can walk* (she pointed to non-disabled children) *all of them could walk except this boy* (she pointed to the disabled child) *he needs a chair and a woman to help him. This child was playing in the garden, the metal fall on his leg, his leg is broken and that's why he cannot walk*"

1.35.3.3 Games as facilitators

I designed four games to help the children have fun as they expressed their views. These games were a sorting game, a matching game, an adapted matching game for children with physical disabilities who could not hold a pen and a balancing game.

1. *Sorting game*

In connection with the group or individual interviews, the children were asked to arrange the pictures of healthy and unhealthy food according to their favourite food and then to sort the images into "good for your teeth" and "bad for your teeth" categories. I placed two large pictures printed on A4 of the happy and sad tooth on the table and asked children to decide if the food was healthy or unhealthy for teeth and to put it next to the appropriate tooth. Children spent much time arranging pictures. They thought aloud about the comparisons between images and the logical basis of their decisions. After they were happy with the results, I asked the child to explain the order they had

selected. I also asked them further follow-up questions such as 'Why did you put this picture here?' 'What is good about it?' 'What makes you dislike this?' Next, I took photographs of the final arrangements. I recorded the interview and documented children's behaviour, for example, attention or distraction during the task, in the field notes. A practical example of this task is in Table 15. I carried out a similar activity with their teachers when they were teaching children about oral health (see Figure 5).

Table 15: Practical example of using sorting game

Example:
Gala is 12 years old and has a mild intellectual disability
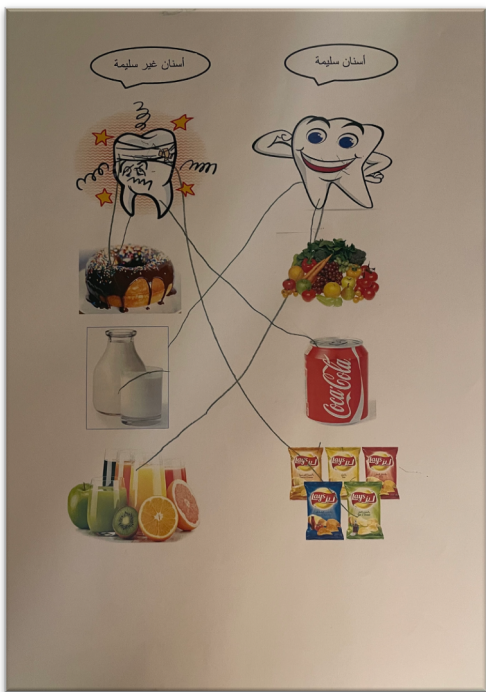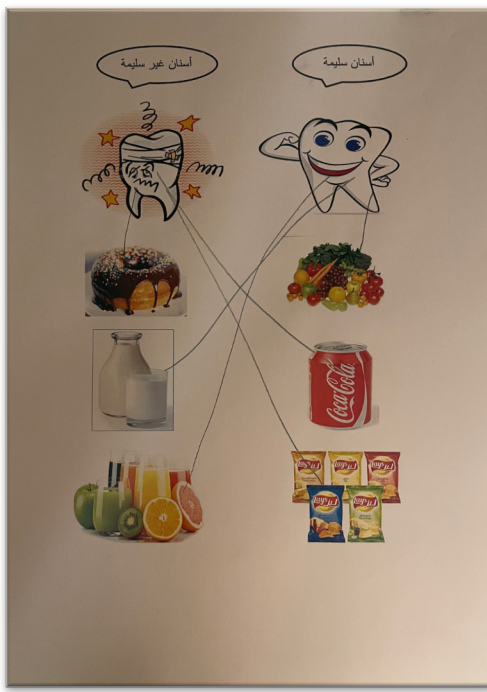
Figure 5: An educational activity designed by teachers of disabled children

2. Matching game

The idea of this task was similar to the sorting game but designed differently. I gave a worksheet to the children, asking them to link healthy and unhealthy foods with the appropriate tooth. I asked them to explain their answers alongside follow-up questions such as 'What are the consequences of eating healthy or unhealthy food?' I recorded the children's responses during the activity and took photographs of the worksheets, which include the final answers. Practical examples of this task are in Table 16.

Table 16: Practical examples of using the matching game

Example 1:	Example 2:
Lina is 9 years old and has a mild intellectual disability	Haneen is 11 years old and has a moderate intellectual disability

This activity worked well with children with intellectual disabilities but not with children with physical disabilities. This was because the latter had great difficulty using the pen or pencil to write. Therefore, I designed the following activity to facilitate their participation in the research.

3. *Specific matching game for children with physical disabilities*

I designed this activity to be suitable for children with physical disabilities because the previous game was not appropriate for many of them. In this activity, four working papers reflected the focus of the research and asked children to answer. Although these papers had similar ideas as those of the previous activities, the way of completing the activity was different. Children were asked to choose the correct answer by dragging the direction to the correct answer, placing stickers, using fingerprints, or drawing a circle using a glossy paste (see Figure 6). I photographed the worksheets, including the final answers, recording the interview. Some practical examples of these activities are in Table 17.

Figure 6: Matching game for children with physical disabilities

Table 17: Practical examples of using games (3)

Example 1:
Deema is 13 years old and has a mild intellectual disability and a physical disability

Example 2:
Haya is 11 years old and has cerebral palsy
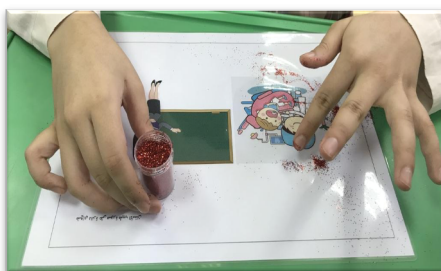
4. Balancing game

Another game involved using a balance. I asked children to choose the correct answers by placing a weight on the right answer, for example, placing healthy and unhealthy foods on both sides of the balance, asking children to put the weight on the side of the food that keeps the teeth healthy or the food they liked (see Figure 7). The children found this game very enjoyable.

Figure 7: Balancing game

1.35.3.4 Guided tours

I conducted guided tours at a later stage of data collection with the children. I invited each child to take me on a tour of the school to show the places that they loved or disliked. Children usually guided the way, walking in front of me, and introducing me to the sites and individuals who worked as tutors and gatekeepers to their worlds. When

we stopped somewhere, I asked children more follow-up questions such as 'What do you usually do here?' 'Who will come with you here?' 'Why do you like or dislike this place?' 'What can be done to improve things?' I recorded and transcribed the conversations. A practical example of this method is in Table 18.

Table 18: Practical example of guided tour

Joud is 14 years old and has a moderate intellectual disability.
I explained that I wanted to know more about the school and what was important to Joud. I asked her to show me the school by taking me on a tour around the place.   Joud led me from her class to the schoolyard and said: *I sit here with my classmates, and we have our meals. There is one of my classmates is sick, she always sits in the wheelchair, and we help her, I push her wheelchair, she doesn't do anything by herself, she is always with her maid. I love all girls; I don't fight any.*

1.35.3.5 Symbols

I used four symbols during the activities to help children express their feelings, needs and desires "Sad Face", "Happy Face", "Red Stop" and "Question Mark" (Figure 8). The children could use signs with facial expressions to display what they felt. They used the "question mark" when they needed to ask questions or if they needed to make requests. Our communications did not involve a scenario in which I was the only one who could ask questions. The "red stop" signal meant that the children did not want to continue. If children used the signals, I listened to them and complied with their requests.

Figure 8: Symbols

1.35.3.6 Children's drawings

Children's drawings have been used to discover the views and experiences of young children (Clark, 2005). The advantages of using drawings in conducting research with children are that children can deliver non-verbal expressions, can be creative and active when drawing. Furthermore, research suggests that most children are familiar with drawing activities, are able to change and add graphics as they wish and drawing often takes time, which means that a rapid answer is not required (Dockett & Perry, 2005; Parkinson, 2001; Punch, 2002). Drawings are visual data providing insights into how children see things. However, many disadvantages of drawing as a method of data collection have been pointed out; for example, children may mimic the drawings of others, and some children do not like to draw (Einarsdóttir, 2007).

I used this method to stimulate children's responses during interviews. I provided pencils and paper to children who participated in the study just in case they felt the need to express themselves. I asked children to draw pictures of what they did and did not like at the dental clinic and at school. I then asked them what they were drawing, alongside more follow-up questions. While recording the activity, I wrote the children's responses on the back of the paper. The drawings by participating children are in Appendix 17.

Overall, at the Centre for Disabled Children, I spent time observing the environment and the participants. I conducted semi-structured interviews with healthcare providers and mothers of disabled children.

At the school, I spent time observing the children, teachers and the environment, building rapport with the children, and engaging with them in informal conversations during mealtimes. I conducted semi-structured interviews with teachers, and once the children were comfortable with my presence, I carried out multiple inclusive activities with them to elicit their views and experiences on oral health and oral health care.

1.35.3.7 Reflection on using inclusive activities with disabled children

One of the current study objectives was to represent children's perspectives and experiences to give them a voice in oral health research. I was particularly careful not to assume what they could or could not do based merely on information about their age, impairment, or other perceptions and comments from adults. To achieve the objective of this study, I used various inclusive approaches on an individual basis with a focus on removing the barriers to participation in research for every child and supporting them to contribute their responses in the most appropriate way. Multiple activities and flexible methods of research with children were important in this research because I observed that the children quickly became bored.

Before starting each interview, I reminded the children that they could stop the interview at any time, move to any specific question, that there were no "correct" or "wrong" answers. I also asked for the child's permission to record the interview. Group interviews helped me build a relationship with the children so that I could become familiar with them, as well as with any particular requirements or procedures they may have. The information gained at this stage helped increase the children's participation and overall research experience. In most interviews, building a relationship was successful, and the children showed confidence towards me both verbally and non-verbally. The youngest child indicated rapport by sitting near and hugging me. Most children during interviews would suddenly say *"Doctor I love you"*. An 11-year-old girl told me: *"I'm waiting for you, when will you take me to your room?"* A teacher brought a 9-year-old girl to me while I had coffee with another teacher saying, *"Please talk to her because she does not want to stay in the classroom. She said she wanted to go to you"*. Then the teacher said, *"What did you do with our students? They love you* (she laughed)*"*. The other teacher who was sitting with me answered, *"I think because she played with them and talked to them, frankly even me I love her"*. This positive environment helped me develop confidence at this research site. It confirmed that the participants were comfortable with my presence and that they were happy to express their views.

Using pictures as a prompt to help children talk or communicate about the research questions was very useful. The images also helped me to ask the children questions.

Using many pictures for each research aspect increased the children's ability to express their views in more depth.

Although the games I used had the same ideas or related to the same knowledge in other studies, I designed them differently for various reasons. Firstly, I intended them to promote engagement by being more attractive to children. Secondly, the variety of games helped me to change the game quickly if I noticed that a particular game did not help a child express their views, or they began to tire. Finally, I based the various designs on the different abilities of the children, with the aim of promoting greater inclusion.

The guided tour activity was productive, and the relationship with the children was quickly developed. Most children started talking about their school life as soon as we started the tour. When walking side by side, it increased the ability for the children to chat informally and appeared to reduce the power imbalance when interviewing in a more formal or structured way. The children appeared to find the activity interesting and enjoyable. I also observed that some children liked this activity as a way to escape the classroom because it gave them the opportunity to go with me to restricted areas. Other children felt that there was not enough time to show me more of their school, even though we had spent 30 minutes together. Conversely, a few children felt tired, got bored very quickly, and wanted to return to the classroom. This method was not appropriate for children who used wheelchairs because I noticed that I was directing them, not the other way around. This may also have had something to do with the environment because it was not purpose-built for wheelchair users.

In the interviews, most children did not use the symbols. I noticed that they distracted them more than they helped. This was because some children found it difficult to focus on doing multiple tasks at the same time. Although other researchers designed this method to help children express their feelings, symbols did not work well with the children in this study.

Drawings in research are usually an enjoyable or fun method for children to reveal their views and experiences (Backett & Alexander, 1991; Oakley et al, 1995; Williams et al, 1989). However, this method did not help children to speak or communicate in this

study. Children often forgot the question and drew only what they wanted to draw. When this happened, the children were given time to make drawings of their choice, and then they were asked to make a special drawing. I observed that it was still difficult for them to maintain their focus. I felt that drawing, as a tool, was a distraction for the children in this study. Furthermore, some children did not have drawing experience, found it boring or uncomfortable because of their physical impairments and viewed it negatively. Therefore, I stopped the activity when I noticed that children were not enjoying the process.

> *"I hate drawing because I am very bad at drawing. I like to match healthy and unhealthy food with an appropriate tooth, and then I will explain to you why I answered like that"* (Haneen, 11)

> *"Sorry! I cannot draw. My hands do not allow me to do so… I would prefer to do matching"* (Haya, 11*)*

Haneen and Haya disliked drawing, Haya because of her physical impairments and Haneen because she struggled with concentration and staying on task. The other activities did not create excessive cognitive load or physical expectations, and both participants felt happier and that they could still take part.

Despite my efforts to facilitate communication with the children, there were times when I faced difficulties, such as when children refused to respond if they were tired or wanted to play. I largely overcame this by staying in the classroom and school environment for extended periods with the children and providing them with frequent breaks. In many cases, communication with their teacher before the interview helped overcome these difficulties because their teachers gave me guidance on how each child communicated in order to achieve successful interactions. Nevertheless, I found it important to learn from each interview when scheduling subsequent interviews. For example, the children sometimes became easily distracted, so it was difficult keeping the conversation flowing without interruption. In these situations, I often allowed the children to finish their comments, regardless of their relevance, in order to value their ideas and prevent them from feeling obligated to commit to my interests. Although most children communicated verbally, some had communication impairments and so needed

longer to respond and interact. I addressed this challenge by staying with the child for an extended period. For example, over a few weeks and just using small chunks of time that were manageable for each child. Paying attention to diversity within and between disabled children whilst implementing innovative and pluralistic methods is important for engendering inclusion in oral health research. Furthermore, it values disabled children's voices and opinions in research that concerns them.

In summary, interviews were successful in terms of children's enjoyment, and they generated rich and interesting data. There was an exciting discussion in all activities and meetings, contrasting ideas between the children, and I facilitated children who needed extra time or assistance in responding. They all understood the activities' ideas and were able to contribute by changing the activities and focusing them more on children's abilities.

1.36 Data analysis

In qualitative research, the purpose of data analysis is to make sense and produce meaning out of it (Merriam & Tisdell, 2015). In order to do this, the researcher needs to establish meaningful themes and highlighted significant patterns, in addition, to decide how to present them (Quinn Patton, 2002). In this research, data were collected and analysed side by side, using a thematic analysis approach to analysing data. The next section outlines the procedure used in the thematic approach to analysing research data.

1.36.1 Thematic analysis

One of the most common analytic approaches in qualitative research is thematic analysis (Guest et al, 2012). "It is a method for identifying, analysing and reporting patterns (themes) within data". "It minimally organises and describes your data set in rich detail" (Braun & Clarke, 2006, p. 79). In qualitative research, the use of thematic analysis is distinguished by its benefits, including flexibility, the provision of a "thick description" of the data set, and the ability to highlight the main features of the data, permitting social and psychological data interpretations and perhaps producing unexpected understandings (Braun & Clarke, 2006). The different phases of thematic analysis followed in data analysis are summarised in Table 19 below.

Table 19: Phases of thematic analysis (Braun & Clarke, 2006)

Phase	Description of the process
1. Becoming familiar with the data	Reading and rereading the data; transcribing data (if necessary); noting down initial ideas.
2. Generating initial codes	Systematic coding of interesting data characteristics across the entire data set; collecting data relevant to each code.
3. Searching for themes	Collecting codes into possible themes; collecting all data related to each possible theme
4. Reviewing themes	Testing that the themes are functioning in relation to the coded extracts (Level 1) and the whole data set (Level 2), creating a thematic "map" of the analysis.
5. Defining and naming themes	Continuing analysis to refine each theme's characteristics, and the whole story presented by the analysis, creating clear meanings and names for each theme.
6. Producing the report	Final analysis of selected extracts; relating the analysis back to the research question and the literature; generating a scholarly report of the analysis.

Unlike the table, I found that the analysis was not a linear process in which I moved from one phase to the next in sequence. Instead, it was more of a recursive process where I moved back and forth through the analysis phases as required. Below is a detailed description of employing the phases of thematic analysis in this study.

1.36.1.1 Becoming familiar with the data

According to Braun & Clarke (2006), the data familiarisation step includes transcribing the data (if required), reading the data and re-reading it, noting the initial ideas. I transcribed the interviews in written form using Microsoft Word after listening carefully to the interview and then translated them into English. By simply preparing and organising the data collected for analysis, familiarity with the data improved and

analytic ideas arose. The following step was to read and re-read the transcripts for initial thoughts and ideas for more data immersion. Consequently, I took notes on emerging patterns and themes.

1.36.1.1.1 Transcribing and translating techniques

It was suggested by Green and Thorogood (2018) that it is worth transcribing an interview directly after its completion and writing field notes in order to document the interviewer's comments on the interview. In my study, the process of transcribing and translating began in conjunction with fieldwork. I initially transcribed the interviews in Arabic. The transcription process included listening to tapes several times. I transcribed each participant's interview by making notes about a crucial laugh, pause, or gesture. The transcription process aimed to create an accurate account of the conversation that took place with each participant, so the transcription was an explanatory activity (King, 2010). Transcribing the interviews early during the fieldwork also provided an excellent opportunity to engage with the data early in the process of data collection. It also enabled early verification of the interview technique and led to some alterations in the questioning style; for example, it resulted in asking more questions based on the participants' answers in order to obtain in-depth data.

After transcription, I translated all interviews into English. The translation was an important but time-consuming part of the data analysis process. Brislin (1970), Phillips (1959) and Regmi et al's (2010) have pointed out that the process of translation itself is a fruitful analytical technique and a crucial task that requires the researcher's effort and time. They also indicated that the method of translation poses various kinds of problems affecting the credibility of the study data and consequences. I was conscious that to reduce these issues and any mistakes, I needed to be careful. A broad range of literature addresses the various ways in which researchers in a research study can resolve linguistic differences (Birbili, 2001; Denzin, 1989; Esposito, 2001; Regmi et al, 2010; Temple, 1997; Twinn, 1997). These studies agree that the first step towards producing quality translation and reducing translation errors is when someone who knows both languages and is part of the cultural background translates.

Denzin (1989) further argued that the quality of translation depends on the transcriber's ability to retain the meanings of the data gathered. In light of this, I made a great effort to translate the interview literally and to preserve the meaning as far as possible. I preserved each sentence in Arabic and translated it literally into English with the aim of not losing the meaning of the sentences. In order to check if the translation was logical in English, this task involved reading the texts again. This was a very complicated stage since I had to be a translator, interpreter and writer to keep the data as authentic as possible. While this process was time consuming and difficult, it ensured that I was very familiar with my data because I had to check it several times. This made my analysis possible. To test the translation equivalence, a professional bilingual translator compared the two versions of each interview to confirm translation equivalence.

1.36.1.2 Generation of initial codes

This phase includes "coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code" (Braun & Clarke, 2006, p. 87). I used the old method of manual coding with a pen, pencil, paper, and highlighter. Research argues that manual coding gives more control over the research data to the academic (Erik, 2016).

After defining the coding method, the process then started with open coding as the main ideas are inductively created to let the data to speak for itself (Bryman, 2016). Based on three selected interviews, I produced several codes initially, in the first stage of the analysis. I then separated the list of codes according to their matches. I later checked and revised them to remove duplicates. The coding process was continuous and iterative to create meaningful themes. To create connections and links among diverse concepts and ideas, I took notes. New codes emerged when analysing the remaining texts, some of which were more specific and accurate in comparison with the previous codes. Then I collected all data extracts with the same code. Using this process, I reduced the data and organised into meaningful sections. An example of extracting data, with codes used in Table 20 below.

Table 20: Examples of extracting data, with codes applied

Data extract	Initial codes
... I know a toothbrush and toothpaste, and I brush my teeth after meals, to get rid of cavities and make the teeth stronger... I usually visit the dental clinic, the dentist examined my teeth, and then she did X-ray. She put something inside my mouth, then left the room. Then she came to fix my teeth. She gave me anesthetic and then fixed my teeth. She filled half of my teeth, and then she pulled out the other half...	Toothbrush, toothpaste, brushing, visiting clinic

Brushing teeth to get rid of cavities and make teeth stronger

Dentist examining teeth, doing x-ray, dentist giving local anaesthetic, filling and extracting teeth |

1.36.1.3 Searching for themes

This stage includes refocusing analysis on the broadest level of themes, rather than codes, sorting diverse codes into possible themes, and collecting all relevant codes data extracts within the identified themes (Braun & Clarke, 2006). I sorted the various codes, either combined or separate, into possible themes to achieve this stage. I then engaged in an ongoing comparison and reflection of the emerging themes to determine the connections between codes and themes. By the end of this stage, corresponding extracts of data were labelled with a set of initial themes and sub-themes. Table 21 shows an example of the codes used and emerging themes.

Table 21: Example of codes used and emerging themes

Initial codes	Initial sub-themes	Initial theme
Toothbrush, toothpaste, brushing, visiting clinic	Oral health practices	Disabled children's knowledge and practices of oral health and dental care
Dentist examining teeth, doing x-ray, dentist giving local anaesthetic, filling and extracting teeth	Awareness and knowledge of dental procedures	

1.36.1.4 Reviewing themes

This phase involves verifying that the themes "work" for both coded extracts and the full data set (Braun & Clarke, 2006). To do this, I applied two levels of reviewing and refining the themes. The first level includes a review at the level of extraction of coded data. A similar procedure, but relating to the entire data set, is involved in the second level. This happened because of two things. This ensured that the themes were identical for data extraction, and I encoded any additional data within themes that might have been missed in the initial coding phases.

1.36.1.5 Defining and naming themes

This phase involved defining and refining themes by "identifying" "the essence" of what each theme is about (in addition to the themes generally) and deciding which elements of the data each theme captures. Being short and punchy and giving the reader a sense of what the theme is about, all of these things were considered in naming the themes (Braun & Clarke, 2006). The final analysis and writing up used the refined theme names.

1.36.1.6 Writing-up of the report

This stage includes writing the report to present a concise, logical, coherent, non-recurring and interesting account of the story told by data within and across themes (Braun & Clarke, 2006). Illustrative extracts were used in writing the analysis to express the data story in a way that convinces the reader of the data's worth and validity (Braun & Clarke, 2006). The overall results will be presented in Chapters 6 to 9.

1.37 Ethical considerations

The University of Sheffield Ethics Committee approved this study in March 2018 (see Appendix 18). I considered ethical guidance from the University of Sheffield on working with vulnerable children and young people. Other ethical guidance from the British Sociological Society and the British Psychological Society guided the study.

Ethics are a critical issue in all research involving young people and children. Scholars conducting research with children highlight the ongoing nature of ethical considerations

at all stages of the study process (Alderson, 1995; Alderson & Morrow, 2011; Hill, 2005; Lindsay, 2000; Morrow & Richards, 1996). Researching with children raises many ethical issues, i.e., the ability of each child to offer informed consent, maintaining confidentiality, achieving privacy, and the power difference between a child and an adult (Fraser et al, 2004; Lewis et al, 2000; Punch, 2002).

These ethical concerns are not special to children, and when researching with adults, many of them occur. Nevertheless, children's experience and understanding of the world varies from adults, variations in how children communicate, and asymmetric relationships of power exist between child contributors and adult researchers (Kirk, 2007; Mauthner, 1997; Punch, 2002; Thomas & O'Kane, 1998). When the participants are disabled children, then researchers could run the risk of unintentionally disabling them because of presumptions about their abilities. This is a further ethical concern.

The following paragraphs provide details about the main ethical concerns that can arise in qualitative research with children and young people, and with adult participants, which I considered in this thesis. These ethical issues comprise; participant information and consent/ assent; power relationships; confidentiality; data protection; and dissemination of results.

Information for participants: I informed potential participants about the aims, methods and intended likely uses of the study through information sheets. The information sheets also provided information on how to contact my supervisors with any concerns, or myself to ask questions or clarify. Information about the research was prepared in a way that was easy to understand by all the participants included in this study (mothers, teachers, healthcare providers, and children).

Consent/ assent: I gave consent sheets to mothers, teachers and healthcare providers in order for them to participate in the interviews. If they agreed to participate, I reinforced the objectives of the study in very basic terms at each meeting and gave them the option to withdraw at any time, and for any reason. Nevertheless, obtaining consent may not be possible with younger children, who could lack the ability to give this level of consent. In this situation, I gained consent from an adult "gatekeeper" and obtained agreement to contribute from the child.

I designed an assent form for children, and if the child did not assent to participate, even if there had been parental consent, I did not involve them in the study. I made sure that the children were not "over-persuaded" to participate, and they gave assent freely. I restricted my research to including children who were able to assent and indicate, verbally or non-verbally, with or without support.

The assent of participants in this research, whatever their age or competence, was obtained in ways suitable to their age and ability. In the case of very young children, and individuals who may struggle with communication, their assent was regularly monitored via sensitive notice to any signs, non-verbal or verbal, that they were not wholly willing to participate. Children can express their assent in different ways. Cree et al. (2002) suggest that a researcher can recognise if children dislike participating in research by looking out for signs, such as crying or refusal to engage with materials or the researcher. Overall, gaining assent should be seen as an ongoing process throughout the research rather than as a one-off agreement (Knox et al, 2000; Lewis & Porter, 2004; Porter, 2009). At the start of each research activity, I checked with children that they were happy to participate and continue, but if they indicated that they were tired or if they began to feel distressed, I stopped and reassured them that this was fine and that they did not have to continue. Before observations, I gained informed consent from the sites' administrators and the research participants.

Power relationships: I was aware that it was my duty to frequently reflect and tackle the power imbalance between the children and myself, their teachers and mothers. Researchers propose various ways to manage the inherent power differences between child participants and adult researchers (Kirk, 2007), see Table 22.

Table 22: Ways of managing the power differential between children and adults in research (Kirk, 2007)

- Using methods that allow children to feel part of the research process and which give them the maximum opportunity to provide their views.
- Being responsive to children's own agendas.
- Involving children as part of the research team.
- Using group interviews.
- Checking on children's willingness to participate throughout the interview (including being aware of non-verbal cues such as body language).
- Rehearsing with children how to decline participating or answering particular questions.
- Giving children control over tape recorders in interviews

I considered Kirk's (2007) recommendations in order to reduce the power imbalance between the children and me, although I was aware that I could not remove it entirely. I adopted several strategies. I informed the children about the study. I obtained assent directly from them, so they could decide whether they wanted to participate in the research or not; they had the right to withdraw at any time they liked. I consulted children about the place and time that they were comfortable with for the activities, respecting them as gatekeepers who could determine what they wanted to share with me. Their wishes to continue participating in the study were continually checked (Clark, 2014). They were free to say "no" to me and to express their dislike or resistance without fretting about the issue of confidentiality or my personal opinion. I assured them that they did not have to feel compelled to answer my queries. Children could say, "I do not know" or tell me when they did not understand my question. I avoided giving the impression that there was only one right answer to any question, so they did not have to deal with our conversations as if it was schoolwork to complete. I selected inclusive activities identified in the evidence and through guidance by the teachers at the school, as suitable for research with the children. By applying all these strategies, I felt this assisted in balancing power relations with children and this was key to the production of data. The children were quite ready to reveal their views to me. Occasionally they did not agree, challenging or laughing at what I was saying.

A further point of consideration was that mothers of disabled children might act as protectors and that it was possible that they might deny their children the opportunities to participate, or, conversely, that they might drive them into participating (Harden et al, 2000). The children might participate or refuse to participate because of power issues between them and their teachers. I alleviated this power imbalance by obtaining assent from the children to participate in the research in ways suitable to their ages and abilities. Children's impairments could have been another factor that affected the power dynamics between the children and me, and this issue has been suggested in other research (Mishna et al, 2004). Consequently, to reduce the imbalance as far as possible, I used inclusive methods with the children (pictures, games) that appealed to them, and I encouraged them to communicate in ways that suited them and with which they were happy. Existing research suggests that using alternative means to communicate with disabled children is empowering as it enables them to contribute to a research study and to express their views (Graham & Fitzgerald, 2011; Lindsay, 2000).

Issues of power might also have arisen within the relationships between mothers and me. Some mothers might have felt that they ought to agree to contribute to the research, so they may have been afraid that refusing to participate could affect the services their child would obtain. To address this concern, mothers were assured and reassured that participation was not compulsory, that they could withdraw at any time, and that this would not lead to any adverse outcome or upset anybody in any way. Throughout the data collection process, I realised that no matter how difficult it was, I could not decrease the power gap totally because I am qualified and hold a particular place in society because of my occupation. I also could not separate myself entirely, as I am a dental professional, plus I am interested in the dental health of disabled children.

Confidentiality: Privacy and confidentiality are crucial in research. Confidentiality means that, unless otherwise agreed, the contributors' identities must be protected, and that any information gathered does not embarrass or harm them in any way (Bogdan & Biklen, 1998). I guaranteed confidentiality through anonymity. I ensured anonymity by giving participants a false name and altering the data to remove anything that could identify participants. In Saudi society, privacy is a major concern. At all times in the research process, I respected the privacy of the participants.

Data protection: I kept digital recordings and transcriptions in a secure place on the university drive, destroying the digital recordings after transcription. I did not move around the research sites with or leave visible, details of interview schedules that would identify individuals.

Dissemination: I kept participants informed of the results throughout the research process and asked them to verify whether my interpretations were accurate in representing their views. I returned to them and discussed the findings verbally with them or gave them a transcript in Arabic of our conversation and asked them to verify. At the end of the study, I plan to send the results to the participants in an appropriate and accessible format and to thank them for their participation in the study.

1.38 Research quality

Quantitative and qualitative scholars need to show reliability and internal and external validity for data analysis in their studies. Reliability indicates consistency such that the research would achieve the same results if repeated. Internal validity indicates the accuracy or validity of the results, while the external validity indicates whether the research findings can be generalised to new settings, people, or samples. Quantitative research primarily uses the terms "internal validity" and "external validity". However, some researchers use the terms "credibility" and "transferability" when determining the rigour of qualitative studies, arguing that these terms are more applicable and appropriate to natural research than the terms "internal validity" and "external validity" (Ritchie et al, 2013). Guba and Lincoln (1994) proposed the term "trustworthiness" in qualitative study rather than "reliability" and "validity". Trustworthiness is a process used by qualitative scholars in order to determine the accuracy of study's findings, an essential technique that increases confidence that the results are accurate and reflect the views of participants (Lietz et al, 2006; Lincoln & Guba, 1985). Many scholars have proposed various strategies and methods to ensure quality research and trustworthiness. Neuman (2011) suggests that the researcher needs to collect "rich" data in order to verify that the results of the study are accurate and valid. Patton (1990) argues that the researcher is the instrument of measurement in a qualitative study. Therefore, the trustworthiness of qualitative studies relies on transparency, the extent of the

researcher's diligence and the care and efficiency with which they conduct research. There are alternative criteria for assessing the trustworthiness of qualitative research (Lincoln & Guba, 1985). These include credibility, transferability, dependability and confirmability.

Credibility seeks to assess whether the results of the research are believable and acceptable (Lincoln & Guba, 1985). In order to achieve this, I used triangulation. Denzin (1978) and Patton (1999) identify four types of triangulations including *Analyst triangulation, Theory/perspective triangulation, Methods triangulation and Triangulation of sources*. Analyst triangulation means using multiple analysts to review findings or using various observers and analysts, and Theory/perspective triangulation, meaning, using multiple theoretical perspectives to examine and interpret the data. Triangulation of sources and methods was adopted in this study, which means that several research methods and sources of data were used to develop a comprehensive understanding of phenomena (Denzin & Lincoln, 2011; Patton, 1999). In this study, I obtained various perspectives or different sources of data. I used numerous research methods during data collection, such as observations, semi-structured interviews, and inclusive activities with children. Using pluralistic methods meant adding depth and increasing understanding, thereby improving trustworthiness.

Transferability (generalisability) in research, generalisation refers to extending of the findings of the study, conclusions, or further accounts which are founded on the study of people, sites, institutions or times to people, places, institutions or times other than those studied directly (Polit & Beck, 2010). The generalisation is a quality criterion in quantitative research; however, it is more controversial in a qualitative study. The objective of most qualitative research is not to generalise but to provide a rich and contextual understanding of some aspect of human experience throughout the rigorous investigation of specific situations (Polit & Beck, 2010).

There is a widely accepted view among both quantitative and qualitative researchers that there are two main strategies of generalisation in social research, these two strategies are statistical generalisation and analytical generalisation (Yin, 2003). The first strategy underlying quantitative studies is to extrapolate from a sample to a population. Quantitative researchers begin by identifying populations who wish to

generalise their outcomes. They select participants from that group, aiming to choose a population representative sample (Yin, 2003). In analytical generalisation, academics use "a theory that has been developed as a template to compare the experimental results of the case study". If two or more cases support the same theory, it is possible to demand repetition (Yin, 2003). Yin (2003) described this strategy as "generalising to theory". The analytical generalisation is often associated with qualitative research, though it is implicitly included in theory-driven quantitative studies additionally (Polit & Beck, 2010).

However, other qualitative scholars have proposed a third approach to generalisation, where the emphasis is not on the generality of results or interpretations as much as on the transferability of one case to another; case-to-case transferability is the usual term for this approach (Jensen, 2008; Lincoln & Guba, 1985; Schwandt, 2007). Transferability does not need the discovery of general conditions in which the result or theory is correct; instead, it includes the transfer of knowledge from study to a particular new position. This would shift the responsibility of making the generalisations from the scholar to the reader or potential user of the results, and Misco (2007, cited in Polit and Beck, 2010) named this "reader generalisation". Achieving transferability occurs through providing a thick description (Holloway, 1997; Ryle, 2009). A researcher who aims to generalise qualitative results must give a clear explanation of the study's context, process and assumptions (Lincoln & Guba, 1985). Rich descriptions provide a framework for others to assess the transferability of results to other contexts (Bryman, 2006).

In my research, I have provided explanations about the settings (see Chapter 6) and characteristics of the participants in the study, the research process, and the challenges encountered. These explanations enable others to judge the transferability of search results. I argue that the results of this research are, to some extent, transferable to similar contexts.

Dependability refers to the consistency of the research results are and can be repeated if following the same processes. Lincoln and Guba (1985) proposed that achieving consistency means researchers need to reflect on the study by adopting an "auditing" technique. This method involves a continuous record of evidence and documents for

each stage of the research process (Creswell, 2007). Throughout my study, I kept complete records of various materials, such as ethical approval, invitation letters, participants' information sheets, consent forms, documents and transcriptions of the interviews, observation notes, and study challenges.

Confirmability refers to the extent to which informants, rather than the researcher's bias, interest, or motivation, form the results of the study (Lincoln & Guba, 1985). In order to improve confirmability, I documented procedures and activities for each stage of the research. I also reflected on this during the process, and I described the procedures in the data analysis.

Reflexivity is central to the quality of ethnographic research (Reeves et al, 2008). It is a process by which the researcher regularly checks the production of data, examines possible sources of error, and recognises, evaluates and understands how his/her own social background or assumptions can intervene in the research process (Foster, 1996). My personal and professional interest in conducting this research grew out of my experience working with disabled children in a dental clinic, and as a woman born and raised in Saudi Arabia. From both experiences, I have obtained a good awareness of the challenges that disabled children and their mothers face in relation to obtaining oral health care. I was also interested in raising their voices because they are often ignored in my culture and most family members may also hide them and not believe they have the ability to speak and live their lives as non-disabled people. These past and present personal experiences influenced my interest in pursuing the research topic. As an Arabic-speaking Saudi woman who shares the same social background as the research participants, this also has helped me in negotiating access, building relationships with gatekeepers, and gaining access to research participants. The research participants were able to trust me and believed that I was sympathetic and understanding to their circumstances. Being a female allowed many women to talk to me freely and openly, which they would not have done if I was man.

I was also aware that I held an insider-outsider position in my study. As mentioned above, I had some common ground with the participants, as we shared common cultural norms and lived in the same city (Riyadh), which made me an insider. However, I started my fieldwork more as an outsider, as I had no formal role in the schools' communities and was unfamiliar with any of the participants. Such positionality should

be considered to potentially shape the data and thus the quality of the study. For example, attention should be paid to the ways in researchers present themselves and build relationships with participants, their appearance and their relevance to the research context (Hennink et al, 2010). It was important for me to properly present myself to the participants and to make my appearance fit into the school environment. In addition, I had to work to build a rapport with the participants before interviewing them. During the fieldwork, although I had expected it to be tough, I did not encounter a lot of difficulty in building rapport with the children. The key was to act differently from the teachers, who often criticised students over exam results or disciplinary issues. Being non-judgemental, friendly, approachable and curious enabled me to be quickly accepted by children; I was always surrounded by them during the breaks. During the interviews, I was consciously aware of the possibility of a power imbalance between myself and the participants, particularly given my professional background. I tried to ensure that a non-judgmental approach was used and realised that I had a duty to frequently reflect and tackle the power imbalance between myself and the research participants as discussed earlier in this chapter. However, I realised that no matter how difficult it was, I could not completely remove the power gap because I am qualified and hold a particular place in society because of my occupation. Furthermore, I could not entirely separate myself as I am a dental professional, plus I am interested in the dental health of disabled children. However, using a reflexive approach helped to realised that it was important to clearly and comprehensively record and interpret children's experiences as they occurred, and to separately record my personal reflections, thus enhancing the objectivity of the data.

In general, the process of reflection gave me the opportunity to provide an appropriate and reasonable view of my experiences and descriptions about the state of the study and the cultural context. Reflexivity ensured that my social and cultural position was clear, helping the reader gain more insight. I reflected that I already shared a similar social background to the research participants. I have also clearly mentioned the assumptions underlying the study clearly, and I have reflected on my own views on the issues posed during the interviews. Furthermore, to ensure reflexivity throughout the research process, I also regularly met with my research supervisors who often participated in discussions on the data analysis. As these supervisors belong to a contextual background that differs from my own, their assistance and support during the data

analysis stage has been advantageous because they were able to identify problems and ask questions. This was a significant part of the reflective process, helping to clarify or reveal hidden meanings that directed to additional interpretation and reflection on the analysis and have undoubtedly influenced the study results. I wrote a diary about my feelings every day during the research. When I came to write the results, I went back to these memos to help me interpret the data. Field research, which includes data collection, simultaneous analysis, and continuous thinking, was an excellent way to assess the scope of my effect on the research data.

1.39 Summary

This chapter has presented a detailed explanation, justification, and appraisal of the research methods used to collect and analyse data. In the next chapter, I will discuss the sites where the research took place to give context to the analysis.

The research settings

1.40 Introduction

The previous chapter discussed the diversity of research methods involved in this study. This chapter introduces the reader to a detailed description of the research settings to provide context to the research. This is essential in ethnography because it provides the thick description described by Clifford (1973) that he argues that to understand people's behaviour, we must consider the context in which they are behaving. For confidentiality reasons, I gave pseudonyms to places and redacted some of the identifying details of search locations from the following description. I obtained verbal approval from the administrators of the sites to take some pictures.

1.41 Research settings

This study was conducted in Riyadh, the capital city of the Kingdom of Saudi Arabia (see Chapter 3 for further discussion about Riyadh and the KSA). I recruited participants from two sites in Riyadh. Site 1 was a centre for disabled children and site 2 was a school for students with intellectual disabilities.

The Centre for Disabled Children

This particular centre is located in Riyadh. There are multiple centres similar to this throughout the Kingdom and some are located in different cities. This centre aims to support disabled children, to enable them to develop skills, which can vary depending on their individual abilities, and assist society in addressing disability. The objectives of this centre are:

1. To provide education, medical and rehabilitation services for disabled children and to support their families.

2. To enlighten and educate society on the causes of disability.

3. To support research in the field by establishing a database for programmes that offer services for disabled children.

This centre provides several services for disabled children. These include support services, such as art workshops and communication and speech units, medical services and educational services.

The medical centre includes consultation clinics, physiotherapy, speech therapy, dental clinics, and social services. A team of national and international specialists in paediatric medicine supervises the whole centre. Educational services for children aged 4–12 years are provided to cover nursery, reception and primary educational stages.

Both the nursery and reception comprise of children aged 4–6 years in mixed ability groups. The focus in these stages is on developing children's perceptions of play, providing a structured educational environment, developing social skills, supporting the individual abilities of the children and preparing them for the next academic stage. The primary stage comprises of children aged 6–12 years. In this stage, long-term and short-term goals are determined according to individual abilities. The following excerpt from the field notes describes the centre, the environment of the educational classroom, and my feelings towards it:

> *The objectives of the centre focus on providing therapeutic, educational and rehabilitative care for disabled children. It also plays a role in raising awareness in society about the causes of disability in order to create positive and to contribute to building a scientific base for programmes for the care of disabled people generally by supporting research and studies. These objectives illustrate that the centre tends to understand disability through the medical model, which may have an impact on the services they provide to disabled children, which will focus on disability reform rather than trying to reduce barriers created through societal attitudes and structures that restrict the life choices of disabled people.*

> *The building of this centre has two sections: the medical and educational department. There is also the administration building, including the administrative, financial and support services, and the meeting room. There are also three outpatient clinics located in a separate building, offering intensive therapeutic care for those who need intensive physical therapy. The centre also*

provides social, psychological, educational and medical services, including dental treatment, physiotherapy, art classes, Holy Quran, Makaton, and computer classes. The aim of social services is to help families, especially those with high levels of need. The centre provides bags containing school tools such as pens and notebooks before the start of the school year and provides food bags before the holy month of Ramadan. Chairs and mattresses are provided for those who need them, or an equivalent value of money to the family, so, it also works as a charity. The psychological services are keen to provide support for the children and their families. Dental services are delivered by a dental hygiene and therapist who provide preventive services such as dental hygiene, oral hygiene instruction and application of fluoride and fissure sealants. There is also a voluntary dentist, who carries out dental examinations and refers children to relevant clinics outside the centre if they need dental treatment. Physical and functional therapy is provided to children to help them to increase bone density and muscle strength, which aids with mobility. There is a hydrotherapy pool for the children to help with developing muscle tone, circulation and reducing pain and anxiety. The art classes provide tools designed according to the ability of children, for example, pen holders for children who have difficulty with writing (see Figure 9). *There is a classroom to teach the Holy Quran where there are aids used to help children to memorise the Quran through pens and a large Quran reader; sometimes images are used to represent the Quran* verses (see Figure 10). *This class is important for children because all aspects of life in Saudi Arabia are based on The Holy Quran, and this is a way of integrating children into society. The Makaton programme assists children with speaking using voice and images* (see Figure 11). *Computer classes use large keyboards and various types of mouse, such as circular and handle, to suit the children's needs* (see Figure 12). *There are also devices for the pronunciation of words; as soon as the child presses on the words or passes their hand over the word, the sensors pronounce the words for non-speaking students. The computer, technical, and Makaton classes are located in the educational building, whereas the psychological, functional and social services are located in the medical building. I observed that the centre appeared to be well prepared to meet the children's needs and provided a supportive environment for both children and their families.*

Figure 9: Art class

Figure 10: A classroom for teaching the Holy Quran

Figure 11: Makaton room

Figure 12: Computer room

Classroom Environment

The classroom size felt small and cramped because of the use of mobility aids, such as a wheelchair. I felt that the design of the building had not taken the use of mobility aids into consideration. The classroom appeared well lit, and the light felt not too harsh or too dull. I observed that there was natural light from the four glazed windows (see Figure 13). *The class consisted of two teachers with 10 to 11 children maximum (approx. 1-5 ratio). It contained four noticeboards split into daily study schedule, attendance, calendar and an enhancement board, described in more detail below.*

Daily Study Schedule: *White cork board, divided into columns and rows, with the days of the week vertically, and all the classes' numbers horizontally; there is a sticker in each box (check-check) and behind each course name (another check-check) to make it easier to change the course name* (see Figure 14).

Attendance board: *A thick cork board with a jar painted on it contains some tree branches, that are spreading, and each one has a flower with a picture of a child in the centre denoting their presence. If the child is absent, their picture will not be placed in the centre* (see Figure 15).

Calendar board: *A thick cork board with a bucket painted on it. From the bucket, there are some tree branches, and the weekdays are illustrated as a flower, the flower corresponding to the correct day will be put inside the bucket* (see Figure 16).

Enhancement board: *Light blue cork board with 11 parachutes painted on it. There is (check-check) in the shape of stairs, and the children's pictures are in the lower part of the board* (see Figure 17). *If any child responds correctly during the class, the teacher will raise his/ her image one step. If the image later reaches the last level up, the child receives a gift.*

The activities offered by the centre are divided into two main parts: within the classroom, which are all activities related to the academic curricula. Outside

the classroom: Food Day, World Day for People with Disabilities, Civil Defense Day, Mental Health Day, World day for Oral Health. These days usually include different activities to raise awareness among staff, parents and students about the topic of the day. For example, on World Oral Health Day, a lecture on oral health was provided to staff and parents by a dentist worked in the Ministry of Health or Education. Meaning, lectures were provided by professionals invited by the centre. It also includes several educational activities for children provided by using toys, gifts and competitions (Research Diary Note, April. 2018).

Figure 13: Classroom

Figure 14: Daily study schedule board
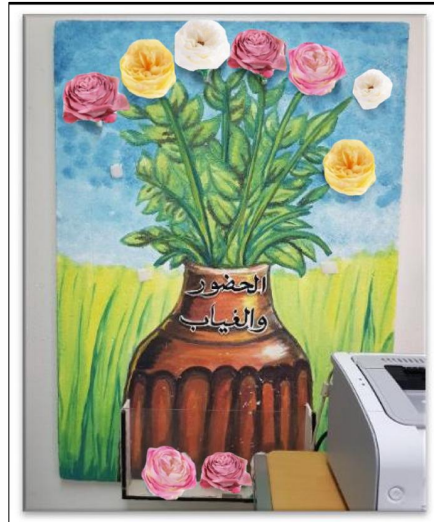
Figure 15: Attendance board

Figure 16: Calendar board
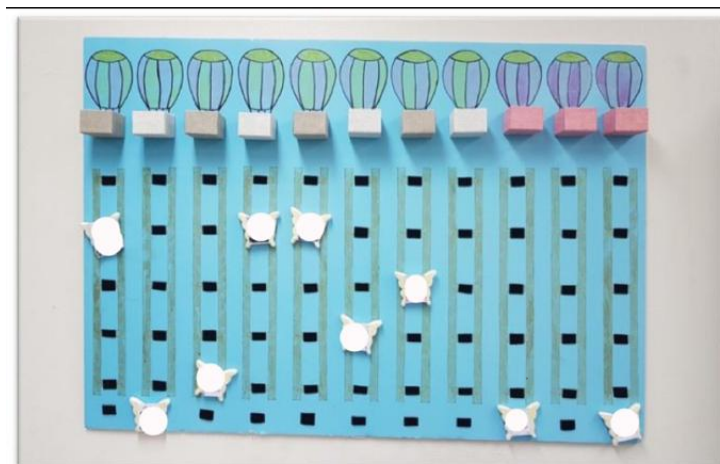
Figure 17: Enhancement board

School for students with intellectual disabilities

The Ministry of Education controls the curriculum and funds the school. The school provides educational services for students with intellectual disabilities aged 7–24 years and covers the primary, middle and high school educational stages. The primary school has 78 children aged 7–15 years; the middle class consists of 47 students aged 16–20 years; and the high school includes 64 students aged 21–24 years.

I felt this was an excellent place to begin my fieldwork because of my knowledge about the system came from working in schools. I gained this knowledge whilst a student in schools supervised by the Ministry of Education and from my work during and post qualifying at a university with a similar system. The following excerpt from the field notes describes the school, the environment of the educational classroom, and my feelings towards this school:

> *The school was established in 1971, as it provides specialised educational services. One of its main objectives is to introduce an educational environment for students' development of life skills by a professional team; its main aim is to build self-esteem, self-care, and the development of a community spirit for those who have intellectual disabilities. It is compulsory to commit to attending early, to consider working sincerely with disabled people for the sake of God, and, finally, to adhere to the school laws. This school includes 22 special education classes with 189 students with disabilities and 60 teachers in general. The school accepts the student from 7 to 24 years of age – cases of multiple disabilities (physical – intellectual). There are several services available in the school, for example, psychological service, social service, speech and communication unit. Services are provided by highly qualified people. They provide services that help students meet their needs.*

Classroom environment

I observed a square classroom with two windows along one side. I considered that the size of the class was somewhat large but realised that it was split into two areas: one for teaching students as a group and the other for individual learning. It also included a play area, and despite splitting the room, there was still space to move around comfortably. I felt this was in contrast to the classroom at the Centre for Disabled Children. There was a locker on one side beside the door, which was a place for the educational tools. The teacher usually decorated the classroom and as a result, each class felt individual. The classroom appeared well lit with the addition of natural light from the two windows which were glazed. I did notice that it was difficult to adjust the temperature of the classroom to an ambient level and when students felt cold or too warm, the teacher adjusted the air conditioner. In general, I felt it was an exciting, colourful classroom environment that enabled learning and gave students a sense of belonging.

The number of students in the class ranged from 5 to 11, and there were two teachers in the class (approx. 1-5 ratio). The class contained several categories (activities); each category had one main goal. The aim of "individual activity" is to provide all the academic skills that the student needs (reading or writing). It consists of forms, pictures and cards on the desk and there is a play activity that encourages the students to move and be active around the classroom (see Figure 18). *The class has five noticeboards which are an attendance sheet, study table, school schedule, a weekdays panel* (Figure 19), *and enhancement (achievements) board* (see Figure 20), *which all placed on the wall. I observed that teachers use multiple methods of teaching, for example, using images, games, and videos as a means of facilitating education and interaction.*

I was very happy to work with the people at this school. They made me feel like I belonged, and they helped me as much as they could. I observed children at this school struggled more compared to children at the Centre for Disabled Children because their parents were of lower socioeconomic status; for example, they could not afford new uniforms. Furthermore, their teachers

always help them if they need some school tools, such as a notebook or pen. The people who are working in this school, in general, were kind, helpful and cooperative (Research Diary Note, April 2018).

Figure 18: Play area

Figure 19: Classrooms panels

Figure 20: Enhancement board

1.42 Summary

This chapter has introduced the settings for the research, creating the context. The Centre for Disabled Children is usually for people of a higher socioeconomic status than the school for children with intellectual disabilities. Despite the socioeconomic differences, I initially felt that the schools' sympathetic design accommodated the needs of disabled children in an inclusive fashion. The next chapter proceeds to discuss the results of the interviews with children, mothers, and educational and health professionals.

Children's knowledge, practices and experiences of oral health and care

1.43 Introduction

This chapter focuses on the findings of interviews and activities with ten Saudi children with a range of disabilities. It explores their knowledge, practices and experiences of oral health and dental services. This chapter fulfils this aim of representing children's perspectives and experiences, giving them a voice in oral health research. The chapter presents common themes from the children's interviews. Pseudonyms replaced the children's names to protect them.

1.44 Emergent themes

The themes were identified through discussions with supervisors, lengthy reading of the evidence base and constantly revisiting the observational notes and interviews with the children.

The main overarching themes were:

- Theme1: Disabled children's knowledge and practices of oral health and dental care

- Theme 2: Disabled children's experiences of oral health care

Table 23: Themes emerged from children's data

Theme 1: Disabled children's knowledge and practices of oral health and dental care	• Oral health practices • Children's understandings of supervision and help with oral health care • Knowledge and practices about diet and food choices • Knowledge of dental treatment • Accessing information about oral health
Theme 2: Disabled children's experiences of oral health care	• Experiences of dental treatment • Experiences of general access to oral health care • Experiences of pain

1.44.1 Disabled children's knowledge and practices of oral health and dental care

Children in this study were able to describe the basic knowledge of oral health and the ways they implemented practices and dietary choices derived from different sources of oral health information. They were also able to articulate their insights about the dental clinic and dental treatment.

Oral health practices

When children discussed their oral health practices, most of them expressed their knowledge of oral hygiene tools when shown pictures of toothbrushes and toothpaste during the interview.

> *"I know what a toothbrush is; we brush our teeth with it"* (Haneen,11*)*

> *"I know the toothbrush and the toothpaste"* (Yara, 15)

The children reported that they clean their teeth using toothpaste and a toothbrush, and some added that they also used mouthwash. They provided further clarification about

the taste of toothpaste and stated their preferences. Children gave a brief description of their oral health practices, accompanied by gestures.

> *"We should brush our teeth daily, and we should use the mouthwash, then our teeth will be white".* (Yara, 15)

> *"Toothpaste doesn't taste good; we don't eat it (she laughs) but brush our teeth with it".* (Joud, 14)

> *".. you should mix toothpaste with water, and then brush your teeth with it"* (Gala,12). *"[...] she is acting like she is brushing her teeth".* (Research Diary Note, 2018).

> *"I brush my teeth with water. I don't like the taste of the toothpaste; it doesn't taste good".* (Renad, 10)

Some participants described the toothpaste they used:

> *"I use the normal toothpaste, adult toothpaste".* (Gala, 12)

> *"I use adult toothpaste".* (Joud, 14) and (Danah,10)

All children interviewed exhibited a range of knowledge and practices about toothbrushing and toothpaste and acted out ways that they brushed their teeth to emphasise the ways they implemented their knowledge.

Children also exhibited knowledge and practices of cultural methods of dental care, including the use of Miswak (See more details about Miswak in Chapter 3). In the children's data, there were several examples of children using Miswak as an oral hygiene tool, such as:

> *"...we clean our teeth with Miswak (she is pointing to her teeth as simulating the way of using it). I use it. My brother bought a long one and he uses it around prayer times"* (Gala, 12)

"I use it on my teeth (pointing to her teeth as simulating the way of using it). My dad buys it usually". (Danah, 10)

"...only my dad uses it". (Basmah, 11)

"I don't use Miswak, yet my dad and brothers use it before prayer times". (Haneen, 11)

*"I don't use Miswak, its harsh, it injures the gum, I use the toothbrush more often". (*Lina, 9)

The above examples show that children are obviously aware of cultural influences on oral health practices. Some of them reported their preference for using a toothbrush rather than a Miswak, which they assumed only older people used before prayer times. Children were also aware of the damage that Miswak can do if used incorrectly and the academic evidence suggests that it can be responsible for dental abrasion (Almas & Almas, 2014; Almas & Atassi, 2002).

In contrast to toothbrushing, toothpaste and Miswak, I observed a lack of knowledge about dental floss. Children did not recognise dental floss as a cleaning device, and *I noticed from their teachers that they did not teach them about it because they believed that children with intellectual disabilities might not understand the correct way to use dental floss and thus may harm themselves. Therefore, this might be a reason they do not even know it"* (Research Diary Note, 2018). My notes indicated the teacher's perceptions of disability creating 'eternal children' alongside elements of protectionism. The predominance of the medical model for the disability discourse was also evident in the opinions and practices of teachers. This is because children were judged according to their disability, not their ability (Press et al, 2011). Children described dental floss in varying ways and related it to other products they thought were similar.

"This is cream". (Basmah, 11) and (Deema, 13)

"This is soap". (Lina, 9)

"This is acetone, manicure remover". (Haneen,11)

I reflected back to my field notes on how some staff members thought about treating the children as 'eternal children' and protecting them, which may prevent offering any further support, teaching and crucially, any further knowledge and practices around oral health from developing. Likewise, the way adults perceive disability can act as an enabler or barrier to supporting children's oral health.

In terms of the frequency of oral health care, most children knew that they should clean their teeth twice a day and others said three times a day. Very few children stated the exact time when cleaning their teeth, such as 'after eating sweets'. However, all were aware of the outcomes of poor oral health practices.

> *"We should brush our teeth daily, once in the morning, once at night, twice a day to prevent tooth decay".* (Yara,15)

> *"We should brush our teeth twice, particularly before bedtime".* (Joud, 14)

> *"I brush my teeth three times, but sometimes I sleep before brushing my teeth".* (Basmah, 11)

> *"We should brush our teeth whenever we eat sweets to prevent tooth decay".* (Joud, 14), (Gala, 12), and (Danah, 10)

Children seemed to understand that leaving sweet foods on their teeth would have a negative impact on their oral health. One child described the consequences of neglecting teeth brushing for more than one day:

> *'...if you don't brush your teeth more than one day, you will have teeth decay and pain. You are supposed to brush before your teeth get tooth decay. But if any of your teeth are infected then you need to go to the dentist to pull them out.* (Wafa, Research Diary Note, 2018)

Furthermore, all participants agreed on the importance of cleaning their teeth. Children expressed this as taking care of their teeth in reference to social acceptance, such as 'looking nice', 'being healthy' and avoiding 'tooth decay'.

> *"Teeth are important. If you laugh or smile the people around you will say mashallah you have beautiful teeth, so people will like them".* (Basmah, 11)

> *"... I am upset of my teeth look. when I take a picture for snapchat, I couldn't smile, because my teeth don't look good, I wish I could take a picture while I'm smiling, but I can't, because I don't like my teeth, I don't want anyone to see them".* (Yara, 15)

> *"We brush our teeth after meals, in order to get rid of tooth decay and to make teeth stronger".* (Haneen, 11) and (Lina, 9)

Children mentioned brushing, but not diet, the importance of a combination of diet and toothbrushing with fluoride toothpaste appeared unlinked by children.

Children felt that preventing bad breath, especially in front of teachers, was an important incentive to maintain oral health.

> *'We must care about our teeth's health so that the teacher will not be upset by the bad smell (simulating the teacher's act by covering her nose with her hand). The teacher once told me you have bad breath, so you need to clean your mouth and teeth'.* (Lina, 9)

Although children were aware of some of the causes of bad breath, they did not mention the use of medication as a possible culprit.

Children's understandings of supervision and help with oral health care

Some children discussed their need for mothers to help them while brushing their teeth, acknowledging their mother's role and expressing awareness of the importance of this to oral health. Children with cerebral palsy considered supervision of brushing essential. Some of these children lacked manual dexterity and brushing on their own was sometimes difficult, various studies on manual dexterity and toothbrushing support them (Maiya et al, 2015; Martens et al, 2000).

"...mum helps me to brush my teeth. It's hard for me to brush my teeth because I'm young; mum needs to help me". (Renad, 10)

"Mum help me. I don't know how to brush by myself. I need help. I know how but I need help". (Haya, 11)

The children did not mention the impact of their impairment on being able to care for their oral health. Instead, they presented themselves as 'too young' and knowing how but still needing help. This may possibly be repeating what parents and teachers have said to protect them. In contrast, there were a number of children who cleaned their own teeth, refusing or without the need for support.

".. my mum forces me to brush sometimes but I refuse because mum wants to brush my teeth herself, and I want to brush them by myself. I want to do everything by myself without any assistance. I can brush them alone, but mum always insists that she wants to help me...". (Deema, 13)

"I do it myself; no need to be assisted by anyone". (Yara, 15)

It is evident that some children considered oral health to be their responsibility and wanted to carry out oral health care unaided. Children with cerebral palsy reported that their mothers played a vital role in enabling them to maintain positive oral health. Although not explicitly discussed, this appears to indicate that some children accepted that they had different abilities and required more support for some areas of self-care.

Knowledge and practices about diet and food choices

When I asked children to sort healthy and unhealthy foods into "good for your teeth" and "bad for your teeth" categories, they all answered correctly. Children generally knew the health value of diverse diets. They could categorise healthy and unhealthy diet pictures. They also could match the right food with the right tooth, as in the game described in Chapter 5. The following picture is an example of children's answers (Figure 21).

Figure 21: Example of using sorting game

Most children explained their answers whilst sorting the images, which showed their understanding. Furthermore, some discussed the consequences of eating unhealthy food and gave a rationale for eating healthy food. This method enabled them to discuss their knowledge and practices in depth. In contrast, one-to-one interviewing only gleaned a surface level of knowledge.

> *"I arranged them like that because the healthy food strengthens the teeth, while the other breaks them".* (Deema,13)

> *"...because ice cream hurts the teeth. I put milk in the smiley tooth list because it makes the teeth stronger".* (Danah, 10)

> *"...we matched it this way, because this is healthy food (she referred to the fruits), the other isn't (she referred to the soft drinks), and it causes tooth decay".* (Renad, 10)

> *"... we should have healthy food and drinks like fruit and milk. But the unhealthy food like chocolate and soft drinks, we should stay away from it to keep our teeth free from tooth decay".* (Yara, 15)

These quotations above clearly show that children were aware of the risks caused by eating cariogenic food. All participants identified diet including the consumption of sugar and soft drinks as a major cause of tooth decay. Despite the distinction between

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the health values of diverse diets, some children revealed that they frequently ate unhealthy diets, which indicated a discrepancy between knowledge and behaviours.

> *"She pointed to the ice cream picture and said I want ice cream like this. I like it, I always buy it and doesn't hurt my teeth. I love it"* (Gala, 12, Research Diary Note, 2018)

> *"I'd like to eat donuts every day; I eat everything, healthy and unhealthy food"* (Wafa, Research Diary Note, 2018)

> "*.... honestly, I like the unhealthy food. But I don't eat much, I eat fruit. I know the healthy and the unhealthy food"*. (Deema, 13)

I further reflected that this may also indicate that the children knew I was a dental professional and so were eager to please me by illustrating their knowledge of what was healthy and unhealthy, but they were unaware of the conflict with what they then told me about their practices and dietary habits. In contrast, some children said they preferred healthy food to keep themselves healthy.

> *"I love to eat oranges. I would not say I like chocolate, because it causes tooth decay, I eat healthy food to be healthy"*. (Danah, 10)

The children mentioned the positive and negative influence of their families on controlling their diet, whether healthy or unhealthy. One girl reported that she usually ate sweets with her nanny whom she spends most of her time with.

> *"I eat chocolate with the nanny. She gives me lots of chocolates, and whenever I ask for chocolate, she gives it to me. I love her; I stay with her and sleep with her always"*. (Danah, 10)

This child appears to be under the care of nannies as she explained when drawing (Figure 22).

"She drew herself on the dental chair and her nanny stood next to her and her mother on the chair is far from her, and then she said, I do not like my mother as much as my nanny. I really love my nanny (she blew here a kiss)". (Danah, 10, Research Diary Note, 2018)
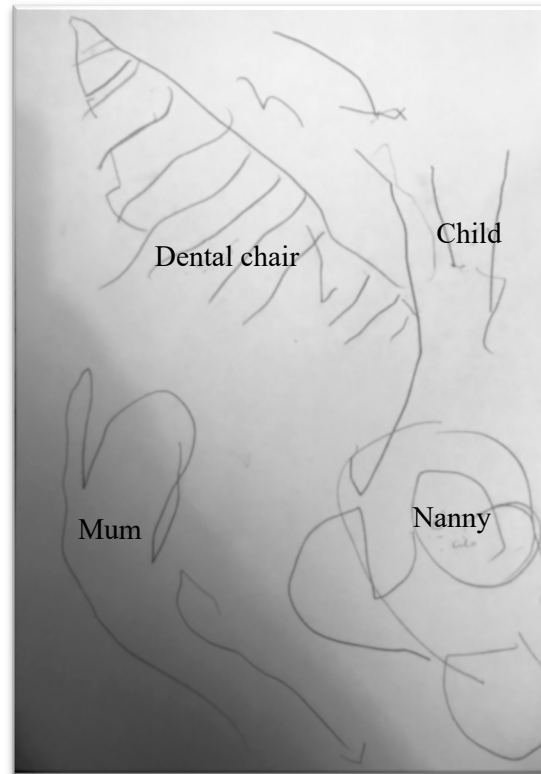
Figure 22: Dana's drawing

What we do not know is the oral health knowledge of nannies and maids as carers in Saudi Arabia, or whether they are equipped to support children with their oral health. The children also reported parental influences on their eating attitudes and behaviour and their roles in controlling their diet:

"I like chocolate. My dad is the one who brings chocolate home". (Haya, 11)

"...this is cake and chocolate. It's not healthy, it hurts our teeth, but we eat it anyway; mum buys it for us" (Danah, 10, guided tour)

"My father buys us healthy food, but my sister says I don't want this, I want chips. Also, we cook diner, my sister drinks soft drinks, but dad tells her to eat healthy". (Basmah, 11)

Some children discussed how their parents had restricted their consumption of sweets, such as allowing them to eat unhealthy food only during the weekend, while on other days they were not allowed to eat sweets. From the children's reports, these parents appeared to encourage healthy lifestyles and prevent tooth decay.

> *"My mum allows me to eat sweets only on weekends because it is unhealthy food. On the other weekdays, I'm not allowed to have them. My sister and I eat together. My mum says its ok, but we need to brush our teeth before bedtime".* (Basmah, 11)

> *"I eat sweets only on weekends. Mum lets me eat whatever I want but only on weekends. But I don't like sweets".* (Haneen, 11)

The above quotations reflect that mother play an important role in supporting children's oral health and the children's understandings of why their mothers control their diets, which illustrates their knowledge of healthy behaviours. However, older children in particular, resisted monitoring by their parents. They indicated that independence and being able to control their diet were of significance for them.

> *"I don't like unhealthy food, I like fruit and vegetables, but I don't like milk. It is not necessary that somebody tells us not to eat unhealthy food; we don't eat sweet because we care about our health".* (Yara, 15)

> *"Honestly, I like unhealthy food. But I don't eat much. Mum monitors my meals, but I don't care, I eat what I love".* (Deema,13)

> *"When I asked one of the students, why did you bring chips with you? She said it's up to me, I eat whatever I want".* (Asala, Research Diary Note, 2018)

In addition to previous influences, many non-family factors had an impact, including commercials and television, school, and the social environment. Advertisements seemed to have a particularly strong impact on children's eating habits. This was emphasised by one of the teachers I spoke to when I was observing the children during their break time:

"The main reason which causes children to eat unhealthy food is the advertisements. There are a lot of many attractive advertisements on the street billboards, and this is also the main reason for poor oral health and obesity. Also, the celebrities on Snapchat advertise and recommend many restaurants and most people are now following them. Most advertisement mainly focuses on unhealthy food. However, I believe that it is important to direct these advertisements toward advertising of healthy foods". (Majdh, Research Diary Note, 2018)

Majdh discusses how advertisements place pressure on people to change their eating behaviours. Some researchers highlight this impact, suggesting that children exposed to advertisements are tempted to make unhealthy food choices, arguing that young children cannot critically evaluate advertisement messages and understand their persuasive intent (Boyland & Halford, 2013; Harris et al, 2009; Vijayalakshmi, 2016). In my study, Majdh realised that advertising and packaging of unhealthy foods made them attractive and suggested that there should be extra advertising on healthy diets and the influences of healthy and unhealthy diets on children's teeth and general health.

To illustrate the impact of schools on children's diet, I noticed during my observations that *there was no canteen at school, but there were free meals for children, and the meals were donated from a company. During the break, the teacher watched the children, the teacher saw that one of the students had a soft drink and eats a burger. She told her that this was a mistake, and you should drink milk or juice in the morning instead of a soft drink. However, while I was observing some classrooms, I noticed that some teachers often use chocolates and sweets as a reward for students. I observed the contrast in what the school guided and what happened in practice; "the school does not allow unhealthy eating, but teachers behaved in another way."* (Research Diary Note, 2018).

Despite my observations, some children reported that they knew that unhealthy food was not allowed in school, which implied that schools functioned as a supportive environment for healthy behaviours.

"It is not allowed to have chips and Pepsi in the school. I haven't seen anyone that brought them to school. if anybody brought unhealthy food to school the principle and teacher said it is not allowed, so most of the student don't bring it". (Lina, 9)

"It is not allowed to have chips and Pepsi in the school. But, sometimes, I see some students with chips and Pepsi, but they always hide it, so the teachers don't see them". (Haneen, 11)

At the Centre for Disabled Children, meals were served from families, and there was no kind of monitoring the quality and quantity of food. Unhealthy food was not prohibited; however, teachers advised children about the importance of healthy food. However, in intensive rehabilitation clinics, meals were provided for each child and a toothbrush as well. A children's meal was prepared daily, and there was a table posted on the fridge giving information about the content of the daily meal for a week (Research Diary Note, 2018).

The differences between policies in both places may be because one school was under the supervision of the Ministry of Education. In Saudi Arabia, the Ministry of Education has banned sugary drinks and unhealthy food in canteens in all public schools in a bid to develop a more supportive environment for healthy lifestyles for students (Musaiger et al, 2014). This is precisely what the Ottawa Charter (WHO, 1986) means for health promotion activities concerning creating supportive environments for maximising healthy lifestyles. An example of promoting dental health in schools is to ensure that only sugar-free diet and beverages are available to students (Locker et al, 2007). However, children do not live-in schools and whether these messages are transmitted and acted upon in their homes is unknown.

Culture and social norms may influence the eating habits of children as described in the following quotations:

"I like oranges. I don't like chocolate because it causes tooth decay. But I eat some with my mum, during coffee time; we drink coffee and I have cake". (Gala, 12)

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"I like chocolate when I drink Arabic coffee with my family". (Haya, 11)

Arabic coffee served with dates or sweets are part of Saudi societal practices as a regular snack. The importance/reputation of coffee is owing to it being a traditional and favourite beverage, but also related to Saudi hospitality and customs in that coffee time encourages the family to sit together socially and serve their guests.

Other participants reported that social gatherings were drivers for increasing sugar consumption. They found it difficult to resist sweets, dates and other types of desserts offered in these gatherings.

"... we go to the resort with our grandfather; a lot of people usually come there. During Eid time we eat lots of chocolate and dates and we dance.". (Haya, 11)

A 10-year-old girl confirmed being encouraged to have black cumin seeds as a traditional food and part of the Saudi culture; she said:

"I drink milk and honey with black seeds to be more beautiful; dad always says I must have that". (Renad, 10)

Within Islamic culture, there are many herbs, plants and fruits believed to have medicinal and healing properties. Olives, pomegranate, dates and figs are amongst those mentioned in the Qur'an as blessed foods. However, black cumin, or 'Habbat ul Sawda' is only the one that can stake a claim as a super food. According to the Hadith, it is narrated from Aishah, may Allah be pleased with her, reported that she heard the Prophet (PBUH) saying, "This black seed is healing for all diseases except As-Sam." Aisha asked, "What is As-Sam?" He (PBUH) said, "Death" (Sahih Al-Bukhari 5687-In-book: Book 76, Hadith 10). The quotes show how strong and effective cultural and religious norms can be even in people's daily diets, which are perhaps why the children could not see the wrong in consuming sugary food and drinks when they form part of a social and religious event or gathering.

Knowledge of dental treatment

The interviews revealed that the children were familiar with a range of dental procedures and were able to describe them including dental crown procedures, fluoride application, radiographs, restorations, and extractions:

> *"The dentist did a dental crown (pointing to the tooth). He told me then I should not eat anything hard. But now it's ok, I eat apples and bread. The second time, I went to the dentist, she put water inside my mouth and used a stick with paste to put over my teeth (like varnish). Then she told me not to eat anything for half an hour, just like if I were fasting. I couldn't eat anything because it doesn't taste good. I don't like the paste that the dentist uses".* (Haya, 11)

> *"I used to go very often to the dental clinic. Once my face swelled up, so they took me to the emergency in the hospital. They booked an appointment for me. When I arrived at the clinic, the dentist did an x-ray, and said there is nothing wrong. My mum asked him why her face swell and he said I don't know, but it is not because of her teeth".* (Deema, 13)

> *"...the dentist checked my teeth, then she did the x-ray. She put something inside my mouth, then left the room. Then she came to fix my teeth. She gave me anaesthetic then she fixed my teeth. She filled half of my teeth, and then she pulled out the other half".* (Lina, 9)

The children were also able to recognise the dental environment including dental equipment from the pictures I showed them, for example the tools used by the dentist. Children described what happened to them at the dentist and imitated the sounds of the equipment.

> *"This is a chair (referring to the dental chair), this a TV (she pointed to the screen). This is the water sucker (She pointed to the suction)".* (Basmah, 11)

"I see a chair and a needle. This is water (suction); this is a sink and paste; this is a light to help the dentist see my teeth". (Haya, 11)

"I see a light, chair, teeth tools and a screen. When I went to the clinic, they put on the news and football games on the screen". (Lina, 9)

"...this is a chair, and this makes sounds (teeth tools). This is water; if you have your teeth pulled out, you need to rinse your teeth here (the sink). This is a light; the dentist uses it to see the teeth". (Wafa, Research Diary Note, 2018)

The children also expressed their knowledge of the need for dental treatment, even if not accurate, by explaining the importance of going to the dentist, i.e., when and why they should go. They identified different reasons, such as going to a dentist for dental examination or treatment (mainly extraction) or if they felt pain:

"It is necessary for children to go to the clinic to get their teeth examined". (Renad, 10) and (Haya, 11)

".... whoever eats sweets goes to the dental clinic. Whoever eats sweets, his teeth will hurt him, and he goes there (pointing to the dental clinic in the picture). It is necessary to go to the clinic frequently. If our teeth hurt, we need to go". (Danah, 10)

"...If we are in so much pain, for example and there is tooth decay, we go to the clinic to pull out our affected tooth". (Gala, 12)

The children here mention pain and take a functional approach to their oral health. Other children indicated that they no longer went to the dentist, suggesting that there was no need to go to the dental clinic if they felt their mouth was healthy.

"Never, I haven't visited a dental clinic before, I have no idea. I only went to the clinic because of my ears. I do not know these things in the picture, but I know this is a bed (dental chair)". (Haneen, 11)

"I don't remember going to a dentist, I've never heard about a dental clinic before, you are the first one to tell me about it". (Sarah, A child told me when I observed them at the class, Research Diary Note, 2018)

"No need for the clinic, my teeth are good. We only go if we have a problem with our teeth". (Lina, 9)

This group of children felt that going to the dentist was because either they were in pain or something was wrong. This underlines the issue that preventive advice may not be at the forefront of dentistry for this particular sample of participants. An essential message that emerged from these findings is that disabled children were able to recognise and communicate about their dental treatment and oral health experiences very effectively. This implies that they understand and have the ability to participate in caring for their own oral health, albeit with some support from time to time. I will now explain how children accessed information about oral health.

Accessing information about oral health

In the previous section, I identified how children developed knowledge through acquiring information from different mediums, such as television, mass media and school. From the different sources, knowledge development from dental information appeared diverse. The majority of children implied that they usually gained information from their family, their teachers and mostly their mothers. Mothers played a significant role in assisting their children to acquire information. Children's clarifications of how to learn tooth brushing tended to be brief:

"Our family, mum, my brothers, and the teacher as well taught me how to brush my teeth and what is the healthy and unhealthy food". (Yara, 15)

"...mum, dad and the teacher taught me how to brush my teeth, my mom always reminds me to brush my teeth". (Lina, 9)

"...my mum told me how to brush my teeth". (Gala,12). *"The child took the jaw model and started to explain to me how to brush her teeth|"*. (Research Diary Note, 2018).

There was consistency in the children's responses about the significance of mothers' role in acquiring information, pointing to mothers as "telling", "showing", and "reminding" them of how to care for their teeth. From the children's examples, it would appear that the accuracy of mothers' knowledge plays a crucial role in including their children in oral healthcare.

One of the children referred to when their teachers usually teach them about brushing and recognised the reasoning for its necessity.

"The teachers teach us how to brush our teeth when there is a lesson about dental health. But it is not very often though. Sometimes, if they smell bad breath, they say you should brush your teeth". (Lina, 9)

During my observations, I noticed that the walls of the school contained posters with oral health advice as a source of information. However, when I toured with Haneen, she pointed to the posters and she mentioned that "*the posters are not clear, no one understands them, and no one has explained them before*". One of the teachers I spoke to also criticised them, noting that the posters are not suitable for children, because they are difficult for children to read, and are supposed to be in the form of pictures rather than written information (see Figure 23). Therefore, it would appear necessary to ensure that information sources are provided in accessible formats for disabled children.

Figure 23: Examples of school posters on oral health

However, three children had contrasting views because they said that their teachers never helped them to learn about oral health practices and they reported another information source.

> *"The teacher didn't teach me how to brush, I knew it from Instagram. I'm too old".* (Yara, 15)

> *"...the teacher didn't tell us about brushing".* (Haya, 11) and (Renad, 10)

As most children learned from their families, school, or the media, some children stated that information from health care providers was limited. This may indicate that there is a lack of access to appropriate and accurate information.

> *"The dentist doesn't teach me how to brush my teeth; he just fixes my teeth, and I do not ask him*". (Joud, 14)

> *"The dentist does not speak to me. The dentist just checks my tooth decay. It would be better if she teaches me how to brush my teeth correctly, but I never ask her; I'm too shy".* (Renad, 10)

The most obvious thing in the previous quotations was that the children did not contact health care providers. The children implied that raising their awareness of oral hygiene is part of the dentist's role. They expressed interest in learning more about their oral

hygiene. The children's perceptions imply that they are not being included in the oral health encounter.

1.44.2 Disabled children's experiences of oral health care

The second overarching theme that arose from the children's data was oral health care experiences. Within this theme, children described their experiences when visiting the dental clinic and explained the possible barriers related to access to dental care. The children additionally described the nature of the pain they had experienced in the dental clinic, their ways of relieving pain and the feelings they experienced.

Experiences of dental treatment

Children in this study described their experiences when visiting the dental clinic, their positive and negative feelings about oral health care and the physical barriers they experienced.

Three children commented that they loved their dentist as a person. They said that their dentist was friendly and kind, but they did not like the treatment offered to them.

> *"I love the dentist. He was kind and friendly. But he is a bit scary, because he hurts a bit when he pulled my teeth out".* (Basmah, 11)

> *"I love the dentist, he is kind, but I don't want to go to the clinic again. The tool that pulls out the tooth, its hurts".* (Joud, 14)

This appears to indicate that the children are separating the dentist as a person from the role of the dentist. This is because they appear to experience conflict between liking the person and the treatment they carry out.

In contrast, the majority of children asserted that they did not like visiting their dentist, explaining that they felt 'sad' when they had to go for a dental appointment, which might suggest some negative feelings concerning dental attendance. As an example, one participant commented when she saw the following pictures (Figure 24).
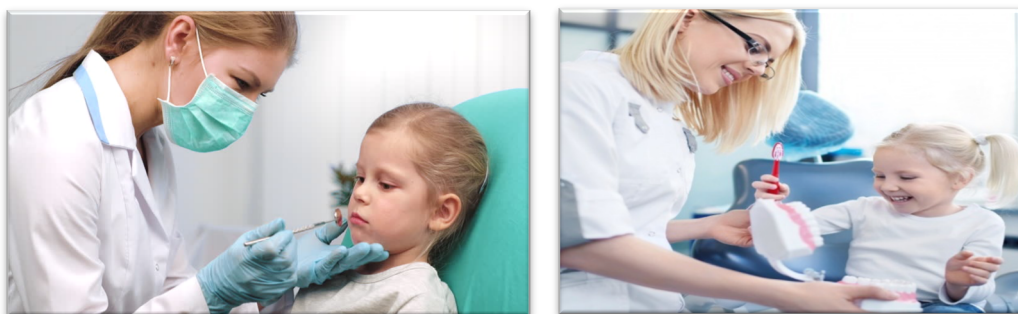
Figure 24: Illustrative pictures reflect dental clinic

> *"The child is happy because the dentist doesn't hurt her. She is only teaching her how to brush, but the other child is sad like me. I cry when I go to the dentist; she hurts my teeth"*. (Danah, 10)

One participant compared the dentist to other physicians, explaining why she did not like the dentist:

> *"...first. I went to the Optometrist, to fix my eyes, so now I can see clearly. (Pointing to her glasses). I like the Optometrist. The Optometrist is kind and I love him, but I don't love the dentist; he is not kind and he hurt me"*. (Renad, 10)

Another participant reported problems communicating with the dentist because of the dentist's attitude and lack of interpersonal skills:

> *"I went to the dental clinic and the dentist applied toothpaste into my teeth then she brushed them. I don't like the dentist, she is harsh, and she asks me loudly, why you don't take care of your teeth, you should take care of your teeth, and her voice is loud. She then let me go to class"*. (Deema, 13)

Six children believed that dentists should provide more information about dental procedures. They felt ignored by the dentist during the consultations or "were talked over" if their caregiver was present. The children reported that dentists did not talk to them at all and said they wanted the dental team to tell them what would happen during the dental visit and did not want to hide anything from them.

"The dentist does not talk to me, and she never explains anything. She focuses only on fixing my teeth, and I would like her to tell me what she is doing without hiding anything. I think dentists like to talk to parents about what happened to the child, but I need to know everything". (Lina, 9)

".... the dentist doesn't talk with me; he only checks my teeth". (Haya, 11)

"...the dentist didn't talk to me; she only hurts my teeth". (Danah, 10)

Furthermore, children in this study indicated that they appreciated clear, honest and straightforward answers. They emphasised that the dentist must be accurate and honest in their advice.

"I like my teeth to be white. I don't like the dentist. All that she says is wrong. She says you should brush your teeth every day and use the mouthwash in order to have white teeth. I do just as she asks, but my teeth are still not white; they still look yellow. I don't know why she is lying. Also, she pulled my teeth out too. At first, when she checked my teeth, she asked me to gaggle because of the blood. Then she pulled out my teeth. Now I don't have teeth at the back, I don't know why she pulled them out. I was wearing my headphone (she has a hearing impairment and headphone means hearing aid). *I heard her very well. Why did she lie to me? I told her that I'm in pain, I just wanted her to clean them and take care of them, but she pulled them out instead. She is stupid. She is a liar. She also said, you should eat healthy, fruit and vegetables, then your teeth will be white. I ate them, I have listened to her. But, still, my teeth are yellow. I don't believe the dentist and I don't think she is telling the truth".* (Yara, 15)

The previous findings highlight the important role of a dentist and that dental treatment affects a child's oral health experiences. Negative attitudes of dentists towards disabled children may be a barrier to inclusion. On the other hand, positive attitudes could be one of the keys to successful inclusion into oral health care. Moreover, the results provide evidence of the exclusion of children with intellectual disabilities from dental consultations. Children in this study also emphasised the lack of interpersonal skills exhibited by some dentists in comparison to other medical professionals. From my own

experiences while working at a dental school in Saudi Arabia, this may possibly be an artefact of a lack of communication skills in the dental curriculum.

In general, the way of receiving and treating disabled persons in the dental clinic is either a barrier or facilitator for access to oral health care services. The following section will discuss additional reasons reported by children that may hinder access to oral health care, which in turn exclude children from appropriate dental care standards.

Experiences of general access to oral health care

Reasons for avoiding dental care were largely due to challenges involving physical access, including clinic access and circulation. All the children with physical impairments indicated that the dental clinic was small, making circulation or walking around the clinic difficult and occasionally impossible endeavour, specifically for children using walking devices or wheelchairs. In other words, most dental clinics were not adapted for the needs of children with physical impairments and lacked such facilities; therefore, accessibility served as a physical barrier to inclusion. This demonstrated how the physical design of dental services excluded children because of their physical impairments

> *"...it is not easy for me to walk using the walker at the clinic; it's small. They let me in, and they take my walker aside. That's why I do not like going to the dental clinic, because I love walking using my walker or wheelchair. But in the class, and in the yard, it's easy to walk using it. At the mall, it is crowded and it's not easy to use my walker there too, so I use the wheelchair. At the mall not everywhere, I could use the walker. If there is a Bump then they need to carry me over, but Alhamdulillah I take my wheelchair with me".* (Deema, 13)

> *"I have a wheelchair at home. yet, it does not function well, but I use it any way when I go to the dental clinic. It is not easy for me to walk using the wheelchair at the clinic. The clinic is too small".* (Haya, 11)

Both children discuss the inaccessibility of the physical dental environment and using the social model of disability, this evidences a lack of inclusion because only people

who do not use mobility aids can access this environment with ease. This fails to consider diversity within the population.

Other critical barriers related to access to oral health care explained by children were the waiting times at the clinic, arrangement of appointments, cost of treatment, and fear of dental clinic visits.

Although the waiting time at the clinic and the scheduling of appointments was a substantial barrier to receiving dental care, one participant commented that it was easy to book an emergency appointment. This may suggest that there is no priority for regular dental treatment or preventive dental care for disabled children.

> *"I wait for 5 hours; it's usually crowded, and I feel exhausted. Whenever I talk to the dentist to go in, he says there are other people waiting".* (Joud, 14)

> *"My mum called them; she took a long time to arrange the appointment. My mum would call them daily to confirm the appointment, but no one answers".* (Basmah, 11)

> *"...we went as an emergency; they gave us the appointment very quickly".* (Deema, 13)

Children also indicated that obtaining access to dental care was quite expensive:

> *"I don't like my teeth. There are some people who have nice teeth; they use the braces. I didn't use the braces because they were expensive and for that reason my father refused. My sister though, she put on the braces, because she has a salary".* (Yara, 15)

Unless Yara can find a job when she leaves education, then the probability is that she will experience exclusion from specialist treatment such as orthodontics because she will be unable to afford it. During my observations, while chatting with people in the field, one of the children expressed a similar view to the previous child:

"My sisters wanted the dental braces, but my father refused; he said it would be expensive and he doesn't have the money". (Research Diary Note, 2018)

One of the teachers mentioned *that the families could afford to enrol their children in school because of the financial aid they receive from the government* (Research Diary Note, 2018). This may reflect the economic and financial situation of some families, because they have to prioritise and why parents refuse to pay for orthodontic treatment.

The children often mentioned fear of dental clinic visits during the interviews, citing fear as the main reason for cancelling and postponing appointments with the dentist. The children cited several reasons for fear, including concerns about dental extraction, injections, and their siblings' fear of the dentist.

All participants had experience of tooth extraction, with either local anaesthesia, general anaesthesia or relative analgesia. Extraction was the main treatment provided by dentists and all children described the role of the dentist in terms of extraction.

"...I know the dentist; he took out my teeth. The dentist used to hurt me, then took out my teeth. I visited a dentist three times. Three of my teeth were hurting me, and then my dentist pulled my teeth out in these three visits. He just took the metal tools and pulled out my teeth". (Basmah, 11)

"...children go to the dentist to pull their teeth out. If we are in so much pain, for example and there is tooth decay, we go to the clinic to pull out our affected teeth". (Gala, 12)

"A dentist is someone who pulls out children's teeth. The dentist only pulls out the teeth, and keeps them with you". (Wafa, Research Diary Note, 2018)

"I was crying at the dental clinic. He was treating my teeth very hard. I was screaming and shouting. He then said, we are almost done, but I was still scared and was shouting the whole time. I was very scared of him". (Joud, 14)

The negativity involved in these perceptions of dentistry may not be essential if more effective oral health promotion occurred for this group. General Anaesthetics appeared to be a regular occurrence.

> *"I had an operation in my mouth before. My dad and mum were waiting for me in a different room. Then he puts the surgical uniform on me, then he started with the operation because I had tooth decay. He gave me a sleeping drug and I asleep. While I was asleep, he injected me, but I didn't feel anything because I was asleep. The operation took a very long time. They told me to sleep in order to proceed with the operation; honestly, I would prefer to sleep in order not to feel any pain, because I get afraid of the needle. If the dentist wants to put paste, I prefer to be sleep as well"*. (Haya, 11)

Another factor that seemed to contribute to the child's fear of visiting the dentist is their siblings' fear of the experience. One of the children said that her sister did not like their visit to the dental clinic and said she was afraid of the dentist. This finding highlights the significance of ensuring that children are comfortable through their dental visit and have positive experiences.

> *"I get afraid of the dentist and my sister gets afraid as well. She always runs out of the clinic into the garden, because she is scared of the blood coming out of her teeth; she only cries in the dental clinic. Sometimes, she stays in her room and locks the door, so that she doesn't go because she doesn't like the dentist. My brother and my mum sometimes try to persuade her to go and other times they hold her strongly and put her in the car, and she will be screaming. My sister doesn't like the dentist; she once threw the metal tool on the ground. She threw it on the floor and tried to run away but my mum closed the clinic door so that she couldn't go out"*. (Basmah, 11)

The description of the fears that await in a dental clinic mean that dental attendance is something that some children fear, and many expect pain. Previous studies support these results and have demonstrated that one reason people do not want to take care of the mouth is the fear of teeth that affects their beliefs and practices (Jamieson & Koopu, 2006). Hilton and colleagues (2007) believed that factors such as negative experiences

of dental care, toothache, and dental extraction have affected going to the dentist and using dental services among children.

In order to make positive adjustments and changes that would make a dental visit more acceptable, it may be useful to know what disabled children see as unlikable aspects concerning going to the dental clinic. In this study, the children preferred a decorated clinic design with posters and toys over a plain dental clinic as well as some little incentives and encouragement from the dentist in the form of small gifts. However, children's views on dental clinic design were not sought.

> *"... The clinic has no toys or any colours on the wall; it's boring. It is a good idea if they ask us how we would like our dental clinic".* (Joud, 14)

> *"I love the clinic if the dentist gave me a gift (toothbrush and toothpaste) and gave me colours and paper".* (Basmah, 11)

Small incentives perhaps but making the environment more child-friendly may be one way of enabling children's perceptions to change from negative to positive. This is evidence of the exclusion of children's opinions from oral health services. It also sends a clear message that professionals either do not care to listen to children about the things that matter to them or more cynically that their voices do not count.

Experiences of pain

The children were also able to describe the nature of the pain they had experienced. They additionally described their ways of relieving pain and the feelings they experienced.

The children described that pain was the most disturbing thing for them. They used the word "hurt" in order to describe the pain of their teeth. Children described pain severity as "too much" or "a lot". In addition, children understood the origins of pain as including tooth decay, unhealthy diets, non-brushing and dental treatment.

> *"What I know about toothache is that it is because of tooth decay. Tooth decay causes lots of pain."* (Joud, 14)

"... toothache comes to those who eat a lot and eat sweets". (Gala, 12)

"A girl is in pain because she doesn't brush her teeth". (Deema, 13)

One child argued that if she received dental treatment, it would be painful, and she would not be able to stop the dentist. In my field observations, I noticed that expectations of pain may discourage the use of dental services. The following conversation, which is a part of an informal side conversation I had with the child, explains this participant's point of view:

Child: *....no, I didn't go to the dental clinic even once. I remember once I had teeth pain, but I didn't go, because they pull out the teeth in a harsh way, it hurts, that's why, I don't like the dentists, even If I have pain or swelling, I wait till its ok, I don't go to the dentist*

Me: *Did you try to go; maybe you're not telling me the whole story? (encouraging smile).*

Child: *I didn't go, but I know they pull our teeth off robustly, that's is how I feel.* (Wafa, Research Diary Note, 2018)

Children linked dental decay, poor oral hygiene, a diet loaded in sugar and dental extraction together as causative factors involved in pain. They then went on to describe how pain was relieved.

One strategy mentioned by the children was to take pain relief medication instead of going to the dental clinic.

"I take medicine if I have toothache like Panadol or other pain relief medicine. I don't like to go to the dental clinic". (Wafa, Research Diary Note, 2018)

Given the difficulties of access to dental care described the children in the previous section, some parents may find administering a drug (as a pain relief medication) from a pharmacy easier than trying to find a dentist to treat their child. However, it may also be

useful to use the pharmacies as a point of contact to refer children for treatment to prevent extensive dental pain from occurring.

Children also described the emotional experiences of pain. They reported that they felt "angry" or "sad" and said the pain caused them to cry.

> *"If I suffer from my teeth, I cry. We cry if we suffer pain from our teeth".* (Joud, 14)

> *"A girl always cries if her teeth hurt"*. (Danah, 10)

> *"I am not upset of anything, but when I go to the dentist. I will be crying from the pain. I go to the dentist only when I feel pain".* (Lina, 9)

Eight children equated the word dentist with pain and fear, expressing high levels of emotion when they discussed their mouths. There was also an underlying feeling that some children felt it was unfair that they suffered more than others did.

> *"I do not like my teeth; there are some people who have nice teeth not the same as my teeth; Why do I always suffer from my teeth ... I feel upset. I always cry because of my teeth".* (Yara, 15)

Given the rise in technology with the field of dentistry and the focus on oral health promotion, the level of pain and distress expressed by these children should not be present. It may reflect the fact that they are a marginalised group and priority appears more focused on general health, rather than oral health.

Overall, this section indicates a lack of children inclusion in oral health and listening to them about their needs and wants. The section on including children in research (Chapter 4) provided evidence that using different tools facilitates gaining their views and opinions and values them as individuals with voices, which need to be heard.

1.45 Summary

The overarching aim of this chapter was to give disabled children a voice in oral health research by exploring their knowledge, practices and experiences of oral health and care. The research methods used enabled children to express their views about oral health and oral health practices. Teacher and parent views of children as 'perpetual children', alongside the desire to protect them, inhibited the potential for further expansion of their existing knowledge. Likewise, the way adults perceive disability can act as an enabler or disruptor to support children's oral health. Children wanting to have more control of their oral health highlighted this position. Children's overall perceptions indicated exclusion from oral health care, by dentists who treat them as if they are invisible by talking over their heads, by teachers wanting to protect them and by parents not facilitating their independence.

Although children expressed that they were not included in oral health practices and care, they acknowledged that their mothers played an important role in supporting oral health. Therefore, the next chapter will explore mothers' perceptions around enablement and supporting their children with oral health.

Mothers' supportive role in oral health and care

1.46 Introduction

The previous chapter presented the findings from children; this chapter presents the findings of interviews with ten Saudi mothers of children with a range of impairments, who were not the mothers of the children in this research study. The children in the previous chapter highlighted that mothers play an important role in supporting oral health. Therefore, this chapter explores mothers' perceptions about enablement and supporting their children with oral health. This chapter fulfils this objective of exploring ways mothers support and include their disabled children with their oral health. To protect the anonymity of mothers, pseudonyms replacing their actual names are used throughout.

1.47 Emergent themes

Overarching themes were: 'Oral health practices' and 'Including and supporting mothers with oral health care'.

Table 24: Themes emerged from mothers' data

Theme 1: Oral health practices	- Oral health-related practices and religion - Oral health practices and uncertainty - Oral health practices and the primary dentition - Oral health practices and early dental visits - Oral health practices and accessing oral health information
Theme 2: Including and supporting mothers with oral health care	- Supporting mothers with oral health practices - The challenges of providing support - Supporting mothers to access oral health services

1.47.1 Oral health practices

Mothers generally expressed positive attitudes toward maintaining the oral health of their children. However, mothers in this study expressed the extent to which they sometimes were unable to do so due to a lack of knowledge and support in the field of oral health that impedes them from including their children in oral health care.

Oral health-related practices and religion

The majority of participants in my study stressed the importance of cleaning teeth as part of following religious instruction. They recognised the role of religion in influencing them to clean their children's teeth because cleanliness is rooted in religious beliefs, and this resonates with other religions around the globe. Islam gives great importance to cleanliness and hygiene is a sign of faith and links to health-related religious behaviours.

> *"Indeed, Islam has taught us to be clean, it's from our faith. In addition to taking care of ourselves"* (Abeer)

> *"God Almighty put mercy in our hearts towards our children, and ordered us to clean their teeth, also, Islam asked us to use Miswak"* (Hessah)

> *"Indeed, there is a strong relationship between cleanliness and our religion. Our prophet peace be upon him taught us to care about our dental health and to use Miswak. Our prophet (peace be upon him), said: "Siwaak cleanses the mouth and pleases the Lord". This means that purification for the mouth is a means to please God. This is a clear expression of taking care of the mouth. I use Miswak, but not with cleaning my children's teeth".* (Nouf)

Mothers expressed their knowledge of cultural tools used to clean teeth, which triangulated with children's views. Only five mothers reported that they actually used Miswak to clean their children's teeth. Overall, this group of mothers felt that their knowledge emerged from their beliefs, and therefore, this indicates that their beliefs were an enabling way to motivate them to achieve oral health for their children.

Oral health practices and uncertainty

The majority of mothers knew that brushing teeth with fluoride toothpaste maintained positive oral health; more specifically, they exhibited knowledge of oral health practices for young children, including the brushing frequency, and the use of fluoride toothpaste.

> *"I brush his teeth daily with toothbrush and toothpaste. I'm keen that he doesn't suffer from any teeth pain and he eats easily".* (Hayat)

> *"Brushing twice a day with fluoride toothpaste is the primary key for our dental health".* (Sarah)

While mothers were keen to clean their children's teeth, most of them were uncertain about the cleaning details, which became evident from the questions they asked during the interviews such as the best toothbrush, the correct way to brush teeth and the recommended age to allow children to brush their own teeth.

> *"I brush his teeth daily with toothbrush and toothpaste, but I do not know whether the toothbrush I used is the best and whether I have cleaned their teeth the right way".* (Hayat)

These gaps in their knowledge of the details of oral health practices seem to suggest that they may be limited in the ways they include their children in oral healthcare.

Oral health practices and the primary dentition

A noticeable number of mothers furthermore considered that primary teeth were not necessary. They were not aware of the long-term importance of primary teeth. They thought they were just baby teeth, which would fall out and had no long-term significance. The idea that primary teeth "will fall anyway" was widely shared amongst mothers.

"I think teeth are the last things that concern me...because there are other things much more critical in relation to my child's health, such as respiratory issues, and the need for steam sessions as in the case of my child. Personally, for the safety of my child, we stay away from dental treatment because we do not want the child to cry as this might cause an increase his heartbeat. Mmmm ... so, teeth are the last things we worry about. Also, all primary teeth will eventually fall out. So, it does not matter if we do not brush them properly and there is no need to seek dental treatment for primary teeth as they will finally fall out, no need to bother the child...". (Nouf)

This mother places the importance of oral health at a low priority according to the immediate needs of her child. She indicates that with her child's respiratory problems there are competing needs for her resources and oral health is of little importance. Moreover, there is the feeling that because the secondary dentition is permanent then the importance of the primary dentition is minimal.

Seven mothers indicated a lack of adequate information about the significance of primary dentition of their children, which may constrain them from developing knowledge and including their children in oral health care at an early age.

Oral health practices and early dental visits

Mothers recognised the need for visiting the dental clinic but there appeared to be a lack of awareness of the significance of early dental visits. Some mothers believed accessing dental care only occurred when there was an obvious problem. The concept of routine and preventive dental visits was absent.

"My daughter does not go to the dental clinic; she does not feel any pain, and her teeth are very good, so there is no need for the clinic, I think ... but then we took her to the clinic because she started to feel pain and complain all the time". (Abeer)

This triangulates with the accounts of children and the fact that toothache was the most common reason to visit a dental clinic suggests that if the pain was not a possible influence, most mothers will not even take their children to the clinic.

Oral health practices and accessing oral health information

Mothers discussed the difficulties in obtaining dental information and the lack of guidelines on how mothers care for their children's teeth.

> *"There is no guidance or teaching for the mother; however, the educated mothers know everything".* (Munerah)

> *"Honestly, I do not get information about my child's teeth anywhere. I deal with it as per my knowledge, but I would like to know more".* (Abeer)

> *"There is no source. I follow my knowledge on that; no one has advised me before".* (Noura)

> *"I know it from my studies and my general knowledge".* (Fatimah)

There is evidence here of inequalities because it was felt that more educated mothers had access to greater resources for oral health and care.

The mothers' awareness of the lack of dental information affected their confidence in the application of oral hygiene practices. Mothers felt uncertain about their current oral health routines and practices and gained their information from other sources. Mothers also reflected on the inadequate distribution of dental awareness and oral hygiene instructions by dentists.

> *"Often from the Internet, I use to get information about my child teeth and oral health. It was accessible and understandable information, but I would also like to know more especially from dentists ... I do not feel more confident".* (Sarah)

> *"... through TV, I learned everything from TV, I did not go to a dental clinic before".* (Munerah)

Mothers suggested that more visits and information should be available through a range of sources including schools, dental facilities and other health professionals or via the internet.

"Disabled children need more attention, and more visits are supposed to be made to their schools to provide oral health education. There are some awareness campaigns, but we need more. We need a lot of awareness sessions to learn more". (Nouf)

In general, Mothers were aware that there was a lack of accessible oral health information. The lack of appropriate and accessible information excludes mothers and disables them from improving and caring for their child's oral health.

1.47.2 Including and supporting mothers with oral health care

Mothers talked about their experiences supporting their children's oral health. They also discussed the challenges they found in including their children in oral health care.

Supporting mothers' oral health practices

All mothers discussed the need to assist their children brush their teeth, but the level of help varied. Some mothers tended to oversee their children's tooth brushing procedures. For example, brushing their children's teeth, re-brushing their children's teeth or supervising the child while brushing. However, none of the mothers in this study focused on facilitating children's independence in oral health care.

"No, he does not know how to brush his teeth by himself; we tried but he couldn't do it. I clean his teeth using a toothbrush". (Munerah)

"My child brushes his teeth, but I need to be with him because I notice that he does not clean them well or the tongue and internal surfaces". (Fatimah)

Three mothers identified why their children needed support in cleaning their teeth. They realised that their children lacked the manual dexterity necessary for toothbrushing.

"Sometimes she brushes her teeth by herself, but her hand is not strong enough to hold things. That's why I help her to brush her teeth. My child has difficulties holding a toothbrush and even a spoon; she can't reach her mouth with the spoon unless it's empty". (Abeer)

Mothers also acknowledged their responsibility for controlling their children's diet to maintain oral health. This places the burden of care firmly in the domain of the mother. Some mothers described how they restricted their children's consumption of sweets, for example, allowing children to eat unhealthy food only at the weekend. However, others felt they had little control over what their children were eating. They noted that the difficulty in controlling sugar consumption was due to child-related factors and this externalised any responsibility or blame firmly onto the children. Mothers' views triangulated with what the children said in the previous chapter and supported the evidence.

> *"The mother is the one that manages her child. I used to manage his sugar intake in order to keep him healthy, and for the sake of his brothers and sisters' health. I always pay attention to the sugar intake, because I have diabetes, so I give them small amounts of sugar. I let them have sweets only at the weekend. They even complain about that, and I always say, you will understand later".* (Sarah)

> *"I normally don't use lots of sugar even when we drink tea. And I use honey as an alternative to sugar in milk".* (Fatimah)

> *"The parents who should control the child no other way around. Whenever she asks for cake or candy, we easily give them to her. We are trying to cut down on sugar, but every time we try, we can't because she eats nothing but candy and sugar".* (Abeer)

Despite attempts by one of the mothers to prevent sweets at home, her husband provided sweets for the children. This indicated a limitation in the agency of this particular mother because she lacks the support of her husband.

> *"Sugar is very bad; I don't like it, but my husband and daughter love it. My husband always brings sweets and chocolate; however, I don't use sugar at all. They depend on the chocolate that my husband always brings".* (Noura)

The evidence here suggests that mothers are often the sole oral health agents for their children, and they often find it challenging to include their child in oral health care.

Mothers also appear to be unsupported and skilled to make it easier for their children to become independent in practicing oral health. This was supported by what some children had mentioned in the previous chapter, who indicated their exclusion from oral health care by parents who did not facilitate their independence.

The challenges of providing support

Several mothers identified situations in which they had experienced difficulties brushing their children's teeth. The challenging behaviours and reduced motor skills of some children made brushing a challenge for their parents. Toothpaste was mentioned as a problem.

> *"Honestly, I neglected his teeth because it is hard to open his jaw and hard to clean his teeth".* (Sarah)

> *"I face some difficulty in taking care of my child's teeth because my daughter can't gargle by herself, and there is no one to help me. She is also not cooperative in this regard (teeth brushing) because of her disability, but I try to get her used to it".* (Noura)

> *"My daughter does not like the toothbrush; I force her, because she closes her mouth because she does not like the taste of the toothpaste".* (Mona)

These examples demonstrate the lack of support for mothers to develop their skills in cleaning their children's teeth and managing behaviour. Moreover, supporting children through adjusting cleaning tools to make toothbrushing more acceptable for the child and enabling children to brush their teeth independently where possible did not appear.

Some mothers also mentioned other reasons affecting their ability to care for their child's oral health. They reported that they did not receive any social support from their families and husbands.

> *"No one helps me; even my husband. Also, I cannot rely on his brothers because they do not know. I am the one who is responsible for the daily practices of my child's dental health".* (Sarah)

"...only me; I am solely responsible for the daily practices of the health of my child's mouth and teeth". (Hayat)

They also found it difficult to control sweets when they were outside the home. During family occasions, such as celebrations, and outings to other family members' homes, which can be weekly, mothers indicated that it became difficult for them to control their children's consumption of sweets because they have to take into account the wishes of their relatives. In Saudi culture, it is impolite to challenge your relative's home practices. This reflects how society and culture can influence children's eating habits. Besides the social gatherings, mothers reported coffee time as one of the critical drivers in increasing sugar consumption, which triangulates with what the children reported. Coffee time is traditional in Saudi Arabia, and this occurred in the schools with mothers bringing in sweets and coffee to share with one another and their children. Mothers found it challenging to resist sweets, dates and other types of desserts offered on these occasions.

"... he eats a lot of sweets because he sees us eat a lot with coffee. He asks me, and I give him". (Hayat)

"Almost daily here in the centre, my child eats sweets. Because all the mothers here bring sweets and coffee, and he often comes to eat with us, and I cannot stop him. I do not bring sweets home, and my children are used to that". (Nouf)

Furthermore, the majority of mothers discussed changes in their lifestyle and role resulting from increased responsibilities as a child caregiver. Mothers reported that they spent most of their time, patience and energy in caring for their children. They reported that their lives centred on looking after their children and attending rehabilitation sessions. This meant that they devoted less time to themselves. Some mothers felt having a disabled child reduced their life chances and that they had reduced quality time with their husbands and other family members. This further emphasised their need for support.

"Now I cannot continue my studies because I need to take care of my child and this is life". (Hessah)

"Yes, I am struggling in taking care of my child's teeth; I'm the one who is responsible for her feeding, changing her clothes, making her hair. She can't do everything by herself, but here in the centre they have started to teach her how to dress herself, but still, I do everything for her at the moment. Frankly, we mothers need to relax; we suffer from emotional stress and I feel tired from frequent appointments. The girls have taken all my time and I've neglected myself. I go with them everywhere and I sleep with them. I have neglected myself because of them, so I suffer from diabetes because of over thinking about them all the time". (Abeer)

"I was a schoolteacher, but after the birth, after I knew of my daughter's disability, I handed in my resignation because I needed to take care of my child". (Mona)

This all suggest that mothers are excluded, unsupported and struggling. Caring for their children's oral health is another challenge. Some mothers felt blamed for neglecting to brush their baby's teeth when the child had extensive dental decay. Other mothers felt that with support they might have been able to prevent their children's dental problems.

"I felt bad when her teeth decayed because we needed to take out her teeth, and all that was because of me, but sometimes I feel like I need support to take care of my child's teeth, I don't want anyone to blame me for not caring about my children's teeth". (Hessah)

This mother feels she is to blame for her child's deteriorating oral health, but there was no indication of support for her to implement care. What become evident overall is that there is little evidence of a supportive environment that developed the skills and knowledge of mothers around oral health and oral health care.

Supporting mothers to access oral health services

Mother's presented contrasting views on experiences of dental services for their children. Two mothers out of ten were satisfied with the services provided to their children and expressed general satisfaction with the system.

"Everywhere that deals with children with special needs is excellent. The services provided in Saudi Arabia are excellent. The oral health services provided to my child are excellent. The doctor explains everything including the medication; he was excellent, and I was very much satisfied. At first, we had a problem with appointments in hospitals, but now everything is easy and available, especially for people with special needs". (Hessah)

Eight mothers highlighted negative experiences including the dentists' failure to respond to their concerns, inappropriate diagnosis, and the "clinical atmosphere" of most waiting rooms and dental offices. This presented a somewhat negative picture of the dental profession.

"Frankly, with the first visit to the dentist, I was not satisfied. When she saw my son, she said to me, keep on using mouthwash. She told me that I was negligent, and she blamed me because I told her that I used to clean his teeth from time to time. I told her that his teeth are decayed. She said that he had a feeding tube, and the smell was because of the tube; just take care of his gums she said. I told her that his teeth were worn out and asked her to pull them out. She said, if you want me to pull out his teeth you have to help me. I told her how I could help you. She said I couldn't do anything for you if you don't help me during the treatment of your child. [....] Finally, she then referred me to another doctor, and he was an excellent doctor. He anesthetised the child and pulled out his teeth". (Sarah)

What this mother appears to be saying is that the dentist lacked interpersonal and communication skills that valued her as the child's mother and exhibited that she knew what she was doing. It also failed to include her in caring for her child's oral health and merely blamed her for the level of decay her child experienced.

Mothers in this study also discussed their negative experiences in accessing dental care services that may constitute barriers in enabling them to include their children in oral health care and support their children with oral health.

In Saudi Arabia, a variety of sources provide dental services, including the state government services, private paediatric dentists, children's hospitals, and the school dental services. Many mothers use state services, but they often had concerns about

accessing urgent treatment. The mothers reported difficulties in accessing routine dental care. The most common causes of reported difficulties were finding the right dentist, arranging appointments, and cost of treatment, which triangulated with children's reports. These structural barriers excluded mothers from supporting their children's oral health.

The majority of mothers stated that it was difficult to find the right dentist for their children, especially when their child had an impairment. Their stories included rejection by dentists and referrals.

Mothers mentioned that dentists usually refused to treat their child once they found out that they had impairments. The main reasons for rejection in some dental clinics were the lack of trained dentists in dealing with disabled children, the need to use general anaesthesia and limited facilities.

In this study, eight mothers stated that it was very difficult to get a dentist for their children, as they may need general anaesthesia to treat or remove the teeth in one session. This needs a trained dentist, an anaesthetist and a private clinic prepared for them. The mothers also blamed the dentists for not being able to handle the child's behaviours, for some like Sarah the dentist had "no awareness of how to deal with a disabled child". This often meant that parents and their children visited several dentists before they obtained a referral, found a dentist they liked, or one who ignored disability as a 'problem' and accepted their children. The mothers insisted that general dentists do not tend to be skilled in treating disabled children, often referring them to a more specialised service. This had more problems because it had fewer trained professionals and so longer waiting lists. Mothers felt that many dentists needed more experience and training in patient management. One suggestion from mothers was to develop specialised dental services with experienced dentists in the field.

> *"Honestly, I used to take him sometimes to the dental clinic, but they didn't accept him because he is disabled. I remembered two months ago; his teeth began to smell bad. I went to private hospitals, but they refused to treat him because he has special needs [....] he needs general anaesthesia, they are afraid to increase the dose, and we have been trying so hard with the (government hospital) to find an appointment".* (Sarah)

"... the disability of my child doesn't cause any problems during treatment. But I saw some cases, where the children suffer from their teeth, and when I ask some of the mothers why they didn't take their children to the doctor, they told me that they refuse to treat their children because of their condition. Because as you know they move a lot, the children must be anesthetised before treatment. This happens in private hospitals often, but I did not face this problem, because my son doesn't move a lot like them". (Fatimah)

"I remember that I went to a private hospital once. The doctor was afraid to deal with my child. She refused to give him treatment because of the convulsions he has. Then I treated my children in state hospitals". (Hessah)

Mothers found the lack of choice of services a barrier alongside a lack of trained dentists and facilities in all forms of dental services. If inclusion is the goal, then disabled children should have the right to have dental treatment available for them as needed. For example, one mother stated that *"my disabled child wants straightening or any cosmetic dentistry [...] but, my experience with the majority of dentists is that they do not feel comfortable or competent when dealing with disabled children, which in my opinion is equivalent to discrimination".* (Research Diary Note, 2018).

"The services provided are bad because the facilities provided are not enough. Besides the employee's efficiency is not that good". (Noura)

"I used to follow up in a government hospital. They told me they did not have enough equipment. I had to go to a special centre for disabled children. There is no quick response to disabled children in accessing health services. Some mothers told me that in the government hospitals, there is no clinic that suits disabled children. They do not have anaesthesia devices that the children need, so they refer patients to other hospitals". (Hayat)

The previous findings in this study have revealed that accessing different types of services for disabled children appears challenging. Services appear to lack appropriately experienced and trained staff and adaptability for oral health treatment. Although the majority of parents expect routine general anaesthetic services, inclusion in more effective prevention could reduce the need for expensive and invasive dental care.

Mothers also reported that referrals were essential in finding the right dentist, but obtaining referrals was challenging. Referrals originated from various sources, including comprehensive research online, by word-of-mouth or by health care professionals. Many mothers mentioned that they were "alone" in finding a dentist for their child, saying they often searched online for dentists and then called the dental clinic to check their readiness to treat a disabled child. They also mentioned that some health care providers recommend going to some dentists who know to deal with disabled patients. Mothers were more likely to trust other mothers to find the right dentist for their children, often finding them through mothers at school or online.

> *"...for everyone to be able to follow up with the dentist, and the efficiency of doctors, especially in private clinics is very challenging. If you're registered with a good doctor and then you leave him for any reason, it's a challenge to find another good doctor. Mothers need to search online or ask other mothers of disabled children if they know a good doctor. Also, some doctors recommended some dentists who know how to deal with disabled children. Mmmm, finding a good doctor is important and challenging. You know, if a doctor makes any mistake in dental treatment you might lose the teeth and not all are happy to treat disabled children".* (Nouf)

One problem identified by a participant was the lack of a referral system between clinics, which mothers reported as the main way of finding a suitable dentist.

> *"There is no cooperation between the clinics, and the dental clinic is separated, for example, the Neurosurgery can refer you to the Orthopaedics and Physiotherapy, but dental and eye clinics are separated".* (Abeer)

This was in contrast to processes at the Centre for Disabled Children; there is a referral system for children between each clinic. A dental hygienist works in the centre and there is a voluntary dentist attending when time permits. However, although the referral works well inside the centre, there is no matching procedure outside. This evidences a lack of continuity of care. One participant commented:

"In the center they do an excellent job, but their abilities are limited. In dental services, for example, radiation does not always work; the dentist is a volunteer and often does not come. There is only one specialist, there is pressure on them, and there is no cooperation between them and external clinics. This is because this center is not supervised by the Ministry of Health". (Fatimah)

Fatimah seems to be implying that the Ministry of Health should co-ordinate services for disabled children and provide more joined up care. What becomes evident generally is that disabled children appear excluded from oral health care because of the way service provision is structured and provided. It also suggests a lack of support for mothers to enable their children with their oral health.

Mothers also cited other barriers related to general access to dental clinics including the lack of availability of dentists, the length of time in obtaining an appointment and the costliness of attendance. Mothers wanted flexible appointments to suit their routine and school hours for both their disabled children and siblings.

"Appointments need time, and also follow-up in order to get an appointment". (Munerah)

"There is no quick response to disabled children accessing health services. Some mothers they had to wait many months for an appointment. There should be attention given to the children in need of treatment and speed up their appointments, especially children with disabilities. They must have priority in treatment". (Hayat)

"Yes, I encountered difficulties in obtaining health services. For the appointments, we have to wait for a long time, and this is exhausting". (Nouf)

Excessive waiting times for dental appointments are a particular barrier in accessing dental services. This is an indication that mothers are excluded and unsupported, struggling to care their children's oral health.

Inequality was also present in mother's descriptions of access to oral health care. Cost of services was a significant factor, although it did not appear to be a problem for all

mothers because of the government services available to them whilst other mothers with greater resources chose private care.

> *"Our financial situation is good somewhat, but the medical services are so expensive, I don't know why. Medical services for people with special needs are supposed to be less expensive".* (Abeer)

> *"Also, in Saudi Arabia, treatment prices are very expensive, it's like a business. We were following up in the government hospital, but they closed his medical file. Later we went to other private hospitals and prices are very high, and they do not perform their duty as required. They ask us to pay, or they do not take care of the child".* (Fatimah)

> *"Financial status might be a big challenge especially if the child used to follow up in a private hospital. And because he is a disabled child, he needs many devices. Availability of transportation, equipment and treatment needs financial support. For private hospitals, sometimes the treatment will be for a short period, for example, the duration of the session will be half an hour and costs a lot. Dental treatment needs a lot of money, so reducing prices is very important".* (Nouf)

Free dental treatment is accessible in Saudi communities in most government hospitals and dental schools. In contrast, dental treatment in private clinics in KSA is usually expensive and was previously limited to families with a high socioeconomic status. Recently, however, the growing popularity of dental insurance services has provided access to services at affordable prices to many families, enabling more appropriate appointments. This may further explain the large number of children who visited a private clinic with pain, or children with medically compromised conditions and why some mothers prefer to access dental treatment from private services.

Overall, the evidence suggests that mothers were dissatisfied with the dental services and that services were unwilling to address the oral health needs of their children. It also appears that there is no kind of support provided to mothers. The barriers to care and the exclusion of mothers, potentially interferes with inclusive care and furthermore disadvantages their children because of their impairments.

1.48 Summary

This chapter explored mothers' perceptions around supporting their children with oral health. Evidence suggests that mothers are often the sole oral health agents for their children, and they often find it challenging to include their child in oral health care. The data revealed little evidence of a supportive environment that developed mothers' skills and knowledge about oral health and oral health care. It also highlighted that mothers are engaged in a struggle to obtain oral health services for their children. Many mothers appear fighting for accessible, equitable, or appropriate oral health services. From the results, it appears that mothers need informational support and skill development as well as an accessible oral health service for their children. These findings generally raise the question of whether professionals include and support mothers in providing oral health care for their children. If mothers are not being supported and included, then it questions how they can support and include their children in oral health? Therefore, the next chapter presents evidence from professionals.

Professional support for oral health and care

1.49 Introduction

The previous chapter presented the results of an interview with mothers of disabled children. This chapter focuses on the findings of interviews with five educational professionals and five health care professionals, who worked with children with different impairments. This chapter achieves this goal of exploring the ways professionals support and include mothers and disabled children with oral health. I maintained anonymity by assigning pseudonyms to replace the participants' names.

I used a framework of inclusion as a lens through which to view the data. This meant looking for evidence about whether professionals supported, enabled and included mothers and their children with oral health practices and accessing services.

1.50 Emergent themes

The overarching themes were 'Including and supporting mothers and children with oral health practices' and 'Professional's perspectives on inclusion and dental care'

Table 25: Themes emerged from the professionals' data

Theme 1: Including and supporting mothers and children with oral health practices	- The significance of oral health - Confusion and conflict - The 'good enough' mother
Theme 2: Professional's perspectives on inclusion and dental care	- Dental treatment for disabled children - Access to oral health care

1.50.1 Including and supporting mothers and children with oral health practices

Findings have revealed that educational and health care professionals acknowledged the importance of oral health and oral health practices. However, in reality, a lack of support for mothers and their children such as not adjusting oral hygiene tools to help mothers and children for oral health care, or any knowledge of them, appeared in the results.

The significance of oral health

All educational and health care professionals agreed on the significance of oral health. They were aware of the link between child dental health and its impact on general health and well-being.

> *"Well... oral health is one of the most important things because it is part of our daily life or the human body. Oral health is very important and affects the rest of the body. I think it is also important for social life because if the person doesn't take care of oral hygiene, of course, they will be shy to face people, they cannot smile or cannot talk so everything is important".* (Jessica)

Educational and health care professionals acknowledged the importance of cleaning the child's teeth to maintain oral health, such as brushing teeth and demonstrated their knowledge of the cleaning tools. They alluded to the impact of oral health on general health, but this reverted to appearance, social interaction and social acceptability. They said children should use a toothbrush with toothpaste or a combination of a toothbrush and other cleaning tools such as dental floss, fingertips and mouthwash to clean their teeth.

> *"For children, a toothbrush and toothpaste would be enough; they should brush at least twice a day". (Hind)*

> *"Toothbrushes, paste, dental floss and sometimes mouthwash is needed for children to clean their teeth".* (Salma)

> *"Electric toothbrushes, gauze and fingertips are the tools that should be used to clean the teeth of children with special needs".* (Samar)

This underlines that knowledge of cleaning a child's teeth and maintaining oral health was present, however, when I probed deeper conflicting responses appeared.

Confusion and conflict

There were some negative comments about the children's ability to use some of the tools such as dental floss and mouthwash and judged their ability to brush properly. Educational and health care professionals also argued that oral hygiene techniques may be difficult to learn by children, and disabled children often depend, to varying degrees, on others to carry out or assist them in daily oral hygiene procedures. This employed a deficit approach to impairment and constructed the children as possessing a lack of ability.

> *"With disabled children, it's hard for them to use the floss. I remind them, but it's hard for them to realise that I remind them periodically. I used to practically show them how to floss on a Jaw model, but now I stopped because students could use things other than dental floss, such as a power cord, or anything else. Now I just demonstrate cleaning with the toothbrush and the toothpaste. If the girls clean their teeth just once a day, I consider that excellent".* (Majdah)

> *"For our disabled children, I expect it is difficult for them to rinse because they will swallow it. I remember the day when I taught them ablution (act of purification and washing before prayers), they were swallowing the water".* (Wafa)

> *"We have to remember that we have children with a physical disability so their use of the toothbrush will be somewhat restricted. Therefore, the mother should be the one who cleans their teeth. If the child fails to reach the inner part of his mouth, then some food will remain inside. The mother or caregiver is supposed to support and do the job, rather than adapt the toothbrush for them".* (Jessica)

What Jessica says is that all of the responsibility rests with the mother, but there was no indication of support for her to implement care. This failed to acknowledge the sharing of this responsibility by all involved in the life of the child.

However, some participants including the dental professional recommended using an electric toothbrush as an effective alternative tool for children that could help children be independent.

> "*In my opinion, the electric brush I think is better for them. It may be easier for them to use and that will help them to be independent. They should try to use the electric brush, because their mothers are not there all the time, nor are their nannies*". (Louisa)

People with intellectual disabilities have used electric toothbrushes over the years because they reduce the need for manual dexterity. Although systematic reviews have proven that an electric toothbrush works as effectively as a manual toothbrush, it is still not cost-effective (Yaacob et al, 2014). The use of this type of brush might be scary for some children because of the noise and the movement. Notwithstanding, other children may be unable to use an electric toothbrush, because of challenges around manual dexterity or depth and perception control, reflecting the limited knowledge of the professionals.

In sum, the evidence suggests that little or no support for children to practice oral health was present because of the lack of information around the adaptation of brushing aids or indeed any knowledge of them. There was also an umbrella approach towards disability and a lack of evidence that there was diversity among the children. This exhibited a disabling approach and a lack of knowledge as to how to include mothers and their children in oral health practices.

The 'good enough' mother

Professionals frequently placed the burden of care firmly in the domain of the mothers and proceeded to blame them for not caring about their children's oral health. This fits with work on the 'good enough' mother and fail to consider any barriers or challenges that mothers may experience when attempting to maintain the oral health of their children.

"It is up to the mothers because the children even if they want to or they have knowledge about it, if they're physically disabled then they cannot do it. It is useless if the carers have not been helping them. Mothers should be the ones who brush their children's teeth patiently and do it every day. They should start with themselves and brush their teeth in front of the child, but I can see they are not starting with themselves (she laughs). The majority of mothers do not practise oral health. The reason for neglecting the practise of oral health, is they do not believe it be very important. I think whether the family are busy or not, if they give importance to oral health, they can do it". (Louisa)

"This is the role of the mother. The mother must be careful about the type of diet and also about cleaning the teeth of the child. Because this is something done every day and it is a lifestyle, the role of the mother is the most important thing. I think that the parents accept the condition of their children and consider it as God's will and treat them properly. They must treat them specially and not to neglect them and give them facilities that let them be ordinary or at least can serve themselves". (Maha)

"The mother should care about the child, and care about his cleanliness, and care about his teeth. However, in some cases there seems to be some neglect from the parents toward their children when it comes to oral hygiene". (Nada)

Furthermore, professionals often mentioned that parents neglect their children's oral health because of their beliefs that the importance is to focus more on treating children and their ability to walk rather than on developing their personal skills, including practising oral hygiene. This demonstrates a lack of awareness for the daily challenges that a parent of a disabled child may experience.

"Some parents are difficult to deal with because they neglect education. They only focus on therapy, and one of their most important beliefs is that the child has to walk not to learn and be educated. They do not know that there are other problems for the child associated with cerebral palsy. Meaning, the problem becomes greater if the child can walk but his mental

abilities are low and therefore, he is unable to protect himself and has no dependence on himself. Parents neglect the child's abilities because of their beliefs and ignorance. With all this, I don't think that mothers could assist their children in this area (oral health). They will do only the basic things, like feeding the child, dressing the child and cleaning the child and that's it. But oral health maybe some people do not pay attention to that because you can see if they're coming ". (Samar)

What Professionals did not discuss was their role in educating and supporting mothers and their children about oral health and assisting with tips around controlling behaviour. In general, it appears that it was easier to blame mothers and there was little evidence of support for mothers and their children from professionals. These left mothers excluded, unsupported and struggling to care for their children's oral health.

1.50.2 Professional's perspectives on inclusion and dental care

In this theme, education and health care professionals expressed a perceived lack of inclusion of children and their parents in oral health care. They provided evidence of the barriers that faced mothers and their children in accessing dental care. These barriers reflected those of children and mothers in previous chapters, indicating that there is little support for mothers and children to be included in oral health.

Professionals' perspectives on dental treatment for disabled children

Educational professionals reported that mothers experienced poor dental treatment experiences for their children because the dentist lacked interpersonal and communication skills. Poor communication skills between the mother, dentist and child may contribute to exclusion from oral health care. Teachers argued that poor communication does not indicate a lack of children's ability, but rather a lack of professional knowledge on the ways to communicate with them. Therefore, they stressed the benefit of effective communication in order to improve the dental care provided to children. They felt that it was easier for the dentist to refuse treatment rather than attempt to interact with a disabled child and get to know them as an individual. This created a cycle of rejection and refusal.

Educational professionals suggested that there was a need for training sessions and activities for dentists on how to deal with children with different types of impairments. This was to enable them to become familiar with and to practice utilising communication facilitation techniques, and to accept the ineffectiveness of verbal communication. They felt that instruction about the different ways of communicating, such as using stories, signs, gestures, photos, images, cards, video presentations, and songs, would be useful for dentists interacting with disabled children. Teachers emphasised a variety of means of communication because each disabled child was differently abled in relation to communication.

"There must be training sessions and activities for doctors on how to deal with children with disabilities, for example, how to deal with people with Down syndrome. Training courses on dealing with patients with autism must be considered as well, also with the patient who speaks through signals and courses based on dealing with children with special needs according to their needs, such as hearing and visual impairments, mental disability, and physical disability. For example, they must be provided with special chairs. This is important.... Generally, we use pictures, cards, iPads, they like smart devices and they understand through it, drawing sometimes, songs and video clips...". (Wafa)

"We must educate the doctor about how to deal with the disabled child. A child cannot open his or her mouth if he\she is not treated well. The communication with the disabled child must be based on tangible means. For example, using the brush while talking and telling a story and then starting to sing during the cleaning of the teeth; children like to relate everything to songs, once they relate anything to the song, once the song is playing, the child starts to practice the brushing steps. That's what I do as a teacher. The negative things that dentists do are talking about cleaning teeth without using a stereogram or a picture, or a video presentation or story, and that is why interaction with these children is useless and does not work". (Arwa)

"Every child has a way in terms of communication. There are many individual differences. Obstacles come from the child herself, for example, if she has linguistic or verbal problems, it's hard for her to express what she wants". (Nada)

Although Nada realised that children had a special way of communicating, she also had a negative perception of their abilities. This is because she used a medical model approach and considered communication impairments to be a problem for children themselves and not in the ways that professionals communicate with them. Findings in this study indicate the need for a social model approach to challenge negative attitudes towards disability in dentistry. Adopting a social model would help to focus on environmental barriers, including attitudes and awareness-raising issues, that prevent disabled people from accessing proper dental care or enhancing dependency and vulnerability.

Professionals' perspective on access to oral health care

Professionals also cited further barriers for disabled patients in accessing dental clinics.

"Costs, limited availability of services, insufficient skills and knowledge of health workers, all these barriers play a role in dental care access. But the main reason is that there are no specialists for the treatment of disabled children and also, the high costs of private clinics. In general, the main reason in my view is that there are no specialised hospitals". (Samar)

Many of the staff in this study reported the exclusion of most disabled children from dental treatment and this was because some dentists may do not have the knowledge to deal with or may not feel comfortable carrying out treatment unless the child is under general anaesthesia. This suggests that there is a risk that the children's impairments or label of disability may be a barrier to receiving equitable dental treatment under the same conditions as other children.

"Here in the Centre, we have to follow up their oral health at least. This is because most of the children are not accepted by other hospital clinics because of their disabilities. So, we do what we can to provide, oral health teaching and hygiene here. The concerns raised by the mothers to us is that

the private clinics in particular are afraid to treat the children because of their disabilities. Most of the dentists are afraid, really afraid. We advise them to go to bigger governmental hospitals which usually accept them". (Louisa)

*"Sometimes the doctor's efficiency might be a reason too. For example, I saw a sad mother after her appointment with the dentist. She says the doctor should be aware of how to deal with the disabled child. She said that the doctor asked the child to open his mouth, and the child refused. The doctor kept on repeating the phrase 'open your mouth', after which the mother told the doctor that the child is disabled and asked him to treat the child with patience and, take time with him. The doctor then said, I will not delay all the patients, the mother wondered why doctors are not given courses in how to deal with disabled children or why the clinic does not provide a special doctor for disabled children. I think dental care professionals are uneducated in to how to deal with and treat disabled children". (*Arwa)

"Through our experience and contact with parents, especially parents of disabled children, it was noted that the regular dentist is not competent in dealing with the disabled child. Sometimes the child, especially those with cerebral palsy, has a clear open bite and has drooling and occlusion problems. Mothers are aware of their children's oral health problems, and once we refer the child to the dentist, the dentist dismisses the child almost immediately. Because the child is perceived as having an intellectual disability, the doctor prefers not to treat him, and this is what the parents say about doctors. I do not know the point of view of doctors, but I think he looks at the child physically and prefers not to treat him saying that their condition will cause them further work and will not collaborate. I don't know but this might be a reason. Also, dentists prefer not to treat some children who suffer from seizures or are uncooperative. The dentists are afraid of treating them because, there is no awareness, and there is no knowledge that the disabled child is normal. When the doctor sees that the child is disabled, he thinks that he is unable to control the child. The disabled child indeed needs special care, and I have heard from some

parents that their children needed general anaesthesia, but I do not understand the reason for general anaesthesia. I think it's because the doctor thinks he cannot control the disabled child. General anaesthesia is unnecessary because some children are cooperative, but doctors once they see that the child is disabled, they completely choose to anaesthetise the child'. (Samar)

According to Samar, most dentists regard general anaesthesia (GA) as the easiest way to treat disabled children and she suggested that this might be the only way to accept them. This approach reduces the children to the label of disability and fails to consider their abilities and diversity. In addition, some professionals argued that a shortage of specialised clinics meant there were not enough places for disabled children, and this led to rejection for treatment without a GA.

"Quite frankly there is a shortage and there are not many clinics. There are only three clinics and the Centre of Disabled Children, and this is not enough". (Samar)

"Also, some places are not specialised in treating disabled children because they don't know how to treat those children, and the specialised clinics are few". (Jessica)

There was also a general agreement that dentists should have professional responsibility for meeting the oral health needs of all categories of patients without discrimination. They stressed that undergraduate dentists need to know how to deal with a wide range of patients, including disabled people.

"I think that everyone should have the right to receive dental treatment. There should be work on specialising some doctors in the field of disabled children, through education and practice and offer them to treat more disabled cases to gain experience. If the doctor is not competent, they don't have the experience to prepare a clinic which can admit children with disabilities. So, there is a problem in the curriculum because the doctor must study how to deal with disabled children and the doctor should have sufficient knowledge about what the disabled child needs". (Samar)

What non-dental professionals seem to say in this study is that if disabled children are included in oral health care, dentists will learn and gain experiences from treating more cases of children with different types of impairments. This means that the more education and experience dental students have with disabled patients, the more able and willing they are to deal with them.

They discussed the difficulties they faced in dealing with disabled patients and the approaches they used with them, especially those with difficult behaviours. Some of the strategies used in professional settings in order to reduce barriers to treatment include individual techniques based on the needs of the child, providing the child with all the necessary information about the treatment, as well as building a relationship with the patient. Health care professionals also believed that regardless of degree of difficulty, treating a disabled patient would always take longer. One positive factor they suggested was investing in time to build trust and relationships to enable treatment, preferably without the need for general anaesthesia. In general, all health professionals who participated in this study had experience in providing care to disabled children and considered treating them as a routine part of their practice.

> *"One of the difficulties is that some children can be aggressive. Those things we resolve with experience, but at the beginning of our work it will be difficult. The experience will help you deal with a child and you will learn how you can overcome any possible problems, and therefore it is important for dentists to deal with more cases to become well trained and more willing to accept the treatment of these children".* (Samar)

> *"There are problems with the behaviour of the children. Some children are pampered, some are nervous, and some may even hit back at you as a result of anger. However, other problems, we deal with them easily [...] the children are treated by calming them down and absorbing their anger through play, or songs, because we understand that if the child is nervous, he will not cooperate with you and will not accept treatment. We do things that the child loves and helps to calm him down, and this takes a long time, and sometimes we ask their mothers for help because they know children well".* (Maha)

What becomes evident from these results is that dental care services appear to lack appropriately experienced and trained staff in dealing with disabled children.

Health care professionals also explained how the referral system worked and confirmed that there was no clear referral pathway. They stated that the process was not easy, and many difficulties made the referral system not fit for purpose. In addition, not all specialists were authorised to refer children to the dental clinic and only the dentist could refer them from outside the centre. Moreover, a lack of confidence, training or experience in treating disabled children was a factor in the referral decision. Health care professionals highlighted that there was no referral system between the clinics, nor was it easy to find a suitable dentist. They were also aware of the referral systems applied at the Centre for Disabled Children and knew that referral worked well inside the centre but was non-existent outside the centre.

> *"There is no specific mechanism of referral, but through experience, the child is sent to a particular dentist for medical consultation. But here, there is a dental clinic. I write the referral and ask for advice from the doctor and sometimes we transfer them to the hospitals".* (Samar)

> *"It is not me who refers the child. It is the dentist coming here. The hospital is selected based on what their parents prefer, and it depends on where they have a file for treatment. I just do a referral to the dentist, and the dentist refers them to the hospitals. There is no collaboration between the dental clinic in the Centre and other dental services, so it is a responsibility of the family to find a dental clinic outside the Centre, and there is no clear referral system to the dental clinic".* (Louisa)

> *"It is very difficult for parents to reach the dental clinics, and they always ask for a dental clinic to be provided here in the centre, but there is no permanent dentist in the centre. Mothers cannot find a doctor that is a specialist outside the centre; there is a shortage of dentists specialised in treating children with disabilities. There is cooperation with schools, but hospitals do not cooperate. It depends on where each child is treated. We advise parents to look for hospitals and mothers are responsible for finding a hospital".* (Maha)

Meanwhile, educational professionals were not authorised to refer children to a dental clinic. This indicated that there was no referral system between the educational environment and the Ministry of Health.

> *"No, I have never referred a disabled child to a dental clinic, we have no authority. The specialist is the one responsible for this. But it's not part of the teacher's authority or role to do so".* (Salma)

These findings provide support for mothers' statements in that obtaining referrals can be challenging and that a clear referral pathway would help mothers to find the right dentist for their children. This indicates that there is limited support for mothers to include their children in oral health.

Educational and health care professionals reported that the cost of dental services served as a barrier to accessing dental care. For example, some families do not have insurance to cover them; others find that their insurance will not cover the most expensive but essential care.

> *"We need more clinics; the expensive costs might hinder some people, and the government hospital appointments take a long time. I wish that the Ministry of Health adds advertisements about health and awareness and help provide health insurance for parents of children with special needs".* (Hind)

> *"I think in terms of the barriers, there are different factors. One barrier is financial. People with low financial status cannot visit a dental clinic because financially they cannot afford".* (Jessica)

> *"The financial situation can also be a hindrance. As for the availability of services, in each neighbourhood, there is a health unit that is free of charge for all Saudis. But it is an obstacle to other nationalities. For these nationalities, it can very expensive because both the private and government clinics do not provide them with free treatment".* (Salma)

> *"I think there should be a special discount on the price for disabled children in private hospitals".* (Nada)

They knew that there were a number of free dental services available, but that these services were not sufficient to meet need and were not accessible to all people of different nationalities. Therefore, some educational professionals recommended that dental services offer discounts or offer free services specifically for disabled children, which means giving priority to them to be included in oral health care.

What is surprising is that all educational professionals highlighted that parental awareness was the main obstacle in accessing dental care services, even though they acknowledged how mothers struggled to obtain dental care for their children. They suggested that all of the above barriers would ease if parents focused more on dental health and were willing to access dental care, while simultaneously ignoring that there is no indication of support for the mother to obtain appropriate dental treatment for her child.

> *"I do not see that there is any shortness in clinics nor in their services; never mashallah. They are cooperative, but the shortness comes from the parent's side. I see that the girls have bad dental health, yet the parents are not keen to do anything about it. I sometimes talk to the mothers of the students, to care about the cleanliness of their teeth; I say to the mother 'your girl is beautiful so try to fix her teeth', but unfortunately the parents do not care".* (Majdh)

> *"Neglecting the child by the parents is a major reason. They may not follow the children's appointments, the cost is 100% a reason too, but the services are all available in the government hospital and are free. In some cases, some students have pain in their teeth, so I ask parents to take the students to the dentist. Sometimes, they argue they do not have enough money to send them to the dentist. I tell them to go to government hospitals, but the culture of parents is very limited regarding oral health". (*Arwa)

It is also interesting to know the changes that professionals propose in order to make positive adjustments and changes that make dental visits acceptable.

Several participants suggested the need for a specialised hospital ready to meet the needs of disabled children. Parents wanted access to high-quality dental services in a globally accepted, non-discriminatory and securely accessible environment supported by expert advice and specialised services.

> *"Of course, it is excellent for them to have priority and advantages of the services provided to them. They have special needs. I have not seen any special clinic for disabled children or special services for them. When I go to hospitals, I do not see a special section for children with intellectual disabilities. There is no place for them, where the doctor talks to them to their level or presents them with toys and things that please them. I haven't seen anything like that, so it is necessary to have a special clinic for them because they are from the community. They need to be treated in the same way as the normal children in other things, for example, the society looks, and that pity look must end. When a disabled person goes to a place, all eyes will be directed to him and this is what we must change and make them equal; However, when it comes to services provided, there must be advantages in the services provided for the disabled; specialised services for them are urgently required".* (Wafa)

What appeared to the recommendations of the professionals is that it may be impossible for children to obtain appropriate treatment and integrate them into general dental care and this may indicate the extent of their exclusion.

From the evidence discussed by health care and educational professionals, it would appear that that disabled children and their parents are more likely to experience exclusion and inequalities in oral health. Lack of prevention services, coupled with inaccessible dental care and an unsupportive environment overall, all serve as barriers for mothers to support their children's oral health. In addition, any barrier is a powerful reminder of the exclusion of disabled people. One area for improvement is the need to challenge the medical model approach by identifying and removing barriers, which remains of paramount importance in providing equitable and high-quality dental care.

1.51 Summary

This chapter aimed to explore the ways professionals support and include mothers and their disabled children with oral health practices and accessing services. The findings indicated that professionals were aware of the importance of oral hygiene practices and the significance of oral health. However, both educational and health care professionals displayed a lack of awareness about the differing abilities of the children. Indeed, none of the professionals realised the need to choose oral hygiene items based on the specific requirements or functional limitations of children. There was also a lack of insight and empathy about the daily challenges' mothers may face carrying out oral health care for their children. These gaps in professional knowledge seem to suggest that they may be limited in including parents and their children in oral health.

The findings also reflect the views of professionals on the role of mothers in oral health care for their disabled children. They recognised that disabled children relied primarily on the knowledge and skills of caregivers in all aspects of oral health care. Simultaneously, they failed to provide mothers with the necessary support. Professionals mainly blamed mothers for their child's deteriorating oral health and for giving oral health less priority, even though mothers could be fighting for other services such as speech therapy and occupational health. This again demonstrated a lack of insight into the daily lives of mothers and the challenges they may face. Professionals did not discuss their role in educating and supporting mothers and their children about oral health, illustrating little evidence of support for mothers. The lack of prevention services, along with a lack of access to dental care and a supportive environment in general, appear to be barriers for mothers to support their children's oral health. This evidence suggests the exclusion of mothers who are struggling to include their children in their oral health.

Discussion

1.52 Introduction

This thesis aimed to study the inclusion of disabled children in oral health. It began with Study 1 which involved a systematic review examining disabled children's inclusion in oral health research. Contrary to research with children without disabilities, the systematic review suggested that oral health research routinely excluded disabled children. The review identified a gap in the current literature, which was addressed by Study 2, employing ethnography as the methodological approach. I aimed to explore ways of including disabled children in oral health and achieved this by fulfilling the objectives below.

- To devise and utilise a range of methods to enable the inclusion of disabled children in oral health research.

- To represent children's perspectives and experiences, giving them a voice in oral health research.

- To explore the ways in which mothers support and include their disabled children with their oral health.

- To explore the ways in which professionals support and include mothers and disabled children with oral health.

The methodology, methods and results of the ethnographic study are presented in Chapters 4 to 9. This chapter will outline and discuss the main findings of this study through the lens of inclusion, in light of the existing evidence base. The strengths and limitations of this study and the implications of the study results will also be explored.

1.53 Key findings and discussion

To devise and utilise a range of methods to enable the inclusion of disabled children in oral health research

This objective was met by demonstrating a range of research methods used with children in this study to support their inclusion in oral health research, as described in Chapter 5. The present study provided evidence that disabled children were able to participate in oral health research. It revealed that although including disabled children in research is somewhat challenging, it was certainly possible. Facilitating successful inclusion meant using a variety of creative data collection methods, which were essential to the success of the study. The knowledge and skills of both the teacher and the researcher became another critical aspect of the study. Existing research guided the researcher to develop skills for working with children, to understand children's communication approaches, and to work on the relationship with the disabled child. Disability activists see this as an essential part of the research process before research activities take place (Abbott, 2013).

Using a range of creative approaches in this study while interviewing children stimulated their responses, becoming an effective way to deal with power differentials as the methods enabled the children's' agency. Moreover, the children themselves appeared to view the activities as non-threatening and enjoyable. They offered similar comments, such as "*I love your class; this is really fun*" (Danah, 10). This study reflected existing research, suggesting that the use of multi-methods with disabled children supports research to be more inclusive and allows children to play to their varying strengths (Ajodhia-Andrews, 2016).

My thesis suggested that not all of the methods used worked well with children. Indeed, some acted as a barrier to children's inclusion. Using pictures as a prompt enabled participation by children and increased the children's ability to express their views in more depth. The children appeared to find the activity exciting and enjoyable. Using pictures is supported by previous research which has shown that images are often used in research with children as a means to stimulate conversation (Hurworth, 2003) and as a means of providing visual references to the areas covered in an interview (Backett & Alexander, 1991; Curry & Russ, 1985; Eiser et al, 1990). Evidence also suggested that

visual techniques provided an innovative way to reduce power dynamics when adults conducted interviews (Bagnoli, 2012; Cappello, 2005; Einarsdottir, 2005). This can make participating in research more interesting for young people and children (Bagnoli, 2012; Darbyshire et al, 2005). Some studies have further argued that these methods can or even must replace current methods, such as interviews and observation when designing work with children (McLaughlin & Coleman-Fountain, 2019), demonstrating the importance of using a variety of creative research methods, rather than relying solely on speech.

Using games facilitated the children's engagement in my study because research became fun, whilst enabling children to express their views. The variety of games I used (see Chapter 5) helped me to change the game quickly if it did not enable a child to express their views, or they began to tire. I found that some methods needed tailoring to the abilities of the children. For example, developing a modified matching game for children with physical impairments, who could not hold a pen, created a greater level of inclusion. This emphasises the importance of modifying the research method according to the child's ability, because it enables the diversity of disabled children included in research that concerns them. This employs the social model of disability and a rights-based approach.

The guided tour activity was productive because it eased the development of relationships with the children. Furthermore, it increased their ability to chat informally and appeared to reduce the power imbalance, compared to formal, structured interviews. The use of the guided tour is supported by former research with non-disabled children (Clark & Moss, 2001). My research added to the evidence base because this approach included disabled children in oral health research. Conversely, a few children did feel tired, become bored very quickly, or wanted to return to the classroom. I found that this method was not appropriate for children who used wheelchairs because I became the one who guided them, and not vice versa. This literally made it researcher led. One explanation is that the environment was not purpose built for wheelchair users, even though the centre was for disabled children. This created a strange tension in that I was in a centre used for disabled children, but it was not physically accessible for them.

In reviewing the literature, previous research suggested that focus groups achieved goals, as they may be less difficult than individual interviews for young children, and because they can diffuse the balance of power between an adult interviewer and child interviewees (Brooker, 2001; Carr, 2000; Mauthner, 1997). Contrary to expectations, my research demonstrated that this method did not work well in this study, partly due to my lack of experience in managing a group of five disabled children with differing needs and abilities. The children appeared to find being part of a group distracting and challenging to focus on. Some children were more articulate than others, but despite my efforts not all children had an opportunity to speak. I felt that the use of a focus group in this research was disabling for some children, preventing their participation. In Chapter 5, I described how individual and pair interviews were conducted instead of group interviews at the request of the children. These different preferences were unsurprising as different children have different ways of communicating and thus prefer different ways of expressing their opinions (Einarsdóttir, 2007). After interviewing the children individually or in groups of two, they became more familiar with me, allowing more specific questioning, helping to provide descriptions and justifications for their experiences and views.

My research suggested that using symbols acted as a barrier to children's participation. Most children did not use the symbols, and they often distracted them more than they helped. Although other researchers (Fane et al, 2016) have successfully used this method to help children express their feelings, they did not work well with the children in this study. This is likely because some children found it difficult to focus on doing multiple tasks at the same time and I observed that small-chunked tasks with a tight focus worked better.

Drawings in research have been shown to typically be an enjoyable or fun method for children to reveal their views and experiences (Backett & Alexander, 1991; Oakley et al, 1995; Williams et al, 1989). Uses of drawings included as an icebreaker, to assist children in establishing rapport and acting as catalysts and triggers to remember or stimulate discussion or assisting children to organise their own narratives. It has also been suggested that this method might also support children to gain more control over the interview (Einarsdóttir, 2007; Punch, 2002) (the advantages and disadvantages of using drawings in research with children are outlined in more detail in Chapters 4 and

5). Despite research with children without disabilities arguing in favour of this method (Clark, 2005; Leonard, 2006), for this group of children drawing created a barrier to their inclusion. I observed that drawing was a distraction for the children. Furthermore, some children lacked drawing experience, found it boring or uncomfortable because of their physical impairments, or viewed it negatively. I therefore discontinued the task when children revealed they did not enjoy the process.

Despite my efforts to facilitate communication with children, there were still times when difficulties occurred (see Chapter 5). Examples included when children refused to respond if they were tired or wanted to play. Sometimes they became easily distracted, so it was difficult keeping the conversation flowing without interruption. Although most children communicated verbally, some had communication impairments and so needed longer to respond and interact. I overcame these barriers by staying in the classroom and school environment for extended periods with the children and providing them with frequent breaks. In many cases, communication with their teacher before the activity helped to overcome these difficulties because their teachers gave me guidance on how each child communicated in order to achieve successful interactions. I learnt that paying attention to diversity within and between disabled children, whilst implementing innovative and pluralistic methods, was important for engendering inclusion in oral health research. Furthermore, this approach valued disabled children's voices and opinions in research that concerned them.

The methods used with children in this study highlighted the opportunities and potential challenges in their application for research with disabled children. I do not claim that the activities used in the research mentioned here are particularly original or new. Instead, the innovation is in the way I designed and used the methods for children with a range of impairments in oral health research. Furthermore, this underlines that research methods are powerful tools that can either exclude or include children's voices, depending on how they are developed and designed. I learnt that we as researchers must create ways to enable children to participate in research that shapes the political and planning discourses that affect their lives. Through developing research approaches that enable children's voices, we have the potential to challenge stereotypical assumptions that marginalise the voices of disabled children. These insights underline that their contribution to the advancement of knowledge may be realised.

To represent children's perspectives and experiences, giving them a voice in oral health research

In contrast to Study 1 (Chapter 1), Study 2 used ethnography and produced evidence that disabled children possess agency and can participate in research. The results from this study demonstrated that enabling the voices of children entailed shifting the research relationship into researching with children, using creative approaches and respecting their contributions as competent social actors. Chapter 7 illustrated that disabled children were able to voice their experiences and demonstrate their practices of oral health clearly and effectively. They described oral health practices and demonstrated a knowledge of cultural influences on oral health practices, discussing different sources of oral health information, which developed their knowledge. Children expressed their insights of the dental clinic and dental treatment, explaining their experiences and possible barriers to accessing dental care. They also described experiences of pain and the ways in which it was relieved. My thesis contributes new understandings about Saudi disabled children's perspectives and experiences of oral health care, which were previously undocumented and unrecognised. It does so in order to improve oral health outcomes.

My study provided evidence that disabled children have opinions and can express them with support in the right environment, and that they value being included. Furthermore, the successful contribution of disabled children in this study has provided an insight into their abilities and competencies to participate in oral health research. Previous research in disability studies has demonstrated that all children can participate in research when properly considered and approached, researching with disabled children rather than on them (Abbott, 2013; Davis et al, 2008; Franklin & Sloper, 2009). Other studies in childhood research using a variety of methods have also revealed that young children are reliable informants and provide useful and valuable information (see, for instance, Clark & Moss, 2001; Einarsdóttir, 2003; Warming, 2005). These pieces of evidence have asserted that children, just like adults, possess their own experiences and views, have the right to be heard, and are able to speak for themselves if inclusive methods are used. I reflect this understanding in my study, which is the first extended study in dental research with disabled children in Saudi Arabia.

One assumption may be that the invisibility of children's voices in research is the result of inadequate research methods and lack of researcher knowledge of how to relate to different groups, more so than the informants' shortcomings. For instance, as Booth and Booth (1996) suggested, researchers should pay more attention to their own shortcomings than to the limitations imposed on their informants. Likewise, Argent and Kerrane (1997) noticed that "[…] they do not understand", often means "I cannot think how to explain it to them" (p. 73). Unless employing suitable methods with an emphasis on potential rather than limitations, disabled children could continue to be marginalised from dental research. Oral health research therefore runs the risk of stagnating and remaining largely unaffected by all the progress made in children's policies, leading to further marginalisation.

Gallacher and Gallagher (2008) suggested that research on or about children is insufficient. Scholars must research with and for children and involve them as participants in the research process, with priority given to children rather than the adults speaking on their behalf as has conventionally been the case (Punch, 2002). Research recognises that children's views and experiences differ from those of adults (Christensen & James, 2008; Lansdown, 2011) and place significance on the services and the support they receive; it is inappropriate to rely on adult proxies to provide reliable accounts of the views and experiences of children (Beresford, 1997; Markham & Dean, 2006; Markham et al, 2009). For clarity, children in this study reported various suggestions for improving dental care as compared to their professionals and parents. They highlighted the necessity to provide a little incentive from the dentist in the form of small gifts in the dental clinic and make the environment more child friendly to make dental visits acceptable. However, this has not been reported by professionals or parents. The specialists suggested the necessity of having a specialised hospital ready to meet the needs of disabled children. Parents wanted access to high-quality dental services in a globally accepted, non-discriminatory and securely accessible environment backed by expert advice and specialist services. This made it clear that it might be necessary to consult the children and enable them to have a voice in research to improve the services they received to best meet their needs. However, it is a significant step to realise that while we cannot rely on adult proxy accounts of the experiences of children alone, parents or paid carers are a good source of information on how their children already communicate (Dickins, 2004) and skilled interpreters of the signals of their

children (Press et al, 2011). Moreover, the abilities of speakers and listeners affect effective communication (Jenkin et al, 2020). Therefore, although proxy use is unavoidable in some circumstances, for the purpose of this study, I used information from adults to complement the opinions of disabled children, rather than as a substitute.

Furthermore, the inclusion of children in all matters relating to them has been emphasised in human rights conventions (see Chapter 2). Therefore, the inclusion of disabled children in research can be considered not only a requirement but also as an ethical obligation (Carpenter & McConkey, 2012), along with the right to speak for themselves and not through proxies (Einarsdóttir, 2007; Gray & Winter, 2011; Kembhavi-Tam & Wickenden, 2014). This, in general, illustrates the importance of listening to children.

My study underlines the contribution that disabled children can make to oral health research, providing that the right approaches are used. Therefore, future research in the field of oral health should not underestimate the ability of disabled children to participate in dental research. Researchers must find the most effective way that suits children's knowledge, competence, contexts and interests in order to communicate with them and elicit their views on matters that concern them. Failure to include the views and perspectives of disabled children may impact service delivery and policy because we cannot recognise areas for improvements in oral health promotion strategies and dental services without it.

To explore the ways in which mothers support and include their disabled children with their oral health

The data suggested that mothers are often the sole oral health agents for their children. Mothers in this study generally expressed positive attitudes toward maintaining the oral health of their children. They were aware of the significance of oral health practices to avoid tooth decay and dental pain and to prevent the need for any additional dental treatment. The results also revealed that most mothers observed their children's oral health practices and acknowledged their responsibility to control their children's diet to maintain oral health. Several prior studies recognise the role and enthusiasm of mothers concerning the oral health of their children (Al-Hussyeen & Al-Sadhan, 2006; Al-Tamimi & Petersen, 1998; Bilgin & Kucuk, 2010). The results in my study triangulated

with the reports of the children, highlighting that mothers played an important role in supporting oral health and played an essential role in helping them develop knowledge. These indicated that supporting mothers could be the main facilitators of their children's inclusion in oral health.

In contrast, the results of this research illustrated the extent to which mothers sometimes found it challenging to support and include their children regarding oral health. This was due to the lack of information and support in the field of oral health that impeded them from including their children in oral health care. While the mothers were keen to clean their children's teeth, the findings showed that the mothers did not have detailed information about dental cleaning practices for children of different abilities. The lack of adequate information about the importance of their children's primary teeth and early dental visits was also been evidenced in this study. Mothers also discussed the difficulties in obtaining dental information and the lack of guidance on how they should care for their children's teeth. The lack of appropriate and easily accessible information appears to be a barrier to enabling mothers to improve and care for their children's oral health. Some studies in Saudi Arabia have documented poor parental knowledge of oral health but failed to acknowledge the crucial role of services in providing accessible information (Aldosari et al, 2019; Alshehri & Nasim, 2015; Hamasha et al, 2019). This seems to indicate that mothers needed accessible information in order to be able to support and include their children in oral health. Parents with existing knowledge of oral health and preventive practices may play a more significant role in maintaining optimal oral health for their children. Evidence suggests that parents' knowledge and beliefs about the oral health behaviours of their children greatly influenced oral care (Agostini et al, 2014; Finlayson et al, 2007; Jokovic et al, 2004; Salama et al, 2020) and was essential for behavioural changes (Gussy et al, 2008). Parents with better oral hygiene themselves tended to have children with optimal oral hygiene, and vice versa (Al-Shalan, 2003; Kopycka-Kedzierawski & Auinger, 2008; Saied-Moallemi et al, 2008; Wyne et al, 2004). Most of these published findings targeted either the parents of children without disabilities or parents of children with different medical conditions. My study suggested the need for more organised programs of promotion, education and prevention in Saudi societies to increase awareness of oral health.

My results also suggested that the lack of social support acted as barriers in enabling mothers to take care of their children's teeth. Mothers identified significant stressors, finding it challenging to manage external influences such as social occasions when trying to control their child's exposure to snacks, dates, and other types of sweet treats. They also reported that caregiving of a disabled child was difficult and time-consuming. Some mothers felt that having a disabled child reduced their life chances and that they decreased quality time with their husbands and other family members. There appeared to be little about fathers, and the evidence placed the responsibility firmly in the domain of the role of the mother. This may be because most fathers in Saudi society are the primary source of income for their families outside the home, and usually, it was the mothers who cared for the children and homes (Chapter 3). Extant academic literature suggested that caregiving from husbands can allow mothers to have more time and energy to provide care for their children (Glasscock, 2000). Furthermore, the development of self-advocacy or support groups may enable mothers to be more involved and aware of their children's rights and enhance their ability to deal with the challenging role of raising a disabled child (Duvdevany & Abboud, 2003). My study further suggested that there was a lack of insight and empathy about the daily challenges' mothers may face providing oral healthcare for their offspring. Care professionals placed the burden of care firmly in the maternal domain and blamed them for not caring about their children's oral health. However, they did not discuss their role in educating and supporting mothers and their children about oral health.

My thesis's findings have provided essential insights into the concerns and needs of these mothers in providing oral health care to their children. There appeared to be a lack of oral health promotion, including the dissemination of oral health information, practical health advice and increasing access to dental care in order to support mothers and their children to be included in oral health.

To explore the ways in which professionals support and include mothers and disabled children with oral health

The data reflected research participants' views of the challenges dental professionals faced when supporting, enabling, and including mothers and their children in oral health. The participants felt that oral health professionals had subjected disabled children to unfair treatment or discrimination. There were accounts of negative

employee attitudes and behaviours, failure of staff to speak directly to children or failure to modify their communication skills and their unwillingness and competence to provide effective treatment. Oral health care professionals' attitudes, skills and knowledge, appeared to play a main role in acting as a barrier or facilitator for disabled children to be included in oral health.

Children in my study emphasised the lack of interpersonal skills exhibited by some dentists in comparison to other medical professionals, which triangulated with the mother's reports. Children felt that dentists should provide more information about dental procedures. Children and mothers both wanted support to make oral health decisions. My thesis identified that little attention has been paid to establishing good lines of communication and information between dental professionals and children. Frequently, dentists failed to communicate directly with children or involve them in decision-making. They also failed to adjust and adapt their communication to the patient's needs. Children in my study revealed that they often felt ignored in the consultations or 'talked over' if the caregiver was present, implying that they were not being included in the oral health encounter. This appeared to suggest that oral professional attitudes revolved around a medical model of care in which people are viewed as objects, not people as defined in the UN rights of the child (UNICEF, 1989). This reduces value and excludes children from discussions about oral health. Children must have the right to participate in the choices and decisions about their health. The Convention on the Rights of the Child emphasises treating a child with dignity, as an individual with the same fundamental rights of all human beings, including freedom and equality (UNICEF, 1989). CRC further suggested that children must have access to the best health care standards, being treated with dignity as a human being, the right to information, and the right to privacy. This implies that all children are rights-holders, even if they cannot express their rights and that anyone involved with children has the responsibility to promote them and facilitate their voices being heard (De Lourdes Levy et al, 2003).

My study further suggested that health care and education workers also demonstrated consistency with the medical model of disability in their opinions and practices. This was because they appeared to work from a deficit perspective, assuming it would be difficult for the children to understand, or be unable to practice oral health, because of

their impairments. In this case, children were judged on the basis of their impairment rather than their capacity (Press et al, 2011). The evidence in my study demonstrated that although the older children considered oral health their responsibility and wanted to carry out oral health care without assistance, professionals argued that oral hygiene techniques might be difficult for them to learn. Disabled children often depend, to varying degrees, on others to carry out or assist them in daily oral hygiene procedures. Professionals reported children's lack of ability to use particular tools such as mouthwash and dental floss and judged their ability to brush properly. Their views prevented any additional child support, education and, most importantly, any additional knowledge about oral health care from developing. This was confirmed by the children's data and their lack of awareness of dental floss as a cleaning tool. Their teachers omitted this practice, believing that children with intellectual disabilities may not understand the correct way to use dental floss and may harm themselves. This suggested that the way in which adults understood disability can act as an enabling or disabling factor for children to achieve independence and have a voice or be included, particularly in oral health.

To support children to be included in oral health, there seems to be a need to forge a professional understanding of disability discourse in line with the social model of disability (Oliver, 1996). The social model is more inclusive in approach and proactively discusses how persons with impairments can contribute on an equal basis with non-disabled persons in most activities. Making changes, even when it relates to time or resources, aims to include disabled individuals and the onus is on the organisers of the event or activity to ensure accessibility (Press et al, 2011). Within my study, using the social model of disability suggested that the responsibility rests with adjusting societal structures and professional attitudes to include disabled children in their oral health.

The field of education provides examples of how orientations in various models of disability impact the decisions made by teachers of physical education in interacting and working with disabled students. Physical education teachers who aligned with the medical model of disability can be defined as reluctant to change practices, assuming students to 'fit' into their current curriculum, and attributing non-participation to the personal characteristics of the student (Haegele & Hodge, 2016). When a disabled

student fails in class, the teacher assumes that the reason is due to the students' disability rendering them as bodily defective and limiting their capabilities (Fitzgerald, 2006; Haegele & Hodge, 2016). Conversely, those who endorsed the social model of disability would possible view disability as an aspect of diversity that needed to be appreciated rather than as an obstacle to contribution (Haegele & Hodge, 2016). These teachers do not mind changing activities/games to accommodate the varying abilities of individuals. They would also take responsibility for failing to modify the activity, subsequently making additional accommodations if students did not progress. Grenier (2011) suggested that when educators viewed disabled students in ways that went beyond their individual features, they could gain insight into the abilities of student beyond their medical profile. They could then provide more positive and engaging experiences for students. This, in general, has provided evidence that the way physical education teachers viewed disabled students could affect their perceptions and experiences with them (Barton, 2009). Using these reflections garnered from the field of education and returning to oral health, I suggest that critical reflection on how they defined and addressed disability was important for those working with disabled people.

The definition of disability in Saudi Arabia, as discussed in Chapter 3, is one that tends to understand disability through the medical model, rather than the social model. It considers the primary cause of disability as impairment and not the social barriers, which perhaps exerts an impact on professionals' educational policies that concern disabled people, as well as on adult thinking. Therefore, it appears that redefining disability using the social model of disability may be necessary as a means to support children to integrate into oral health in the KSA. This is because the continued dominance of the medical model of disability may mean that the barriers disabled children face in order to include them in oral health will not be addressed.

In addition to the dental professionals' lack of interpersonal skills, the data showed that they were not prepared to provide effective treatment. My research provided evidence that mothers of disabled children experienced difficulties in finding dentists willing to treat their children. This in turn may contribute to their exclusion from oral health encounters. This finding is consistent with previous studies conducted in Saudi Arabia suggesting that caregivers of disabled children reported difficulty obtaining dental care (Al-Shehri, 2012; Murshid, 2011). Dentists' refusal to deal with disabled children may

be linked to inadequate the dental education and training of dentists in the treatment of disabled children. The evidence suggested the omission of special care dentistry from the dental curricula of undergraduates in both dentistry and dental hygiene (Dao et al, 2005; Dehaitem et al, 2008; Delucia & Davis, 2009). The same appeared to occur in the KSA, as shown in this study. This emphasised the significance of delivering high-quality dental education programs in order to prepare undergraduate dental students and to raise their readiness to interact with and treat disabled people (Chávez et al, 2011; Moore et al, 2009). Increasing dental student's encounters with disabled patients increased their abilities, developing positive attitudes, competence and confidence (Alkahtani et al, 2014; Alumran et al, 2019; Casamassimo et al, 2004; Wolff et al, 2004). This appeared to suggest that communication skills, disability awareness and awareness of the needs of disabled people should be included in the dental curriculum in Saudi Arabia. Therefore, more focused training of future dental care professionals may enable them to support the inclusion of disabled children in oral health and assist in reducing oral health inequalities.

A lack of access to dental services indicated exclusion from oral health, coupled with negative experiences when services were accessed, may mean that mothers are disabled from supporting and including their children in oral health. Participants cited scheduling of dental appointments, cost of dental services, limited availability of services, and unclear referral pathways as barriers to accessing dental care services. Children also added that fears associated with dental visits and the inaccessible physical design of dental services limited their access to oral health services. Children in wheelchairs or walking devices indicated that the dental clinic was small, making circulation or walking around the clinic difficult. This indicated in turn that the physical design of dental services and construction occurred without consideration of the needs of disabled children, thus acting as a barrier to inclusion. The inaccessible built environment is a direct violation of the Convention on the Rights of Persons with Disabilities. Following this Convention, designing the built environment should be inclusive, avoiding the exclusion of certain groups of people based on their disability (UNCRPD, 2006, article 9). Disability policies in Saudi Arabia claim to focus on the rights of disabled persons to access all services and to live with dignity (KSA, 2002). However, although disability laws have been in place in Saudi Arabia for a long time, the struggle to deliver under this section of the law appears to still exhibit challenges.

Studies from the perspectives of parents and clinicians conducted in Saudi Arabia identified similar barriers to those found in my research, but with the key difference that they excluded children (Al-Shehri, 2012, Murshid 2011). Over a third of disabled children were referred for general anaesthetic with little attempt made to treat them without and over half in one study had no experience of routine dental care (Murshid, 2011). Research in other countries has suggested that finding an appointment and long waiting lists are barriers to accessing dental services. These studies suggested that such barriers could be mitigated using private services, but several researchers cited cost as the highest barrier (Rapalo et al, 2010; Schultz et al, 2001). My research in Saudi Arabia reflected this work, with parents and children citing cost as a particular obstacle to accessing private clinics. Irregular dental visits and inability to access dental appointments may lead to the need for emergency management for pain relief and extractions rather than preventative or restorative care. In my research, children and parents reported extraction as the main treatment provided by dentists, without any mention of prevention. This may suggest that the priority for regular dental treatment or preventive dental care for disabled children was low and not at the forefront of dentistry for this particular sample of participants. In addition, da Rosa et al. (2020), in the context of a systematic review in other European, North and South American and Australian countries with different health systems, found similar barriers to my research. The review revealed that dentists' unwillingness to care for the teeth of disabled people, the cost of treatment, lack of adaptation of access routes to dental offices and health care facilities, and inadequate dental facilities accessible to disabled people were common barriers found among the selected studies. Moreover, da Rosa and colleagues failed to discuss the facilitators of access to oral health services for disabled people studies in their review. Facilitators of access may resolve barriers to accessing dental services.

Some professionals in my study suggested the necessity of having a specialised hospital ready to meet the needs of disabled children. What emerged from their recommendations was that it may be impossible for disabled children to obtain appropriate treatment and integrate them into general dental care and this may indicate the extent of their exclusion. Disabled children can be treated similarly to children without disabilities with reasonable accommodation; this has already been suggested for adults with disabilities in the UK dental literature (Owens et al, 2010). Owens and

colleagues suggested that the creation of specialist services led by newly formed consultants in special care dentistry could have the unintended consequence of reducing choice if general dental practitioners were encouraged to refer all those with the label of disability. Similarly, labelling a group of children as disabled and advising special provision of services for them creates the possibility of more referrals and longer waiting lists for treatment, thus increasing rather than decreasing oral health inequalities. There would appear to be a delicate balancing act between the allocation of resources for services and ensuring that any change to services did not increase existing oral health inequalities for disabled children and further their exclusion.

Overall, my thesis has argued that disabled children still faced forms of marginalisation and exclusion in oral health. In addition, there was little evidence to suggest support and enablement of mothers and their children, and my evidence suggested that oral health professionals failed to include disabled children in oral health. Moreover, access to oral health care was also an area that appeared challenging for both children and their parents, with parents facing various obstacles in accessing oral health information and dental services for their children. The CRC advocates that disabled children have a right to be included in choices and decisions about their health and this includes oral health. My study found no evidence for the inclusion of disabled children in oral health.

1.54 The strengths and limitations of the study

One of the main strengths of this study is that it represents the voices of disabled children in oral health research. This study sought to elicit opinions from the children themselves, rather than relying on responses from parents or caregivers or the opinions of professionals. This addressed a gap in the existing dental literature and was also significant from an ethical standpoint. The majority of oral health research has used disabled children as objects with no other participation (Alwadi et al, 2018). In contrast, I provide evidence that disabled children possess agency and can participate in research.

The use of ethnographic research advocates the use of a range of data collection methods as long as they fit comfortably with the environment (Brewer, 2000). This is a further strength of my research. For example, I use pluralistic research methods during data collection adapted to the abilities of the children. Using semi-structured interviews gave the children the freedom to express their opinions, while observing them in their

environment provided more depth and richness to the data collected. The use of creative activities was vital to the success of the study because it enables children's participation by creating an inclusive and supportive research environment. Adapting the methods to the children's abilities, then, considers the diversity of children's abilities, which is another strength.

My thesis adopted the social model of disability as a lens through which to view the children and their environment. In contrast, the majority of disability-related oral health research in the KSA tends to use the medical model of disability, consequently viewing the problem as being within the individual. Opening out the research by using the social model of disability therefore enables a more rounded perspective. Rather than focusing on impairment, my work highlights the structural and societal barriers faced by disabled children and the ways in which this excludes them from oral health.

A final strength of this study is that I triangulate children's accounts with those of parents and professionals. This approach reduces claims of subjectivity and produces genuine, credible and trustworthy research. These strategies are discussed in more detail in Chapter 5.

The study has achieved its objectives but has some limitations. One of these limitations was the relatively short period available for data collection in this study. Prolonged exposure to the participants and greater access to research sites might have enriched the study by enabling me to collect more information. The reason for this limitation was mostly practical; as is common in this type of academic research, the timeframe was constrained.

Qualitative research does not use statistical generalisation to populations, instead theoretical generalisability of findings can be related to transferability (see Chapter 5), via providing the reader with detailed descriptions about the area being researched, allowing for transfer to other settings and contexts. Indeed, while acknowledging the limitations of a small sample from a discrete area in generalising findings to other, or broader contexts, the relative disparity of the sample introduces a set of different perspectives that provide a cohesive overview of the context in Saudi Arabia.

Gender segregation is one of the cultural barriers that exist in Saudi society. It is common practice in Saudi Arabia and segregation in educational institutions has been part of Saudi Arabia's culture for most of the 20th century and remains so. As a female researcher, I was unable to enter an all-male establishment, which constituted a barrier to recruiting boys, fathers, male teachers and health care providers. The consequence of this is that females and their voices dominated my sample. This may be another limitation of my study. Repeating the study to include both males and females would entail male and female researchers working independently in different areas but sharing results. This has its own inherent challenges because of gender segregation in KSA but might provide more information as females and males may have different experiences regarding the study focus.

A further limitation of the research is that the views of children with severe and profound intellectual disabilities and those who were pre-verbal have not been taken into account. In other words, their voices are omitted from this study. This goes against the core spirit of the study, which is that all children should be included, regardless of their abilities. The reason for this omission is that the education system in Saudi Arabia does not cater for children with profound impairments and they are likely to remain at home. Cultural reasons forbid the recruitment of participants from their homes because it might violate the privacy of the family. In general, Saudis are conservative as a society. As a Saudi citizen with a deep intrinsic understanding of the nature of Saudi culture, I have complied by operating within certain set boundaries. Nevertheless, there is a need to include these children's voices in further research because those with different impairments may have different perspectives and experiences that could yield different data and insights. However, special training may be required on the part of the researcher to gather data appropriately from these participants and also to analyse and interpret the data professionally.

1.55 The implications of the study

The evidence from my study provided a strong argument that the voices of disabled children are consistently absent in dentistry. Dental research fails to address perceptions, opinions, experiences, and making choices and decisions. My study demonstrates the possibility of including disabled children in future research, service development and evaluation, providing examples of pluralistic inclusive research methods and identifying research methods that may be barriers to the inclusion of disabled children in oral health research. It also provides evidence that disabled children can participate in oral health research. The development of research methods that enable children's voices to be heard in oral health research should be a consideration for future dental research. My thesis adopts a rights-based approach in an attempt to avoid disempowerment and discrimination by including children's voices in an area concerning them. Obtaining their perspectives by listening to their voices is important but the next stage will mean acting on and increasing opportunities to improve their oral health outcomes.

The results of my study also reveal little evidence of a supportive environment that develops mothers' skills and knowledge about oral health and oral health care for their children, namely that mothers lack informational support and oral health education. Instead, they are engaged in a struggle to obtain oral health services for their children. Many mothers are fighting for inaccessible, equitable, or appropriate oral health services as promised in Saudi policy. This suggests that there are still many barriers to be overcome. The study further suggests that oral health professionals fail to include mothers and children in oral health. Furthermore, disabled children appear subjected to discrimination by oral health professionals' attitudes, which results in turn from a need for disability-focused dental education, exposure to disabled children and skill development.

What the findings suggest overall is that mothers need informational support, skill development and an accessible oral health service for their children to enable them to include their children in oral health. An understanding of what is also required to support mothers and their children acquired through this study can help guide the development and improvement of oral health education programs, policies and

interventions to minimise the difficulties encountered. Policymakers can also learn from the experiences of children and mothers and use the research findings set out here to help them reshape oral health policy. My study suggests revisiting the dental curriculum in Saudi Arabia with a focus on improving the training of dental health professionals in communication skills, disability awareness and more exposure to treating disabled children and adults in the KSA. The information from my study may assist oral health professionals to prioritise planning efforts to address the oral health needs of disabled children, become more creative in designing new research methods and develop collaborations with other practitioners who typically work with disabled children (e.g., psychologists, behavioural therapists, and occupational therapists). The lack of inclusion of the views and perspectives of disabled children may have an impact on service delivery and policy because, without them, we cannot identify areas for improvement in oral health services. The next chapter presents several recommendations that may help support the integration of mothers and their children in oral health.

1.56 Summary

The essence of this research has been to give children a voice that is often overlooked in oral health research. Although I can accept that there may be limitations with my study, it has contributed to new findings in this area, in terms of giving children a voice in the dental evidence and in Saudi Arabia. It also triangulated children's perspectives with those of parents and professionals. This chapter presented the main findings of study 2, discussed the meanings and linked them to the existing evidence base. The next chapter concludes with an overall discussion and recommendations.

Conclusion and recommendations

1.57 Introduction

The work within my thesis aimed to explore the inclusion of disabled children in oral health. It began with a systematic review focusing on their inclusion in oral health research. Contrary to research with children without disabilities, my study shows that oral health research routinely excludes disabled children, thus adding to the existing knowledge base.

My thesis further added to oral health knowledge as it illustrated the ways that inclusion might occur by demonstrating a range of inclusive research methods used with the participating children. Employing pluralistic methods creates an inclusive, supportive and interesting research environment for the children.

My thesis contributed new understandings about Saudi disabled children's perspectives and experiences of oral health, which were previously undocumented and unrecognised. Moreover, in triangulating the views of children, parents, educational and health professionals, it provides a cohesive overview within the context of Saudi Arabia.

This concluding chapter begins with an overall discussion of both studies' key results in this thesis and ends with the recommendations.

1.58 Summary of the main findings and discussions

The overarching question for this thesis is: In what ways are disabled children included in oral health? Study 1, a systematic review (presented in Chapter 1), highlighted the gap in the current knowledge base. The principal finding of this review suggested that oral health research routinely excluded disabled children. This was, in contrast, to research with children without disabilities (Marshman et al, 2007; Marshman et al, 2015). There is a significant lack of oral health research with disabled children as active participants, and there is no research which includes them sharing power and responsibility for the research design and process.

Heywood (2001) suggests that children enter the adult world at a far slower rate compared to pre-industrialisation, spending their childhood lives in childcare and schools. For disabled children, this entry into the adult world appears delayed even further with the usage of residential and day schools past the age of 18, extending the notion of the eternal child as vulnerable and in need of protection. Furthermore, disabled children are viewed as 'different' and 'not like us', thus othering them and undermining their competence (Davis & Watson, 2001). The systematic review undertaken here suggests that dental research appears to support this position as it often excludes the voices of disabled children, denies their agency and fails to recognise the diversity of childhood and children's experiences that James et al. (1998) advocate.

The disability research has suggested that disabled children are "denied agency not because they were incapable of making choices, but simply because their ability to make choices went unrecognised" (Davis & Watson, 2000, p. 214). For many disabled children, there is also the notion of competency attached to the label of disability (Corker & Davis, 2001). This position is emphasised in case law in the UK, where taking a child's views into consideration occurs only if they are clear and consistent; any ambivalence lessens the credibility and weight of their perspectives (Kay et al, 2012). This measures disabled children against normative standards and places the onus on them to increase their communicative abilities, rather than for others to alter the communication environment to enable children's participation and involvement, thereby recognising their agency. Naturally, this does not deny that there are challenges in involving disabled children in research, mainly because they are a diverse group with a range of abilities.

Dental research, in order to adopt a rights-based approach, may need to recognise the rights and potentials of disabled children, in the process avoiding accusations of othering and exclusion, whilst acknowledging the challenges. Roche (1999) further expands this point by stating, "We need to think through the terms on which participation is being offered, […] The languages of participation and empowerment are cosy, but we need to be more critical of the circumstances of inclusion and the kinds of adult support (e.g., advocacy and representations) that children might need" (p. 489). This is particularly pertinent to research, because some disabled children may need different forms of support to enable their participation.

Whilst research with parents or paid carers of disabled children and professionals is of value, it merely reproduces the perspectives of those who are more powerful (Stalker & Connors, 2003). This systematic review suggests that there is a need for studies conducted with children in oral health research rather than on them. This would rightly use a rights-based approach and challenge reductive notions about their ability to participate and capacity due to their age or disability (Davis & Watson, 2000; Heath et al, 2007).

This published systematic review also identified a gap in the current evidence that was addressed by conducting an ethnographic study on the inclusion of disabled children in oral health (presented in Chapters 2 to 10). This approach provides evidence that disabled children can participate in oral health research. Furthermore, it acknowledges the role that mothers play in supporting their children and the need for professionals to consider the position of parents as pathways to inclusion for oral health. It also shows that dental professionals need more education around disability awareness and experience of, and exposure to, treating disabled children.

My research suggests that children want to be respected, listened to, valued, given truthful information and that many want to participate in decisions about their care. It also reveals that professionals appear to employ a deficit approach to impairment, assuming the children lacked ability, thus preventing them from offering any additional support to enable children to achieve independence and have a voice or to be included in oral health.

1.59 Recommendations

1.59.1 Recommendations for future research

- Further oral health research using inclusive research methods needs to occur in order to enable disabled children to participate in issues that concern them.
- Inclusive methods should continue to be implemented and refined in future research. Consequently, this may lead to gaining more in-depth information on the merits of different methods and provide more guidance on ways to combine these methods in a single study.

- Repeating this study in whole or in part in other countries globally could provide a multiplicity of perspectives for comparing and contrasting purposes, thereby increasing the evidence base.

- Qualitative studies need to include children with more severe and profound intellectual disabilities to avoid excluding their voices in matters relating to them.

- Inclusion of both boys and girls in different geographical contexts within the KSA may determine any gender differences or inequalities.

- Future research could explore the perspectives of other dental professionals, mothers and fathers from different geographic areas globally to enhance insight into the area and increase the evidence base.

- Further research could explore the healthcare input of nannies and maids as carers in Saudi Arabia and whether they require support to enable children with their oral health.

- Epidemiological research is required on disability in the KSA. There is insufficient data on the prevalence, incidence or types of impairments. There is also insufficient data on the prevalence and incidence of different types of oral diseases among disabled people. This would help more accurately represent the oral health needs of disabled children to formulate services and ensure that they are appropriate and acceptable to the level of specific needs. This can also help commissioners of services to provide the most effective oral health care services for disabled people.

- Research in Saudi Arabia could address ways of overcoming attitudinal and structural barriers using the social model of disability when improving the provision of oral care for disabled children and adults.

1.59.2 *Recommendations for clinical care and policy*

- Greater efforts are needed to improve dental education to prepare future dental service providers to care for disabled patients. This aims at reducing inequality in oral health for disabled children and adults. Increasing disability awareness and exposure to treating disabled people influences the professional behaviours and attitudes of future service providers, practice characteristics, competence

and confidence. Developing disability confidence in the dental team can be through training in disability discrimination and related legislation, disability-confident language, an understanding of the impact of different types of disability and medical and social models of disability. Moreover, oral healthcare professionals need to gain competence in communicating with disabled patients to maximise the flow of information and improve clinical efficacy. This can generally provide a basis for reducing the discriminatory barriers that children face in dental practice.

- Increasing the employment of oral health promoters and dentists with a focus on prevention may assist in reducing the image of a dentist as someone who extracts teeth and inflicts pain. Dental services could target schools, nurseries, and link with parents in order for prevention messages to reach homes. Oral health information needs disseminating to parents and carers alongside practical oral health advice and strategies. Moreover, an awareness campaign may be required across Saudi Arabia regarding the importance of oral health. It would also be necessary to ensure the provision of information resources in accessible formats for disabled children. Thus, providing parents and their children with full support in the form of oral health education and dental care facilities can help enable them to integrate into oral health.

- An evaluation of new and old buildings providing oral health and medical services is required throughout the KSA with regard to physical accessibility for disabled children and adults.

- There is a need for disability policies in the KSA to move away from individualising disability (the medical model) towards those based on the social model, where the social model focuses on addressing and removing barriers that prevent the individual's full and equal participation in society.

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Appendices

Appendix 1: Search strategy

Medline Via Ovid	Web of science (Core Collections)	Scopus
1. "Learning disabilit*".ab,ti.	1. TS=("Learning disabilit*")	1. TITLE-ABS-KEY ("Learning disabilit*")
2. "learning difficult*".ab,ti.	2. TS=("learning difficult*")	2. TITLE-ABS-KEY ("learning difficult*")
3. exp Disabled Persons/	3. TS=(disabilit*)	3. TITLE-ABS-KEY (disabilit*)
4. "mental disabilit*".ab,ti.	4. TS=("mental disabilit*")	4. TITLE-ABS-KEY ("mental disabilit*")
5. mental retardation.ab,ti.	5. TS=("mental retardation")	5. TITLE-ABS-KEY ("mental retardation")
6. mentally retarded.ab,ti.	6. TS=("mentally retarded")	6. TITLE-ABS-KEY ("mentally retarded")
7. cognitive impairment.ab,ti.	7. TS=("cognitive impairment")	7. TITLE-ABS-KEY ("cognitive impairment")
8. "cognitive disabilit*".ab,ti.	8. TS=("cognitive disabilit*")	8. TITLE-ABS-KEY ("cognitive disabilit*")
9. reduced cognitive functionality.ab,ti.	9. TS=("reduced cognitive functionality")	9. TITLE-ABS-KEY ("reduced cognitive functionality")
10. "developmental disabilit*".ab,ti.	10. TS=("developmental disabilit*")	10. TITLE-ABS-KEY ("developmental disabilit*")
11. "developmental difficult*".ab,ti.	11. TS=("developmental difficult*")	11. TITLE-ABS-KEY ("developmental difficult*") O
12. developmental disorder*.ab,ti.	12. TS=("developmental disorder*")	12. TITLE-ABS-KEY ("developmental disorder*") O
13. "intellectual disabilit*".ab,ti.	13. TS=("intellectual disabilit*")	13. TITLE-ABS-KEY ("intellectual disabilit*")
14. mentally handicapped.ab,ti.	14. TS=("mentally handicapped")	14. TITLE-ABS-KEY ("mentally handicapped")
15. special needs.ab,ti.	15. TS=("special needs")	15. TITLE-ABS-KEY ("special needs")
16. blind.ab,ti.	16. TS=(blind)	16. TITLE-ABS-KEY (blind)
17. deaf.ab,ti.	17. TS=(deaf)	17. TITLE-ABS-KEY (deaf)
18. down syndrome.ab,ti.	18. TS=("down syndrome")	18. TITLE-ABS-KEY ("down syndrome")
19. cerebral palsy.ab,ti.	19. TS=("cerebral palsy")	19. TITLE-ABS-KEY ("cerebral palsy")
20. autism.ab,ti.	20. TS=(autism)	20. TITLE-ABS-KEY (autism)
21. ADHD.ab,ti.	21. TS=(ADHD)	21. TITLE-ABS-KEY (adhd)
22. handicapped.ab,ti.	22. TS=(handicapped)	22. TITLE-ABS-KEY (handicapped)
23. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or	23. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22	
	24. TS=("erosion and dent*")	

20 or 21 or 22 24. (erosion and dent*).ab,ti. 25. (trauma and dent*).ab,ti. 26. (fluorosis and dent*).ab,ti. 27. "periodont*".ab,ti. 28. malocclusion.ab,ti. 29. orofacial.ab,ti. 30. exp Oral Health/ 31. "orthodont*".ab,ti. 32. exp Dental Caries/ 33. oral health care.ab,ti. 34. special health care need.ab,ti. 35. oral hygiene.ab,ti. 36. oral treatment.ab,ti. 37. dental care.ab,ti. 38. dental treatment.ab,ti. 39. dental health.ab,ti. 40. dental health care.ab,ti. 41. special care dentistry.ab,ti. 42. 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 43. 23 and 42 44. limit 43 to (english language and yr="2001 - 2017" and "all child (0 to 18 years)" and dentistry journals)	25. TS=("trauma and dent*") 26. TS=("fluorosis and dent*") 27. TS=(periodont*) 28. TS=(malocclusion) 29. TS=(orofacial) 30. TS=("oral Health") 31. TS=(orthodont*) 32. TS=("dental caries") 33. TS=("oral health care") 34. TS=("special health care need") 35. TS=("oral hygiene") 36. TS=("oral treatment") 37. TS=("dental care") 38. TS=("dental treatment") 39. TS=("dental health") 40. TS=("dental health care") 41. TS=("special care dentistry") 42. 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 43. TS=(child*) 44. TS=("young person") 45. TS=("young people") 46. 43or 44 or 45 47. 23 and 42 and 46 48. limit 47 to (English language and yr="2001 - 2017" and dentistry journals and reviews and articles)	23. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 24. TITLE-ABS-KEY ("erosion and dent*") 25. TITLE-ABS-KEY ("trauma and dent*") 26. TITLE-ABS-KEY ("fluorosis and dent*") 27. TITLE-ABS-KEY (periodont*) 28. TITLE-ABS-KEY (malocclusion) 29. TITLE-ABS-KEY (orofacial) 30. TITLE-ABS-KEY ("oral Health") 31. TITLE-ABS-KEY (orthodont*) 32. TITLE-ABS-KEY ("dental caries") 33. TITLE-ABS-KEY ("oral health care") 34. TITLE-ABS-KEY ("special health care need") 35. TITLE-ABS-KEY ("oral hygiene") 36. TITLE-ABS-KEY ("oral treatment") 37. TITLE-ABS-KEY ("dental care") 38. TITLE-ABS-KEY ("dental treatment") 39. TITLE-ABS-KEY ("dental health") 40. TITLE-ABS-KEY ("dental health care") 41. TITLE-ABS-KEY ("special care dentistry") 42. 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 43. TS=(child*) 44. TS=("young person") 45. TS=("young people") 46. 43or 44 or 45 47. 23 and 42 and 46 48. limit 47 to (English language and yr="2001 - 2017" and dentistry journals and reviews and articles)
Number of references found	862	528	1,027

Appendix 2: Details for all studies included within the review

Author / Publication year	Type of study	Country	Sample size	Participants ages	Type of impairment
Abanto et al, 2012	Cross sectional study	Brazil	60	6-14	Cerebral palsy
Abanto et al, 2014b	Cross sectional study	Brazil	60	6 - 14	Cerebral palsy
Abanto et al, 2014a	Cross sectional study	Brazil	60	6-14	Cerebral palsy
Acharya et al, 2010	Unknown	USA	86	8-15	Mixed
Al Habashneh et al, 2012	Comparative study	Jordan	206	12-16	Down syndrome
Al-Maweri & Zimmer, 2015	Cross sectional study	Yemen	401	6-14	Mixed
Al-Qahtani & Wyne, 2004	Unknown	Saudi Arabia	218	6-7 and 11-12	Mixed
Al-Sarheed et al, 2004	Unknown	Saudi Arabia	781	11-16	Mixed
Al-Sarheed et al, 2014	Prospective study	Saudi Arabia	781	11-16	Mixed
Al-Sufyani et al, 2014	Cross sectional study	Yemen	101	6 - 16	Down syndrome
Alaki & Bakry, 2012	Unknown	Saudi Arabia	86	Birth to 16	Intellectual disabilities
Alhammad & Wyne, 2010	Unknown	Saudi Arabia	140	3 - 12	Cerebral palsy
Alhammad, 2011	Unknown	Saudi Arabia	140	3 - 12	Cerebral palsy
AlSarheed et al, 2003	Unknown	Saudi Arabia	698	11-16	Mixed
AlSarheed, 2015	Cross sectional study	Saudi Arabia	192	7–15	Down syndrome
Altun et al, 2012	Cross sectional study	Turkey	194	7–15	ADHD
Aminabadi et al, 2016	Unknown	Iran	120	6- 9	ADHD
Andersson et al, 2016	Cross sectional study	Norway	32	8	Down syndrome
Andersson et al, 2014	Cross sectional study	Norway	29	8 - 9	Down syndrome
Asokan et al, 2008a	Cross sectional study	India	102	≤15	Down syndrome
Asokan et al, 2008b	Cross sectional study	India	102	≤15	Down syndrome
Atmetlla et al, 2006	Observational study	Costa-Rica	83	5-13	ADHD
Baens-Ferrer et al, 2005	Unknown	USA	107		Mixed
Bakry & Alaki, 2012	Unknown	Egypt	86	3-13	Intellectual disabilities
Bassoukou et al, 2008	Case controlled study	Brazil	50	3-14	Autism

Bekiroglu et al, 2012	Cross sectional study	Turkey	178	7-16	Visual impairment
Bhowate & Dubey, 2005	Unknown	India	69	10-14	Mental disabilities
Bimstein et al, 2008	Comparative study	USA	152	Mean age= 88.6 months	ADHD
Blomqvist et al, 2004	Retrospective study	Sweden	259	1-10	ADHD
Blomqvist et al, 2005	Observational study	Sweden	69	14	ADHD
Blomqvist et al, 2006	Case controlled study	Sweden	83	11	ADHD
Blomqvist et al, 2007a	Case controlled study	Sweden	100	13	ADHD
Blomqvist et al, 2007b	Case controlled study	Sweden	89	13	ADHD
Botti Rodrigues Dos Santos & Souza, 2009	Cross-sectional study	Brazil	200	1–15	Cerebral palsy
Bradley & McAlister, 2004	Unknown	Ireland	71	5-15	Down syndrome
Broadbent et al, 2004	Case controlled study	New Zealand	14	11-13	ADHD
Cagetti et al, 2015	Unknown	Italy	83	6-12	Autism
Carrillo et al, 2008	Prospective study	Brazil	51	3 - 10	Mixed
Chandra et al, 2009	Unknown	India	80	6-14	ADHD
Chhajed et al, 2016	Cross sectional study	India	152	5–15	Mental retardation
Chu & Lo, 2010	Unknown	Hong Kong	65	12 or older	Cerebral palsy
Cogulu et al, 2006a	Case controlled study	Turkey	143	7–12	Down syndrome
Cogulu et al, 2006b	Case controlled study	Turkey	124	7–12	Down syndrome
Davidovich et al, 2010	Comparative study	Israel	112	1-9	Down Syndrome
de Jongh et al, 2008	Unknown	Netherlands	61	4-12	Mental disability
De Oliveira Guare & Ciampioni, 2004	Case controlled study	Brazil	200	30-37 months	Cerebral palsy
Denloye et al, 2012	Unknown	Nigeria	61	1-13	Neurological disabilities
Desai et al, 2001	Unknown	Australia	300	9–13	Mixed
Dharmadhikari et al, 2016	Comparative study	India	75	4–14	Down syndrome
dos Santos et al, 2002	Comparative study	Brazil	129	6 - 16	Cerebral palsy
Du et al, 2014	Case controlled study	Hong Kong	142	30 - 77 months	Cerebral palsy
El Ashiry et al, 2016	Case controlled study	Saudi Arabia	162	6 -12	Cerebral palsy

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El Khatib et al, 2014	Cross sectional study	Egypt	200	3 - 13	Autism
Fakroon et al, 2015	Case controlled study	Libya	100	3 -14	Autism
Gardens et al, 2014	Cross sectional study	India	402	6 -12	Mixed
Grooms et al, 2005	Cross sectional study	USA	76	6.10 – 10.11	ADHD
Guare Rde & Ciamponi, 2003	Unknown	Brazil	Unknown	Unknown	Cerebral palsy
Guare Rde & Ciampioni, 2004	Case controlled study	Brazil	200	30-73 months	Cerebral palsy
Guare Rde et al, 2008	Comparative study	Brazil	20	5-12	Down syndrome
Guare et al, 2012	Comparative study	Brazil	46	3 - 13	Cerebral palsy
Hasan & Ciancio, 2004	Comparative study	USA	40	6 and 14	ADHD
Hashizume et al, 2017	Comparative study	Brazil	113	6 - 14	Down syndrome
Herguner et al, 2015	Unknown	Turkey	55	7 - 16	ADHD
Hidas et al, 2010	Comparative study	Israel	45	1.5–10	Mixed
Huebner et al, 2015	Cross sectional study	USA	90	23 - 60 months	Mixed
Jaber, 2011	Case controlled study	UAE	121	6-16	Autism
Katz-Sagi et al, 2010	Unknown	Israel	46	9-12	ADHD
Kumar et al, 2015	Cross sectional study	India	395	12-15	Mixed
Liu et al, 2009	Unknown	Taiwan	168	6 - 12	Mental retardation
Lopez-Perez et al, 2008	Case controlled study	Mexico	57	3 - 15	Down syndrome
Loyola-Rodriguez et al, 2009	Cross sectional study	Mexico	80	2-7	Mixed
Luppanapornlarp et al, 2010	Unknown	Thailand	80	8 - 12	Autism
Marques et al, 2015	Unknown	Brazil	120	9-15	Down syndrome
Mathias et al, 2011	Case controlled study	Brazil	138	1-7	Down syndrome
Mayoral-Trias et al, 2016	Cross sectional study	Spain	83	9-13	Down syndrome
Miamoto et al, 2011c	Cross sectional study	Brazil	120	7-16	Cerebral palsy
Miamoto et al, 2011b	Unknown	Brazil	180	3-10	Mixed
Miamoto et al, 2011a	Case controlled study	Brazil	120	10 or older	Cerebral palsy
Mitsea et al, 2001	Unknown	Greece	170	6-15	Mixed
Moreira et al, 2015	Cross sectional study	Brazil	131	6 to 12	Down syndrome
Morinushi et al, 2006	Comparative study	Japan	153	2 to 14	Down syndrome
Murthy et al, 2013	Cross sectional study	India	462	6–16	Mixed

Naidoo et al, 2005	Cross sectional study	South Africa	180	7-16	Foetal alcohol syndrome
Naka et al, 2009	Unknown	Japan	187	1-6	Mixed
Namal et al, 2007	Cross sectional study	Turkey	363	7 -12	Autism
Nandini, 2003	Unknown	India	150	Unknown	Visual impairment
Nelson et al, 2011	Cross sectional study	USA	1,128	1-17	Mixed
O'Leary et al, 2007	Unknown	Ireland	51	4-15	Mixed
Oliveira et al, 2011	Cross sectional study	Brazil	181	3–12	Mixed
Pani et al, 2013	Unknown	Saudi Arabia	118	8–13	Autism
Peres et al, 2007	Unknown	Brazil	121	4 -9	Cerebral palsy
Pilebro & Backman, 2005	Prospective study	Sweden	14	5 and 13	Autism
Prashanth et al, 2011	Unknown	India	85	8 - 13	Visual impairment
Purohit et al, 2010	Cross sectional study	India	575	5 -15	Mixed
Radha et al, 2016	Cross sectional study	India	100	9–15	Intellectual disabilities
Rai et al, 2012	Comparative study	India	161	6-12	Autism
Reddy & Sharma, 2011	Comparative study	India	228	6-15	Visually impairment
Rekha et al, 2012	Cross sectional study	India	483	4-16	Autism
Richa et al, 2014	Cross sectional study	India	270	4-15	Autism
Rodrigues Dos Santos et al, 2003	Comparative study	Brazil	129	6-16	Cerebral palsy
Sagheri et al, 2013	Unknown	Ireland	377	0-6	Mixed
Sandeep et al, 2014	Interventional study	India	372	6-16	Hearing impairment
Sandeep et al, 2016	Cross sectional study	India	180	6-16	Hearing impairment
Sarnat et al, 2016	Unknown	Israel	91	3-5	Autism
Shetty et al, 2010	Unknown	India	Unknown	6-12	Visual impairment
Siqueira et al, 2005	Unknown	Brazil	46	2–60 months	Down syndrome
Subramaniam et al, 2010	Comparative study	India	100	5-12	Cerebral palsy
Subramaniam & Gupta, 2011	Unknown	India	106	4-15	Autism
Tak et al, 2012	Cross sectional study	India	344	12-15	Poliomyelitis
Teixeira et al, 2015	Cross sectional study	Brazil	181	3 - 12	Mentally disabilities

Trias et al, 2016	Cross sectional study	Spain	41	9-13	Down syndrome
Versloot et al, 2008	Unknown	Canada	58	6 and 13	Learning disabilities
Weckwerth et al, 2016	Cross sectional study	Brazil	100	6- 14	Intellectual disability
Yesudian et al, 2012	Qualitative study	UK	18	8-11	Learning disabilities

Details for all studies included within the updated review

Author / Publication year	Type of study	Country	Sample size	Participants ages	Type of impairment
Alacam et al, 2020	Unknown	Turkey	84	3 - 16	Cerebral palsy
Alzahrani, 2019	Cross-sectional study	Saudi Arabia	92	12 - 16	Intellectual disabilities
Assery et al, 2020	Unknown	Saudi Arabia	60	7 - 12	Down syndrome
Bagattoni et al, 2020	Prospective study	Italy	241	3 - 13	Intellectual disability
Bakarčić et al, 2020	Unknown	Croatia	86	7 - 16	Cerebral palsy
Cakolli et al, 2019	Prospective study	Kosovo	60	7 - 15	Down syndrome
Cancio et al, 2019	Cross-sectional study	Brazil	70	2 - 14	Autism
da Silva et al, 2020	Cross-sectional study	Brazil	148	2 - 14	Cerebral palsy
Das et al, 2019	Randomized controlled trial	India	60	10 - 15	Visual impairment
Du et al, 2020	Interventional study	Hong Kong	122	2.5 - 7	Autism
Du et al, 2020	Case controlled study	Hong Kong	510	2 - 6	Autism
Dutra et al, 2019	Paired study	Brazil	136	3 - 14	Intellectual disability
Ehlers et al, 2019	Unknown	Germany	79	9 - 15	ADHD
Faker et al, 2019	Cross-sectional study	Brazil	128	1 - 9	Mixed
Farmani et al, 2020	Cross sectional study	Iran	96	7 - 15	Autism
Farsi et al, 2018	Prospective study	Saudi Arabia	213	6 years or younger	Mixed
Ferreira et al, 2020	Cross sectional study	Brazil	366	3 - 12	Mixed
Gautam et al, 2018	Prospective study	India	60	6 - 16	Visual impairment
Hage et al, 2020	Unknown	Brazil	120	4 - 12	Autism
Kuter & Guler, 2019	Unknown	Turkey	407	5 - 16	Autism

Mansoor et al, 2018	Case controlled study	Dubai	137	8 - 11	Autism
Morales-Chávez et al, 2019	Unknown	Venezuela	68	4 - 13	Autism
Moreira et al, 2019	Unknown	Brazil	17	6 - 12	Down syndrome
Naidoo & Singh, 2018	Cross sectional study	South Africa	149	7 - 14	Autism
Nasu et al, 2020	Unknown	Japan	30	0 - 16	Motor and intellectual disabilities
Putri et al, 2019	Experimental study	Indonesia	25	7 - 12	Down syndrome
Rajput et al, 2020	Cross sectional study	India	600	7 - 15	Mixed
Rizal et al, 2019	Experimental study	Indonesia	25	7 - 12	Down syndrome
Robertson et al, 2020	Prospective study	UK	16	4-12	Learning disabilities
Shyagali et al, 2019	Cross sectional study	India	324	12 - 16	Sensory disabilities
Silva et al, 2020	Randomized clinical trial	Brazil	29	6 - 14	Down syndrome
Sudhindra Baliga et al, 2020	Cross sectional study	India	68	6 - 13	Hearing impairments
Thomas et al, 2018	Qualitative study	UK	17	4 - 13	Autism
Vafaei et al, 2018	Cross sectional study	Iran	72	6 - 12	ADHD
Vandal et al, 2018	Unknown	India	86	5 - 12	Cerebral palsy
Yoshida et al, 2019	Non-randomized clinical trial	Brazil	38	6 - 14	Cerebral palsy
Zhou et al, 2019	Cross sectional study	Hong Kong	383	2 - 6	Mixed
Zhou et al, 2020	Randomized controlled trial	Hong Kong	306	2 - 6	Mixed
Zink et al, 2018	Unknown	Brazil	40	9 - 15	Autism

Appendix 3:Approval letter from the Center for Disabled Children

9-1-2018

Dear MS Maram Ali Alwadani

Initially we don't mind conducting your research at   as long as it's not including any therapeutic or invasive intervention. You'd only observe the children after taking the mothers and teachers approval for participation in the research.

          accepts primarily physical children with disability who are educable. Some children have mental disabilities (don't exceed moderate disability) beside the physical disabilities. I School doesn't have upper grades of general education section, there's only the first grade. Unlike the intellectual education section which include: early intervention, pre-school and lower grades (maximum 3rd grades). School classes don't exceed 10 classes. I don't know the number of teachers since they are in a different department.

If you want a bigger place for your research, you might consider since they have large number of students and different grades   School isn't under the Ministry of Education but it's a part of the rehabilitation programs and its main goal is integrating students in general education schools.

We do have dental clinic and dental hygienist.

Wish you all the best .

Appendix 4: Approval letter from the school

Appendix 5: Participant invitation letter

Dear …,

My name is Maram; I am a PhD student at the School of Clinical Dentistry in Sheffield, UK. I am looking to explore ways to include disabled children in oral health. Your views and experiences may help define those ways to include children in oral health care and practices. If you feel that you can help me and participate in a research study, I will ask you to consent to be interviewed by me.

In the interview, you will be asked to:

Talk about your views and experiences about oral health and oral health services for disabled children. This interview will take place at the centre/ school (this might take up to an hour and a half). I will tape the interview, and then the tape will be destroyed after I have transcribed what has been said. After the interview, I will discuss what I have understood to understand all you have told me correctly. I will also give you a false name, this is so nobody will know who you are, and I will remove all details that may identify you.

It is up to you to decide whether or not to take part. If you decide not to, I will entirely respect your decision and, of course, it will not cause any negative consequences. There is no direct benefit to the participants; this research is an exploration. If you would like the research results in an accessible read format, please let me know, and I will arrange to send them to you. An information sheet, which provides further details of the study, is attached. Please read this carefully as it will help you decide whether you wish to participate. If you decide to take part, I will contact you to arrange a date for the interview.

Ethical approval for this research has been obtained from the University of Sheffield. Permission has also been granted by [..]; Deans of the research settings, Riyadh, KSA. If you have any questions or problems concerning the research, please contact me; Maram, by phone or email.

Best regards,
Maram Alwadi

Appendix 6: Participant information sheet

Research project title: The Inclusion of Disabled Children in Oral Health

You are being invited to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
The purpose of this research is to explore ways to include disabled children in oral health. Your opinions and experiences may help define those ways to include children in oral health care and practices. Information from my study may help identify any areas for improving the oral health outcome of disabled children.

Do I have to take part?
It is completely up to you to decide whether or not to take part in this research. If you choose to participate, you will be asked to sign a consent form. You can still withdraw at any time, without giving a reason.

What will happen to me if I participate in this study?
If you decide to participate in this study, the project will be explained and discussed further to you, and you will have the opportunity to ask questions before you decide to consent to participate. I will conduct an interview with you about the research focus. The interview will be in a spare room at the centre/school. They may take up to an hour and a half. When I talk to you, I will record your answers with a small audio recording machine. The interview's audio records will be transcribed into written text, and this data will be analysed. The tape will be destroyed immediately after transcription. After analysis, the data will be written up for publication, but the data will be anonymised, and no-one will know who you are.

What are the possible risks of taking part?
There are no known risks in participating in this study. If you feel uncomfortable discussing any specific topic during the interview, then you are under no obligation to continue with the topic.

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What are the possible benefits of taking part?
There are no immediate benefits for those who are taking part. However, the interview may help determine if more care and support are needed for disabled children to be included in oral health, which may help their oral health outcome.

Will my participation in this research be kept confidential?
All information that you provide will remain anonymous. All data will be kept and used only by the research team. In the transcript, the participant's names and those you mention will be changed so you will not be identifiable, and any other identifiable data will be removed. All transcribed data will be kept on a password-protected computer. Tapes will be destroyed immediately after transcription in agreement with participants.

What will happen to the results of the research study?
The results of this study will be published as a part of my PhD thesis. The results of this research also may be reported in journal papers and conferences.

Who is organising and funding the research?
The study is organised under the supervision of the School of Dentistry academic members of the University of Sheffield at UK. The Saudi Cultural Bureau and King Saud University at Saudi Arabia are funding the study

Who has reviewed the study?
The study's protocol has been reviewed and approved by the University of Sheffield Research Ethics Committee. Permission has been granted by [..]; Deans of the research settings.

Who can I contact for further information?
In case you wish to obtain more information or have questions about the study, please contact me (Maram Alwadi) directly at the email address or phone number […]. Alternatively, you can contact Dr Janine Owens (Email/ phone number); and Professor Sarah Baker; (Email/ phone number) Academic Unit of Oral Health, Dentistry and Society, School of Clinical Dentistry, University of Sheffield, Sheffield, S10 2TA

Thank you for taking time to read this information sheet.

Research project title: The Inclusion of Disabled Children in Oral Health

I, the undersigned, confirm that (please tick box as appropriate):

1.	I have read and understood the description of the research project, as provided in the information sheet dated _____.	☐
2.	I have the opportunity to ask questions about the project and have had these answered satisfactorily.	☐
3.	I understand that my participation is voluntary and that I am free to withdraw at any time, without any negative consequences.	☐
4.	I understand that my responses will be kept strictly confidential, that my name or identity will not be linked to any research materials, and that I will not be identified or identifiable in any reports that result from the research.	☐
5.	I give permission to research team members to access anonymous responses.	☐
6.	I agree to take part in this study	☐

_____ _____ _____
Participant Name   Signature   Date

_____ _____ _____
Researcher Name   Signature   Date

Appendix 8: Children information sheet

The University Of Sheffield.

School Of Clinical Dentistry.

Information sheet for young people

This information sheet has been written so that parents, guardians, or supporters can show/read it to the child to talk to them about the research project

Hello, My name is Maram Alwadi, and I am a dental hygienist who helps disabled children.

I want to know what children think and feel about their mouths and going to the dental clinic.

I would like you to tell me what you think about going to the dentist

I would also like to know what you think about your teeth

You do not have to tell me anything if you do not want to. If you want to take part in the study, I will come to your school to talk to you.

I may ask you to take photos.

I may ask you to make up a story.

I may ask you to draw a picture.

I may ask you to talk in a group.

You can choose what you want to do.

If you want to stop or change your mind, then that is fine. I do not want to make you feel unhappy.

Appendix 9: Children assent form

Have you read the information sheet, or had it explained to you?

- o **YES**
- o **NO**

Do you have any questions about the study?

- o **YES**
- o **NO**

Do you understand that you can choose to participate in the study?

- o **YES**
- o **NO**

Do you understand that I will be using a tape recorder as part of the study?

- o **YES**
- o **NO**

Do you understand that you can stop at any time?
(You do not have to say why you want to stop).

- o **YES**
- o **NO**

Are you happy to take part in the study?

- o **YES**
- o **NO**

NAME……………………………………………

Appendix 10 : Observer consent support form

NAME:

_____

Relationship to participant

_____

Any comments on the communication observed:

I observed the project being explained

to_____

and feel that they would be happy to take part in the project.

Signature _____**Date** _____

Appendix 11: Parent/Guardian information sheet

Research project title: The Inclusion of Disabled Children in Oral Health

Your child being invited to take part in a research study. Before you decide if you would like your child to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you are happy for your child to take part. The information sheet will tell you the purpose of this study and what will happen if your child takes part.

What is the purpose of the study?
The purpose of this research is to explore ways to include disabled children in oral health. It aims to explore children's perspectives and experiences in the field of oral health to represent their voices and include them in oral health and research. The lack of inclusion of the views and perspectives of disabled children has an impact on service provision and policy because without them we are unable to identify areas for improvements in oral health services and oral health promotion initiatives.

Does my child have to take part?
It is completely up to you and your child to decide whether or not you wish your child to join the study. If you agree to participate, we will then ask you to sign a consent form. You are free to withdraw your child at any time during the research without giving a reason

What will happen to my child if we agree to participate in this study?
I would like to observe the children while they are in school. Your child will also be invited to talk with me where we will chat about their teeth.

Is there anything to be worried about if my child takes part?
There are no known risks to your child taking part in the study.

What are the possible benefits of taking part?
There are no immediate benefits for those who are taking part. However, the interview may help determine if more care and support are needed for disabled children to be included in oral health, which may help their oral health outcome.

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Will my child's taking part in this study be kept confidential?

All information that your child provides through their participation in this study will be kept private. All information will remain anonymous. All data will be kept and used only by the research team. In the transcript, the participant's names and those the children mention will be changed so the child will not be identifiable, and any other identifiable data will be removed. All transcribed data will be kept on a password-protected computer. Tapes will be destroyed immediately after transcription in agreement with participants.

What will happen to the results of the research study?

The results of this study will be published as a part of my PhD thesis. The results of this research also may be reported in journal papers and conferences.

Who is organising and funding the research?

The study is organised under the supervision of the School of Dentistry academic members of the University of Sheffield at UK. The Saudi Cultural Bureau and King Saud University at Saudi Arabia are funding the study

Who has reviewed the study?

The study's protocol has been reviewed and approved by the University of Sheffield Research Ethics Committee. Permission has been granted by [..]; Deans of the research settings.

What do I do next?

Please read the children's information sheet with or to your child and help them to complete the assent form. If you and your child are both happy to take part in the research, we would like to ask you to sign the consent form and return both the consent and assent forms to the school.

Who can I contact for further information?

In case you wish to obtain more information or have questions about the study, please contact me (Maram Alwadi) directly at the email address or phone number […]. Alternatively, you can contact Dr Janine Owens; (Email/ phone number) and Professor Sarah Baker; (Email/ phone number) Academic Unit of Oral Health, Dentistry and Society, School of Clinical Dentistry, University of Sheffield, Sheffield, S10 2TA

Thank you for taking time to read this information sheet.

Appendix 12: Parent/Guardian consent form

Research project title: The Inclusion of Disabled Children in Oral Health

I, the undersigned, confirm that (please tick box as appropriate):

1.	I have read and understood the description of the research project, as provided in the information sheet dated _____.	☐
2.	I have the opportunity to ask questions about the project and have had these answered satisfactorily.	☐
3.	I understand that my child participation is voluntary and that my child is free to withdraw at any time, without any negative consequences.	☐
4.	I understand that my child responses will be kept strictly confidential, that my child's name or identity will not be linked to any research materials, and that my child will not be identified or identifiable in any reports that result from the research.	☐
5.	I give permission to research team members to access anonymous responses.	☐
6.	I agree for my child to take part in this study	☐

_____ _____ _____

Name of parent/ guardian　　　Signature　　　　　Date

_____ _____ _____

Researcher Name　　　　　　Signature　　　　　Date

Appendix 13: Observation form/ school

School …………………………………   Date of observation ………………………………………….

Length of observation ……………………..   Number of children at time of visit: ……………………..

Areas of observations	Examples of issues for consideration (Check all that apply during observation)	Examples/ Further note for clarification
Healthy school environment	o Healthy foods available in the school canteen o A ban on sugary drinks and foods on the school premises o A ban on smoking on the school premises o Safe water and good sanitation facilities o Fluoridation (e.g., of Milk) o Safe and well-designed school building and playgrounds to prevent injuries o A caring and respectful psychosocial environment o A protocol for dealing with interpersonal conflicts and violent behaviors o Promotion of brushing at a school time	
Oral health education	o Oral health education is a part of all subjects in the school curriculum o Training for parents about good oral health and encouragement for them to take part in oral health activities at school o Training for school staff o Types of oral health activities in the school	

Mental health and well being	o Mental health and wellness issues is adequately addressed in the school o Counseling services and support available in the school o Oral health issues considered in promoting well-being and health	
Oral health services	o Dealing with dental emergencies o Working closely with central or local oral health service providers o Role of teachers in oral health screening, surveillance and basic treatment o Training for school staff o Types of oral health services and support provided	
Communication methods used in the classroom	o Flash cards o Stories o Photographs o Sign language o Assistive technology	

Appendix 14: Observation form/ the Centre for Disabled Children (Clinics)

Date of observation ……………………………….   Number of children at time of visit: …………………

Length of observation ………………………………

Areas of observations	Examples of issues for consideration (Check all that apply during observation)	Examples/ Further note for clarification
Physical environment	o Wheelchair access available o Caring, understanding environment for individual with learning disabilities o Clinic designed for individuals with different types of disabilities	
Oral health services	o Oral health care is a part of the treatment o Dealing with dental emergencies o Working closely with oral health service provider	
Referral system to dental clinic	o Health care provider and carers of patients aware about the referral system o Health care provider is the one who responsible for deciding the need of the patient for dental treatment o There is a direct referral to dental clinic o Referral system indirect and complex	

Appendix 15: Interview guides

Interview guide: (Mothers)

The interviewer used this interview guide during the interview in this project to explore the ways mothers support and include their disabled children with their oral health.

General information about her child
- Child's age
- Type of disability
- Meaning of disability and oral health

SES, education level
- Structure of the household
- Parent in paid employment
- Level of education of the parent

Family structure, number of children
- Number of children in family living arrangements; extended or nuclear
- Managing a child's oral health; support or barriers

Source of oral health knowledge
- Where do you get your children's oral health information, was it easy to obtain and understand?
- What do you know about sugar and how it affects teeth?
- Do you feel your child has (or has had) an oral health problem?
- If yes, then explore how they knew

Oral health behaviours and practices
- Who is responsible for the oral health daily practices (brushing, flossing)?
- Is there anyone who helps you to take care of your child/ren's oral practices?
- (If a maid or sibling) Who has taught them about oral health?
- What does your child/ren use for mouth cleaning?
- Does your child brush independently?
- How often?
- Approximately how old was your child when he/she started cleaning their teeth?
- How often does your child eat sweets?
- What helps you to control your child's sweet intake at home?
- What helps you to control sugar in their diet?
- What are the difficulties in caring for your child or children's oral health?

Religion, beliefs

- In what ways do you think Islam is involved in oral health care?
- What beliefs do you hold about oral health?
- In what ways do you feel SA compares with other countries about the oral health of disabled children?

Importance of dental services or dental visit, access

- Have your child/ren visited a dental professional?
- How often?
- At what age did your child/ren begin to visit the dentist?
- Why did you have to see your dentist on that visit? (Checkup, Emergency, Treatment)
- What happened when they visited, whether they had to wait, felt they were treated kindly, and how the treatment was explained?
- What are your thoughts about oral health care provided for your child?
- Did your child/ren disability cause problems during treatment?
- Could you briefly describe how your child/ren disability affected the treatment?
- Are you pleased with the services offered by the other staff of this place?
- If not, what is it that you are not pleased with?

Now I would like to know a few things about how you travelled to reach this place

- How did you travel here today?
- Are you satisfied with your travel to dental service? If no, what is it that caused you to be dissatisfied?
- What support did your disabled child receive to access oral healthcare?
- What might additional support be needed?
- Are you pleased with the accessibility/getting into and around the dental unit?
- What were you unhappy about?

Lastly, I would be grateful to know what changes that you feel would improve the quality of dental services provided for your children?

Interview guides: (Teaching staff)

The interviewer used this interview guide during the interview in this project to explore the ways professionals support and include mothers and disabled children with oral health

General information about teachers
- What is your major degree?
- Which age group do you teach?
- What type of disabilities do children have that you usually teach?
- What does disability and oral health mean to you?
- What do you see as the future of oral health care for disabled children?

Religion, beliefs
- In what ways do you feel Islam is involved in oral health care?
- What beliefs do you hold about oral health?
- In what ways do you feel SA compares with other countries about the oral health of disabled children?

Source of oral health knowledge
- How do you rate your knowledge about oral health for disabled children? (No knowledge, Incomplete knowledge. Limited knowledge)
- What do you measure your knowledge against to reach this conclusion?
- Where do you get the oral health information? (Friends, school, social media etc.)

Oral health behaviours and practices
- Have you ever advised the parents of a disabled child to brush their child's teeth?
- In your opinion, how many times should children with disability practice good oral health per day?
- In your opinion, what tools should be used to clean the teeth of disabled children?
- In your opinion, if the child is unable to practice oral health, what support should be offered?

Oral health and school environment
- What communication methods do you use with disabled children? What are the barriers to communication?
- What examples are there of oral health being integrated into the school curriculum?
- Can you tell me what you feel the reasons are to monitor the snacks of disabled children?

Importance of dental services or dental visit

- At what age do you believe that disabled children should have their first dental visit?
- What reasons have you had to look in the mouth of a disabled child?
- Have you ever referred a child with a disability to a dental clinic?
- If yes, what were the reasons and the process?
- What do you think what the barriers that prevent disabled children from visiting health care services are? (Prohibitive costs, Limited availability of services, Physical barriers, Inadequate skills and knowledge of health workers)

Lastly, I would be grateful to know what changes you feel would improve the school environment to promote oral health for disabled children?

Interview guides: (Healthcare providers)

This topic guide used by the interviewer during the interview in this project in order to explore the ways professionals support and include mothers and disabled children with oral health

General information about the health care providers

- What is your major degree?
- What is your job?
- What type of children disabilities do you usually treat?
- What do disability and oral health mean to you?
- What do you see as the future of oral health care for disabled children?

Religion, beliefs

- In what ways do you feel Islam is involved in oral health care?
- What beliefs do you hold about oral health?
- In what ways do you feel SA compares with other countries about the oral health of disabled children?

Source of oral health knowledge

- How do you rate your knowledge about dental medicine for disabled children? (No knowledge, Incomplete knowledge. Limited knowledge)
- What do you measure your knowledge against to reach this conclusion?
- Where do you get the oral health information? (Friends, social media ..etc.)

Oral health behaviours and practices

- Have you ever advised the parents of a disabled child to brush their child's teeth?
- In your opinion, how many times should children with disabilities practice oral health per day?
- In your opinion, what tools should be used to clean the teeth of disabled children?
- In your opinion, if the child is unable to practice oral health, what support should be offered?

Importance of dental services or dental visit

- At what age do you believe that disabled children should have their first dental visit?
- Have you ever treated patients with a disability?
- What do you feel are the difficulties in working with disabled children? (Negative attitude and behaviour, aggressive behaviour against the health care providers)
- Have you ever examined the teeth of a disabled child?
- Have you ever referred a child with a disability to a dental clinic?
- If yes, why and what was the process?
- What do you think the barriers that prevent disabled children from visiting health care services? (Prohibitive costs, Limited availability of services, Physical barriers, Inadequate skills and knowledge of health workers)

Lastly, I would be grateful to know what changes you feel would improve the quality of services provided for disabled children?

Appendix 16: Aspects considered in the interviews (Children)

Data on the following different aspects were collected:

- Age of children
- What does disability mean to children?
- What does oral health mean to them?
- What do they know about teeth?
- What is their favourite food?
- What do they feel is good or bad for their teeth?
- What do they use to clean their teeth?
- What is important about having a clean mouth?
- Does anyone help them in cleaning their teeth?
- What do they know about the dentist and the dental clinic?
- Why do children go to the dentist?
- Why do grown-ups go to the dentist?
- What do they think helps them when they go to the dentist?
- Is there anything you want to tell me about going to the dentist?
- Is there anything you want to tell me about your teeth?

Appendix 17: Drawings of participating children
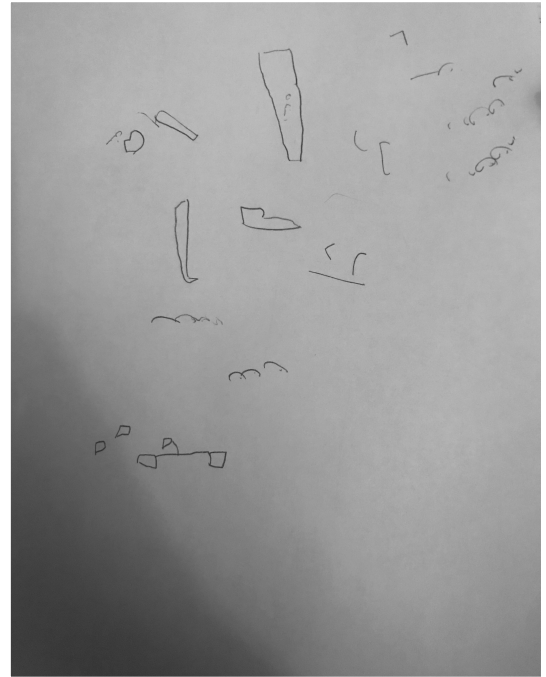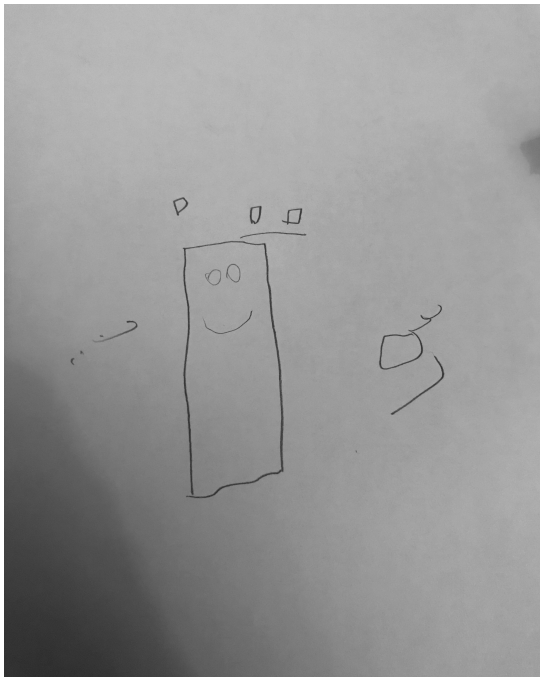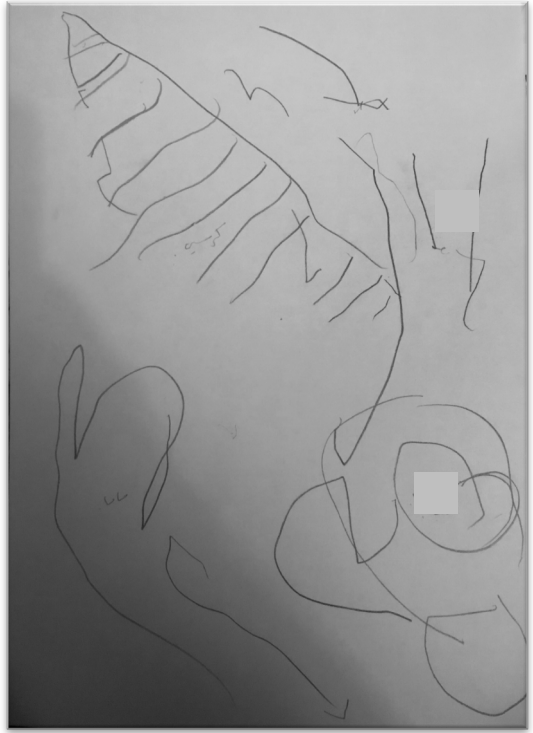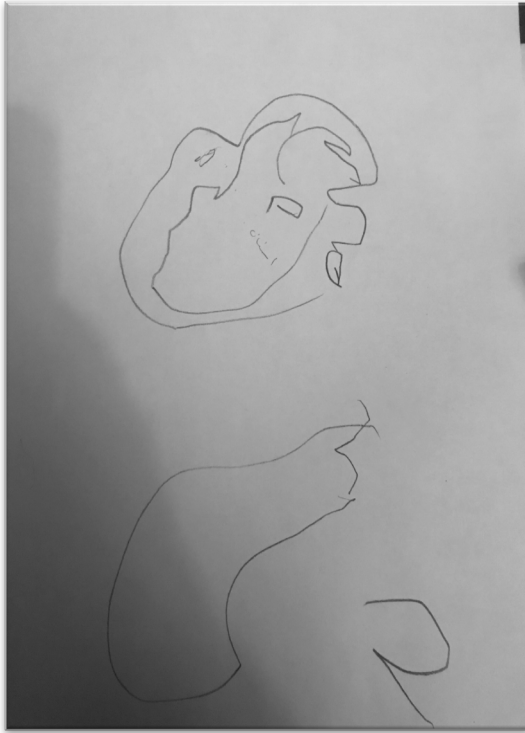
Appendix 18: Ethical approval letter

Maram Ali M Alwadi
Registration number: 160263499
School of Clinical Dentistry
Programme: Oral Health Dentistry and society

Dear Maram Ali M

PROJECT TITLE: The Inclusion of Disabled Children in Oral Health Research
APPLICATION: Reference Number 018466

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 23/03/2018 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 018466 (dated 08/03/2018).
- Participant information sheet 1041413 version 1 (08/03/2018).
- Participant consent form 1041414 version 1 (08/03/2018).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Yours sincerely

Janine Owens
Ethics Administrator
School of Clinical Dentistry