Bangor University

PROFESSIONAL DOCTORATES

VIEWS AND EXPERIENCES OF CHILDREN LIVING WITH DISABILITIES AND COMPLEX HEALTH NEEDS, AND THOSE OF THEIR FAMILIES

Davies, Jean

Award date:
2023

Awarding institution:
Bangor University

[Link to publication](#)

PROFESSIONAL DOCTORATES

VIEWS AND EXPERIENCES OF CHILDREN LIVING WITH DISABILITIES AND COMPLEX HEALTH NEEDS, AND THOSE OF THEIR FAMILIES

Davies, Jean

Award date:
2023

Awarding institution:
Bangor University

Link to publication

VIEWS AND EXPERIENCES OF CHILDREN LIVING WITH DISABILITIES AND COMPLEX HEALTH NEEDS, AND THOSE OF THEIR FAMILIES

School of Medical and Health Sciences

Professional Doctorate DHealthcare (DHLTH) Implementation

Jean Angela Davies

Banner Number 500567854

January 2023

DECLARATION

'Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.'

Rwy'n cadarnhau fy mod yn cyflwyno'r gwaith gyda chytundeb fy Ngoruchwyliwr (Goruchwylwyr)'

'I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.'

I confirm that I am submitting the work with the agreement of my supervisors.

ACKNOWLEDGEMENTS

ABSTRACT

Background

This study explores the research question, 'What are the views and experiences of children with complex health needs and those of their families on the provision of healthcare?'

This thesis presents the views of children living in the southwest region of Scotland who are diagnosed and living with disabilities and complex health needs, including speech, language and communication needs (SLCN) and whose voices, and those of their families, are seldom heard in relation to their healthcare experiences. The four countries of the United Kingdom (UK) advocate for the implementation of children's rights through the 54 articles of the United Nations Convention on the Rights of the Child (UNCRC,1995). These rights seek to protect and improve the lives of all children, including those growing up in Scotland, and are enshrined in legislation demonstrated within the Children Act (1989), and the Children and Young People (Scotland) Act 2014. This study will focus on Article 2 which is the right to non-discrimination and Article 12 which is the child's right to participate, to be listened to and to be taken seriously. In addition, the study will examine the importance of Article 19 which states that children must be protected from harm, and Article 24 which advocates for the provision of safe, effective and appropriate healthcare for children (UNCRC, 2009).

The Department for Work & Pensions reported that in 2021 there were approximately 1,100,000 UK children from birth to eighteen years of age who are living with a substantial and long-term physical or mental health impairment. Gilljam et al. (2016) indicate that the participation and influence of children and young people is crucial to the quality of health services. Serious consequences of patient mortality, morbidity and sub-optimal healthcare can occur due to failings in leadership, professionalism and

management (Nursing and Midwifery Council [NMC], 2018), and the duty of care to protect patients provides a strong motivation to conduct this research. Compassionate and intelligent leadership within healthcare can transform patient care and leaders can exert influence over care standards and the experiences of children and their families (NHS, 2020). There is limited evidence to date which takes account of children and families' experiences of the healthcare services provided for children living with disabilities, complex health needs and SLCN. Therefore, the opportunity to investigate children's and families' experiences through the lens of policy and legislation in Scotland by the researcher, who has an extensive clinical nursing and management background within children's services, will provide a timely and warranted research contribution.

Literature review

The aim of the literature review was to identify the body of current knowledge available on the topic of healthcare, education and social care provision for children living with complex health needs, disabilities and SLCN and to establish whether care provision was linked to children's rights and safeguards. The literature review was conducted employing a systematic approach and the selected articles were reviewed. The results of the review informed the choice of the most suitable research methodology and methods to employ within this study, and to address the proposed research question.

Methodology and methods

This mixed methods qualitative study was conducted using a phenomenological approach to enable a deep, rich picture to be gained of the lived experiences of the children and their families. The qualitative approach and the three data collection methods employed were informed by the results of the literature review. The three data generation techniques were semi-structured interviews, influenced by Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009), case study which was gained from the supplementary, personal information provided by two of the

participants, Lily aged 15 years and Amber aged 8 years, and the Talking Mats® (TM) method developed by Murphy (1998a).

The original TM method provides three choice options to respond to a question, these are a positive, negative or neutral response. To potentially reduce the cognitive overload and stress for the child participants who would need to use the TM method and to best suit the needs of the children, the TM method was purposefully and suitably adapted by the removal of the ambivalent neutral response option. This enabled the children to provide a dichotomous positive or negative choice only to each question posed within the study. The World Health Organisation (WHO, 2001) Effectiveness Framework of Functional Communication (EFFC) was employed as an adjunct to TM to assess the children's understanding of the TM communication method and their ability to participate in its use. The adapted Talking Mats® provided a novel approach regarding listening to children and enabled two children who were living with SLCN, to successfully demonstrate their positive and negative daily experiences through the rich picture of Talking Mats®.

Analysis

The rich, deep data of the children's and families' lived experiences generated from the collection methods of semi-structured interviews and case study was analysed using the six steps analysis framework of Interpretative Phenomenological Analysis (IPA) developed by Smith et al. (2009). The data from the adapted Talking Mats® was analysed using the Effectiveness Framework of Functional Communication (WHO, 2001). The analyses identified several themes which related to the participants' quality of life and to the strengths and difficulties they had experienced when receiving healthcare services.

Results

Literature review

The literature review found that researchers seldom approach children living with disabilities, complex health needs and SLCN to take part in research due to the belief of researchers that this cohort of children are unable to participate. As a result of this study, it is believed that research can successfully be undertaken with a wider range of this study population providing that the issues raised regarding discrimination, cultural, and conscious or unconscious bias are addressed. In addition, researchers have recognised the difficulty of gaining access to the participants due to the reluctance of gatekeepers (clinicians granting access to participants) to approach this cohort of children as possible participants.

Semi-structured interviews

Five themes were identified from the analysis of the semi-structured interviews which were Theme1. Choices and control., Theme 2. Relationships., Theme 3. Living with my condition., Theme 4. Living with my child's condition and Theme 5. Bringing it all together. The themes were addressed as both challenges and opportunities in relation to the children's and families' resilience and adaption to their daily living situations.

Case study

The written material provided by Lily and narrated during her semi-structured interview demonstrated the emotionally overwhelming, deep and far-reaching impact that living with an unpredictable health condition had caused her. Similarly, Amber displayed an emotional enactment of feelings about her healthcare experience through her physical handling of a tangible object, a necklace of beads. Amber described the necklace as 'beads of courage' and the analysis of her semi-structured interview revealed that the beads connected her to both positive and negative lived experiences. Amber's feelings were those of confusion and trauma, mixed with the pleasure of

receiving a reward, a bead, each time that she had attended hospital for a blood test and other procedures. There were fourteen beads in total in her necklace of courage, and these were counted out one by one by Amber in a slow and deliberate tone of voice during her interview.

Talking Mats®

Three of the themes generated from the TM analyses provided an insight into the perspectives of the children, Jack aged eight years and John aged nine years. The themes were, Theme 1. Mobility and transport., Theme 2. Activities of daily living., and Theme 3. Choices and preferences.

The discussion presented within this study from the semi-structured interviews, case study reviews and the Talking Mats® results highlight the importance of conducting research with this group of children. The results found that the participants' lived experiences and their quality of life consisted of disadvantages and sub-optimal experiences within health, social care, and education services. The children and their parents gave examples of being stigmatised and negatively perceived by the individuals and teams involved with their child. The parents believed and were concerned that these factors presented an increased risk to the children of experiencing physical and emotional harm. The impact of harm caused in childhood is termed adverse childhood experiences (ACEs) and care must be taken to prevent the immediate and long-term emotional damage caused by ACEs (Bellis et al., 2015). This study found that there was a lack of support for the children's daily needs and that there was either a lack of funding, or unsustainable funding, for the services required for the children's changing and often unpredictable health needs. The strengths, coping skills and positive achievements of the children and their families were not routinely appreciated, developed, or encouraged by the teams involved with the children and their families.

The results of this study conclude that children living with disabilities, complex health needs and SLCN are impacted predominantly negatively during receiving healthcare service provision. In addition, this group of

children and their families are underrepresented in research and more research with this study population is required.

Discussion

The discussion from this study highlights that a disconnect exists between the participants' lived experiences and the tenets within the legislation detailed in the Children and Young People (Scotland) Act 2014.

Exploration of the views of children with disabilities, complex health needs and SLCN, and their families, was achievable by using the most appropriate methodologies and methods. An important factor of this study was the recognition of Scottish legislation in relation to disabled children and of the rights of children to participate, and to be included in research. The children and families discussed the lack of information, education, support and services, along with the positive and negative relationships they had developed with all those involved with their service provision. The children and families were proud of the coping skills and resilience they had developed to manage their living with unpredictable illness, disabilities and SLCN, and of how they were perceived by health professionals as 'experts by experience'. This positive aspect of life was counter-balanced by the undue pressure that families felt was placed on them to inform and educate the teams around the child. This included teaching about complex clinical techniques, feeding regimens and the medicines management essential for the child's daily routine and regarding emergency care. Parents stated that this onus of responsibility reduced the opportunity to just enjoy being 'Mum or Dad'.

Recommendations for further research

This thesis may provide researchers with novel methods to help engage children and families in future research studies on this topic. Researchers may consider undertaking the relevant Talking Mats® training to enable similar studies to be undertaken in Wales with children of all abilities and with those who are living with complex health needs, disabilities and SLCN.

Conclusion

This study provided an opportunity for the children and their families to tell their life stories and to paint a rich picture of their experiences through the application of a qualitative, phenomenological approach. The literature review informed the suitability of the methods employed in this study in relation to the research question. The semi-structured interviews, case study and adapted Talking Mats® enabled three data generation techniques to be used. The collected data was analysed using the six steps analysis framework of Interpretative Phenomenological Analysis (IPA) developed by Smith et al. (2009) and the Effectiveness Framework of Functional Communication (WHO, 2001). The analysis produced results which identified themes relating to the participants' lived experiences of service provision, the impact of this on meeting their daily needs and the subsequent effect on their quality of life.

Children who were living with SLCN and who previously had not had an opportunity to take part in research, were enabled to demonstrate their lived experiences through the visual symbols of Talking Mats®. This approach provided a novel phenomenological understanding of the children's perspectives alongside those of their parents. Insight was provided from the completed mats into the areas of agreement and dispute between the children and their parents. It was evident that the participants in this study developed the ability to adapt to the challenges of their health conditions which revealed personal and familial resilience in the face of their adversity.

The potential is evident to enable solutions to be sought for improving children's participation and inclusion in research, and this would promote upholding and implementing children's rights as recommended within the articles of the United Nations Convention on the Rights of the Child (UNCRC, 2009). The study findings inform health, social care and education providers what matters to children living with disabilities, complex health needs and SLCN when they receive services, and provides a basis for the consideration of future research. In addition, the findings inform policy recommendations to

promote children's rights and safeguards through compassionate and intelligent leadership within healthcare. The study outlines the potential to transform and improve patient care by gaining and implementing patient feedback, and by ensuring that the information is made available to service planners and healthcare providers.

CONTENTS

INDEX OF TABLES

INDEX OF FIGURES

ABBREVIATIONS

AAC	Augmentative and Assisted Communication
ACEs	Adverse Childhood Experiences
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autistic Spectrum Disorders
BSL	British Sign Language
Child **Children**	Child or children means everyone below the age of 18 years
EI	Emotional Intelligence
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
GDPR	General Data Protection Regulations
IPA	Interpretative Phenomenological Analysis
LI	Language impairment
LR	Literature review
NAS	Neonatal Abstinence Syndrome
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research.
N-SLI	Non-Specific Language Impairment
SaLT	Speech and Language Therapists
SEN	Special Educational Needs
SLCI	Speech, Language and Communication Impairments
SLCN	Speech, Language and Communication Needs

SR	Systematic Review
UNCRC	United Nations Convention on the Rights of the Child
UK	United Kingdom
VIPER	Voice. Inclusion. Participation. Empowerment. Research
Young person	Young person aged between 14 and 18 years old
Young people	Young people, those aged between 14 and 18 years old

CHAPTER 1:
THESIS OVERVIEW AND STRUCTURE

This chapter will provide an overview of the PhD thesis titled 'What are the views and experiences of children living with disabilities and complex health needs, and those of their families?'

1.1 Thesis overview and structure

The structure of this thesis follows the steps of a logical progression to complete the research process. Chapter 1 introduces this qualitative study and provides the background and rationale for the study which was conducted with a specific cohort of children and their families. The child participants have a diagnosis of and are living with disabilities, which include speech, language and communication needs (SLCN), and complex health needs. The motivation for the research will be provided along with the details of the study's aim and objectives.

Chapter 2 presents the literature review (LR) that was conducted using a systematic approach. The review of the current literature available which explores children's and families' views of their healthcare experiences, enabled a decision to be made about the most suitable methodologies and methods to apply to this study. The LR both informed and confirmed the relevance of the research question being posed for this study to current children's nursing knowledge and practice.

The value of literature reviews in research is discussed and an explanation is provided of how this LR, using a systematic approach was conducted to identify the relevant studies in relation to the proposed study. Cochrane principles were followed during the literature search, and 145,652 results were returned (Moher et al., 2009). This number of studies was practically unmanageable to realistically and effectively process, and a quality accredited system was required to reduce these results. The reduction

process and the final ten studies selected for review are presented within the PRISMA diagram (Figure 1). The final ten included papers are each examined for suitability and quality by using the Critical Appraisal Skills Checklists (CASP) from the Critical Appraisal Skills Programme (Long et al., 2020). The CASP tool for qualitative studies is used to summarise the overall quality of the chosen studies by assessing several factors which relate to the suitability of methodology and method. The appropriateness of the study sample, the ethical considerations and the limitations of the study are also considered.

The results of the LR identified the value of the Talking Mats® (TM) communication method (Murphy, 1998a). TM successfully uses 'Matty', a cartoon character, and similar friends as visual picture symbols. Talking Mats® is used within research studies with people of all ages who are living with SLCN and disabilities. Chapter 2 will provide the justification for choosing an LR and discusses the themes arising from the chosen studies. The LR results help to address the issue of employing the most suitable data collection method for gaining the views of two of the participants, Jack, aged eight years and John, aged nine years who are living with SLCN. Chapter 2 concludes with the provision of the research question that is proposed for this study.

Chapter 3 details the research design, methodologies and methods and an account is presented of the decision-making process used to select the qualitative methodology of phenomenology for this study. The rationale is presented in relation to the suitability of the qualitative methods of semi-structured interviews, case study and Talking Mats® (Murphy, 1998a) employed within this study. Murphy (1998a) outlined the Effectiveness Framework of Functional Communication (WHO, 2001) as a relevant analytical approach to use with Talking Mats® and from which to develop themes from participants' data gained during a Talking Mats® interaction. The Effectiveness Framework of Functional Communication (EFFC) is presented in Section 3.8 to 3.8.3. The study methods provide three suitable data collection techniques for the process of data generation regarding the

lived experiences of children living with speech, language and communication needs (SLCN).

A discussion is included which describes the decision regarding the selection of the population sample using the PICO (P, Patient or problem. I, Intervention or Exposure. C, Comparator. O, Outcome) framework as advocated by Glasper and Rees (2012). The process undertaken to recruit the participants is discussed in Chapter 3 and the justification is given for the inclusion and exclusion criteria used for the participant selection. Thirteen participants, eight adults and five children between the ages of eight and fifteen years, were interviewed by the author of this thesis utilising a phenomenological approach and the semi-structured method. In addition, case studies are presented from two of the children who also provided semi-structured interviews. The two girls are Lily aged 15 years who was living with Cystic Fibrosis, repeated infections and panic attacks, and Amber aged 8 years who was living with heart disease, epilepsy and the impact of a cerebral-vascular event (a stroke). Lily and Amber offered supplementary (additional) personal information through a discussion about the personal objects which were of significance to them.

Participants' use of objects, drawings, photographs and written accounts or poems composed by the participants provide researchers with a powerful, visual ethnographical perspective of the participant and with enriched data. Boden et al. (2019) advocate the inclusion of the participants' views of the meaning of their personal objects and written accounts to expand the concept of hermeneutic phenomenology. Chapter 3 will detail the supplementary information from Lily and Amber and the contribution made by the additional information to their interviews will be presented. In addition, Chapter 3 will outline the interview schedule and interview questions and details of the interviews will be provided. In addition, the reasons will be explored regarding why children living with disabilities and complex health needs are seldom asked to take part in research studies due to some researchers perceived practical difficulties in relation to the children's

physical, psychological, cognitive and emotional abilities to participate in research (McFadyen & Rankin, 2016).

The chosen methodology and methods applied in this study are deemed the most appropriate for the research question being posed. The rigorous methods employed to gain the children's and families' lived experiences of healthcare will be presented in Chapter 3. The ethical considerations of the study will be explored and will include the issues considered in gaining approval from the local and Regional Ethics Committees. The selection and recruitment of the study sample will be discussed in addition to the measures taken for the provision of emotional support for, and the safeguarding of, the participants. The timeline for the study is explained along with how the General Data Protection Regulations (2018) are used to extract, protect and to store the data. The importance is also detailed of ensuring on the completion of the study that there is the correct disposal of the participants' data which was collected during the research interviews (GDPR, 2018).

Chapter 4 presents an analysis of the data collected from the participants by using each of the three research methods employed in this study. The three data collection methods of semi-structured interviews, case study and Talking Mats® produced rich, deep data of the children's and families' lived experiences. The data generated from the three collection methods was analysed using the six steps analysis framework of Interpretative Phenomenological Analysis (IPA) developed by Smith et al. (2009) and the Effectiveness Framework of Functional Communication (WHO, 2001). The analysis produced results which identified themes relating to the participants' lived experiences within healthcare services and about their quality of life. The themes developed from the semi-structured interviews were:

 1. Relationships, 2. Choices and control, 3. Living with my condition, 4. Living with my child's condition and 5. Bringing it all together.

The themes developed from the Talking Mats® were 1. Mobility and transport, 2, Activities of daily living and 3, Choices and preferences.

Chapter 5 will present the findings from the research process and the analyses which were described in Chapters 3 and 4. The semi-structured interviews and the information from each participant's case study will be analysed using the six steps of Interpretative Phenomenological Analysis (Smith et al., 2009). A discussion of the qualitative interview findings and a summary of the key aspects of the chapter, including the themes generated from the analysis regarding the daily routines, strengths and difficulties experienced by the participants are presented in Chapter 5 and a summary will be provided to complete the chapter.

Chapter 6 will present the discussion regarding employing Talking Mats® (Murphy, 1998a) as a novel method for data collection and will explain why Talking Mats® (TM) is the chosen approach taken to communicate with children who are living with SLCN. The advantages of using the TM approach with Jack aged eight years and John aged nine years will be presented in this chapter. The NSPCC (2018) state that children are vulnerable and must be protected in all situations. Safeguarding Jack and John from the risk of possible emotional trauma and adverse childhood experiences during the research process was an important consideration within this study. Jack's and John's health and safety as participants is explained, in addition to how the children must be protected from the risk of confusion and the cognitive overload which research and interviews may cause (Edwards & Smith, 2014). Further consideration was given to the impact on the children's cognitive abilities, and the potential for an increased psychological and emotional load on the children during the research interviews. To mitigate this risk an adapted version of the TM communication tool was developed to enable the perspectives of the children to be gained. The interview schedules and questions will be discussed, and an analysis of the chosen approach will be presented. In addition, Chapter 6 will be devoted to the evidence for using the TM method and the advantages of using this approach with Jack and John. The participants' completed Talking Mats ® will be presented in this chapter and the findings will be discussed. A

synthesis of all the study results is presented in this chapter, followed by a summary of Chapter 6.

Chapter 7 is the discussion chapter and will present and explore the key findings taken from the literature review and the semi-structured interviews. The case study results from the supplementary personal material provided by Lily and Amber, and the results of the Talking Mats ® will also be presented. An exploration of the information in Chapters 5 and 6 will be provided in Chapter 7 using the lens of children's rights in relation to healthcare and the expectations of services from their families and the links to policy, legislation and supporting evidence will be explored. This chapter will present the combined findings from this study and will link the participants' lived experiences to the tenets within the cited legislation. The legal recommendations related to children are detailed within the Children and Young People (Scotland) Act 2014, The Children Act (1989), the Health and Social Care (Reform) ACT (Northern Ireland) (2009), the Rights of Children and Young Persons (Wales) Measure (2011) and the Health and Social Care (Reform) ACT (2012). The key aspects of this discussion will be outlined in the chapter summary. In addition, Chapter 7 will draw together the strengths of the research, along with the limitations of the study and will provide the recommendations arising from the evidence gained within the study. The strengths of this study are first, that the participants identified the importance of healthcare practitioners being able to communicate effectively. In addition, that healthcare staff develop and implement health literacy processes with several populations of vulnerable children, as strongly advocated by Public Health England (2015). Second, to recognise the point highlighted by Bardach et al. (2020) regarding the significance of self-development in researchers as an important skill to be demonstrated throughout the study process to enable a reflective and reflexive approach be taken in research. During the process of conducting this study, the researcher's self-awareness increased which enhanced the ability to be reflective and reflexive, which were necessary skills to demonstrate authenticity within the research process. Personal reflexivity helped with

adapting to the changes which were required to meet the variety and the range of needs of the participants. This thesis presents the personal lessons learned by the researcher throughout the research process and these are demonstrated within the reflexive accounts, and in the closing reflection.

The limitations of the study include the complex issue encountered regarding the recruitment of the child participants. This was due to the small population sample of children living complex health needs and disabilities within the Health Board who were able to be recruited as participants. The primary reason for this was the instruction on recruitment given within the study approval from the Regional Ethics Committee (REC). In addition, the children's health status was often unpredictable and only two children out of a possible three who use the original Talking Mats® method, and who met the selection criteria were well enough to be recruited.

The lack of fathers' perspectives was an additional limitation of this study, out of the eight adult participants, seven were mothers and only one was a father. Hampson (2016) raised the issue of the importance of hearing the voices of fathers to enable a non-stereotypical patriarchal but balanced view to be achieved. Fathers provide a whole family perspective and help researchers to recognise the impact of fathers on the whole family dynamic. An additional issue to address, which could be perceived as both a strength and a limitation, was the position of the researcher who was an experienced children's nurse in current practice with an extensive children's nursing background and a working knowledge of the local Health and Social Care Integrated services. Whilst in clinical practice as a children's services manager, the researcher was a known work colleague of the gatekeepers and this situation presented an ethical dichotomy during the study. First, regarding the advantage of belonging to an established, familiar local group working within a culture who already understood the issues faced by children and families living with disabilities, complex health needs and SLCN. Second, that the researcher's familiarity of the culture of children's nursing in Scotland may have been perceived as a potential risk of researcher bias. The research supervisors recognised the researcher's potential ethical

issues and provided the guidance required to ensure the rigour, transparency, and the integrity of this study's research process.

1.2 Research aim and objectives

The aim of this research is to generate a greater understanding of the first-person experiences of children living with complex health needs and disabilities, and those of their families. The study will explore the views and experiences of children living with complex health needs and disabilities through the lens of children's rights (Gillam et al., 2016). In addition, the study will explore whether children's rights are being upheld in relation to the healthcare provision they receive. Current legislation and existing evidence will be examined to confirm or refute whether children's voices are being listened to and the results of the National Institute of Health Research, VIPER project (NIHR, 2012) have indicated that children's voices are frequently not heard.

The objectives of the study are:

1. To define the issues regarding the population of interest which are children and their families and to facilitate active participation in the research through the choice of an appropriate methodology and suitable methods.

2. To effectively gain and hear the authentic, seldom heard voices of the study participants and to examine the information received.

3. To establish themes from the data to help to understand the first-person lived experiences of the participants through the dissemination of findings to practitioners, health and education providers and students within clinical practice and in educational settings.

4. To promote interest in conducting further studies within this topic area which will add to the existing body of knowledge on the healthcare services provided for children living with disabilities, SLCN and complex health needs, and those of their families.

An overview of the research is provided in this chapter to detail the research intention. The aim and objectives of this study are informed by the tenets of UNCRC (1995), the Children and Young People (Scotland) Act 2014, Bellis et al. (2015) and the Royal College of Paediatrics and Child Health (RCPCH, 2018). The research aim is driven by a strong belief that healthcare service provision must consider the health, wellbeing, safety and protection of the participants along with the ages, stages of development, abilities and health literacy of children and their families (Public Health England, 2015).

Section1.3 provides an overview of the background for the research and Section 1.4 outlines the motivation for this research and summarises the study aim, the objectives and the rationale for undertaking the research. Section 1.5 outlines the thesis contributions to new knowledge and to the application of various research methodologies. Section 1.6 provides a summary of the content of this chapter.

1.3 Background to the research

The four countries of the UK advocate the implementation of children's rights through the 54 articles of the United Nations Convention on the Rights of the Child (UNCRC, 2009). The theory and evidence presented throughout this thesis support the policy context in relation to the application of Articles 2,12, 19, 24 and 41 of the UNCRC (2009) whose premise is the safeguarding, inclusion and participation of children and their right to influence policy and services (Appendix 1). The responsibilities of the UK government to children and young people are found within the Children Act (1989), the Health and Social Care (Reform) ACT (Northern Ireland) (2009), the Rights of Children and Young Persons (Wales) Measure (2011), the Health and Social Care (Reform) ACT (2012) and the Children and Young People (Scotland) Act 2014.

Health and Social Care is integrated in Scotland and delivered through integration partnerships (Appendix 2). The integrated care partnerships (ICP) have a legal responsibility to deliver the national practice model 'Getting it right for every child' (GIRFEC) for children and young people living in

Scotland (Scottish Government, 2014). The Children and Young People (Scotland) Act 2014 mandates the statutory duties of the 'Named Person' (NP), an identified responsible person within this legislation, and the support of a 'Lead Professional' (LP), who is a practitioner within health, education or social services. Where necessary, the NP and LP coordinate and monitor multi-agency activity to address the child's additional complex health needs that are unable to be met by universal services (Appendix 3). Under the Children and Young People (Scotland Act) 2014 the responsibility from Health Boards and Local Authorities applies to children and young people (CYP) up to the age of 18 years who are in the care of their parents or guardians. This includes up to the age of 26 years for children and young people who are cared for within the Local Authority Care system and who have a Corporate Parent as their Named Person. The role of the child's natural parent, including an adoptive parent and legal guardian, is recognised within the Children and Young People (Scotland) Act 2014 alongside the 'Named Person' role. The Health Visitor is the NP for a pre-school child and the Headteacher or Depute Head is the NP for school age children, a representative from social services is the NP from Corporate Parent services. The Children and Young People (Scotland) Act 2014 promotes inclusivity for all children and young people and acknowledges that CYP of every ability have the right to be included in all the decisions made about them. Scottish Government (2019) report that some differences in children's abilities can be due to various factors related to a disability or impairment, or a physical or mental health diagnosis which results in substantial difficulty with day-to-day living activities. This study is concerned with the inclusion of children with all abilities to demonstrate their rights inherent in UNCRC (2009) and within the Children and Young People (Scotland) Act 2014. In addition, this study takes cognisance of a commitment to patient and public engagement from the NHS Institute (2013) using the model of Information, Feedback, Engagement, Co-design and Partnership, and that of the Department of Health & Social Care (2021). The summary of the UNCRC Articles (2009) details the responsibilities of the governments who agreed to collaborate and to meet the basic needs of

children, for example, the provision of healthy food and safe environments. In addition, the signatories of UNCRC must act to maximise the opportunities for children in all countries of the United Nations not to be harmed and to achieve optimal health and wellbeing. Appropriate education and sustainable services to help children achieve positive life experiences must be provided to support the optimum quality of life for CYP (UNCRC, 2009).

The social accountability of service providers to uphold children's rights and to enable children and young people's inclusion and participation was identified by Kay and Tisdall (2016). This view is supported by the Royal College of Paediatrics and Child Health (RCPCH, 2018) who produced evidence regarding the vulnerability of children and the general lack of awareness and respect in relation to children's rights, inclusion and participation. Children in the developed world have the right to express their views and to be heard, particularly in relation to healthcare services. Listening to children and upholding their right to be heard is topical because Williams (2021) from the Children's Rights Alliance England (CRAE) advised that the UK will be assessed by the UNCRC in 2022 on its implementation of children's rights against the Articles of the UNCRC (2009). These rights seek to protect and improve the lives of children growing up in the UK and are enshrined in UK legislation. The Department for Work & Pensions (2021) state that approximately 1,100,000 children in the UK from birth to eighteen years of age have a physical or mental health impairment that is both substantial and long-term and are defined as disabled by the Children Act (1989) and within the Equality Act (2010). Health and health literacy impairments can negatively affect a child's ability, compared to their peers, to understand their health conditions, to undertake routine daily activities, to follow treatment plans and to achieve their maximum potential and abilities (Velardo & Drummond, 2017).

Families of children living with disabilities reported to the Department of Health (DoH, 2015) that their voices were unheard and that their rights were ignored. In addition, that services were either lacking, were inadequate or were not sustained for disabled children, or for those living with

communication needs and for those living with mental health diagnoses and complex health conditions. Research indicates that the participation and influence of children and young people is crucial to the development and the quality standard of health services provided (Gilljam et al., 2016).

The potential risks of harm to children from sub-optimal service provision were identified by the Scottish government in 2014 and the statutory duty of care of providers to assess the risks of harm to children is stated within legislation. The inherent rights, standards and safeguards of children must be acknowledged by healthcare providers (RCPCH, 2018). To enable the duties of care to be met by the service providers, meaningful participation for CYP must be prioritised, and an emphasis must be placed on leadership for CYP services within healthcare (NHS, 2020). Effective leaders must be emotionally intelligent, compassionate, and transformative to drive up the quality of evidence informed, safe, health services (West et al., 2020). Compassionate and intelligent leadership within healthcare can transform patient care and leaders can exert influence over care standards and the resultant experiences of children and their families (NHS, 2020). Legislators, Healthcare providers, Statutory, Third Sector organisations and Charities can take the opportunity to audit service provision, listen to feedback from children and their families and to consider the results with a view to maintaining and improving services to co-develop, co-produce and co-deliver optimal healthcare.

Sub-optimal healthcare provision and negative consequences to health may result from not listening to children and families about the quality and suitability of health services provided (Stalker & Moscardini, 2012). According to Bellis et al. (2015) there is a potential risk of causing adverse experiences in childhood during healthcare interventions. Adverse Childhood Experiences (ACEs) were first identified during seminal research by Felitti (1998) which identified that the physical and psychological harm caused to children had several causes. This can subsequently manifest in negative health and risk-taking behaviours in adulthood which may lead to reduced life expectancy (Appendix 4). The factors of neglect, physical, emotional and

sexual abuse in childhood identified by Felitti (1998) can result in children developing anxiety and depression which continues through to adulthood. These significant findings are supported by Hughes et al. (2018) who suggest that ACEs are significantly detrimental to children's normal brain development, subsequent mental health and their future mental health as adults. The risks of ACEs to health and wellbeing across the age trajectory include lifelong, negative impacts which impair many aspects of human development (Hardcastle et al., 2019). Educational attainment can be restricted by the effect of ACEs and can cause a higher propensity to risk taking behaviour which can negatively affect safety, health and the quality of life (NHS, 2019). In addition, the possibility of affected children later developing offending behaviour was identified by Talbot (2010). The significant evidence cited on ACEs places a duty of care on governments and the Health and Social Care Integrated Partnerships to uphold CYP rights and to realise that the lack of children's rights' implementation has the potential to cause harm to children and their families. Raising the awareness of children's rights is a major driver for UK policy development to improve children's services, along with the implementation of all the other legislation which is applicable to CYP.

Historically, the Royal College of Psychiatrists (RCPsych, 2009) reported the risk of a negative impact on children's health services when health care providers do not listen to the voices of children, or act upon children's views. To mitigate the perceived detrimental impacts of services that are not tailored for the specific needs of children and families, RCPsych (2009) suggest that organisations consistently audit and improve their services. The intention is to help ensure that services are provided by suitably qualified, skilled and knowledgeable healthcare staff. The further aim is to protect children in safe environments of healthcare that are appropriate for the children's ages, stages of development and level of understanding. Gilljam et al. (2016) state that the participation of children and young people is crucial to influence healthcare providers and to the quality of health services. This aim was progressed by RCPCH & Us (2015) during a joint improvement project

undertaken with children and young people. The results of the project recognised the rights of children to be heard about their experiences in healthcare and advocated children's full participation in the review and development of health services for CYP. An audit undertaken by RCPCH (2018) indicated that little action had been taken by health providers to address the concerns originally raised in 2009 by both UNCRC and the Royal College of Psychiatrists.

Representatives from UK charities and professional bodies alerted the UK government and the NHS (Department of Health, 2012) to the sub-optimal healthcare which occurred due to failings in leadership and management in the Winterbourne View hospital, Mid-Staffordshire NHS Foundation Trust and Shrewsbury and Telford hospitals (Care Quality Commission, 2013; Francis, 2013; Ockenden, 2022). The findings of the public inquiry into the avoidable mortality and morbidity of patients led to a lack of public trust in clinicians and clinical services, reputational damage to the healthcare organisation and to the instigation of legal proceedings (Norris & Shepheard, 2017). The resulting evidence cautioned of the risks of ignoring complaints from patients and healthcare staff about the poor quality of health service provision. Children and families' views on their experiences of healthcare may facilitate a review of historical service feedback mechanisms (Wood, 2009) and inform how to provide modern methods to receive customer satisfaction. Luxford et al. (2011) highlighted the importance of patient feedback in improving person centred clinical care and services. Concerns were raised by RCPCH & Us (2015) that children's anxiety about health issues may lead to refusal to attend for healthcare appointments and result in non-concordance with supportive care or vital life-saving healthcare treatments.

Recommendations from a patient feedback review conducted by the National Institute for Health Research (NHIR, 2019) inform health professionals about the importance of hearing and acting on patient feedback, including that of staff within organisations who raise concerns about sub-optimal practice. Staff who speak up about poor practice are often described as

whistleblowers and are acting in the patients' best interest according to the Public Interest Disclosure Act (1998) and NHS Improvement (NHS England, 2016). According to Cleary and Doyle (2016) the need for whistleblowing may be avoided if healthcare providers listened to internal voices and took courageous decisions regarding service provision instead of ignoring the issues being raised.

Vennik (2015) advocates the meaningful involvement of citizens and communities and the co-production of appropriate and sustainable services. Placing the recipients of services at the centre is seen as important to McCormack and McCance (2017) who highlight the significance of person-centred services in minimising potential health risks and sub-optimal patient experiences. This view supports the risks of harm identified by RCPCH (2018) and that person centredness can help reduce the impact of hospital related ACEs. Hardcastle et al. (2019) suggest that these factors raise healthcare professionals' responsibility to listen to children's views, to be cognisant of the impact of adverse experiences in childhood and to mitigate for the risks of ACEs on all aspects of children's lives. This view is supported by RCPsych (2020) who are aware of the increased risks to health and anxiety caused by living with ACEs, particularly how these can transition to adulthood and necessitate active psychiatric treatment to assist coping with adult life. McCormack and Dewing (2019) advocate the implementation of person-centred models of care to tailor services to the person's specific needs and to improve the quality of the patient experience. Compassionate and intelligent leadership within healthcare can transform patient care (Lega et al., 2017) and leaders can exert influence over care standards and the experiences of children and their families (West et al., 2020; NHS, 2020). Legislators, healthcare providers, charities, statutory and Third Sector organisations have the opportunity to audit services, listen to the feedback and to act on the evidence with a view to co-producing and co-delivering optimal quality services (Kay & Tisdall, 2016). Healthcare quality can be improved by valuing patient feedback to co-produce services and can be

sustained through the implementation of recommendations from research, public inquiries, reports and audits (Batalden, 2018).

1.4 Motivation for the research

The primary motivation to conduct the study is to explore the first-person experiences of children who are living with disabilities and complex health needs, and those of their families by asking the research question 'What are the views and experiences of children living with disabilities and complex health needs, and those of their families?'

Children who are living with SLCN comprise a sizeable proportion of the school population and the Department for Work & Pensions (2021) report that 22% of school children diagnosed with Special Educational Needs (SEN) are living with SLCN and whose views, according to Bercow (2018) are often not represented. This evidence indicates a risk of groups of children being excluded from consultations about ICP services and the primary need to consider the mechanisms by which all CYP may be included. To enable the participation of all CYP suitable methods that facilitate effective communication must be identified, for example, Talking Mats® (Murphy,1998a) and British Sign Language (Riley, 2017), both systems enable effective communication for those living with SLCN. Talking Mats® communicates facts, activities, thoughts, ideas and concepts through picture symbols and British Sign Language (BSL) uses hand gestures, finger movements and facial expressions to relay messages from the sender and the receiver (Riley, 2017). Talking Mats® and BSL are considered as suitable methods of communication to use within research. Reitz and Dalemans (2019) recognise Talking Mats® as an effective communication method to use with children and adults living with SLCN and the Talking Mats® method will be purposefully adapted to meet the needs of the children living with SLCN who participating in this study.

RCPCH (2018) state that CYP have the right to receive appropriate and equitable National Health Services (NHS) comparable to those provided for adult populations (NHS, 2019), and the right to be kept safe from harm whilst

receiving NHS services. The results from a critique of the literature on children's rights, as advocated by UNCRC (2009), prompted this research question to be developed and to explore whether healthcare providers are upholding CYP rights to be heard regarding their healthcare experiences. This study will explore if there are opportunities for children living with additional complex health needs, disabilities and SLCN to speak through the preferred and appropriate communication method for the child's abilities. Communication about health and within health, known as health literacy, is important to ensure that patients understand their health conditions and any treatments they require (Public Health England, 2015). Health literacy includes the receiver's ability to read and comprehend any written or digital information provided about their health and healthcare professionals often underestimate the public's health literacy needs (NHS England, 2021). Health literacy needs often remain hidden and some people actively hide their difficulties, in Scotland 26.7% of people have occasional difficulties with day-to-day reading, numeracy and digital competence related to computer skills, and 3.6% have severe constraints on their literary abilities (Scottish Government, 2019). Health literacy is important to the public's reading and understanding of health information because health literacy enables people to make informed decisions about their health and to understand how to follow treatment plans. This issue is important to consider within this study because the children and families are living with complex health conditions and disabilities which require explanation and their ability to follow written advice, treatment plans and the use of equipment, including technological equipment. It is proposed that effective health literacy may positively influence the co-production of healthcare policy and the commissioning and developing of healthcare services. This is because children and families as contributors to health policy will have the relevant understanding of health issues and the impact of health services on service provision. Velardo and Drummond (2017) agree that health literacy is of significance and advocate that the child must be emphasised in child health literacy discussions and proposals. This study is interested in the lived experiences of children and families, with the children's views of paramount importance in informing and

providing children's nursing services and promoting children's nursing research. In addition, my professional, academic and personal motivations demonstrate altruistic reasons for conducting this study and these are now explained.

1.4.1 Professional motivation

The professional influences for embarking on this research journey were identified whilst providing healthcare services in a previous role as a registered children's nurse and nurse manager with duties of care which included providing safe and appropriate clinical services for children and which implemented statutory child protection and safeguarding policies (Nursing and Midwifery Council [NMC], 2018). An integral part of the role was to lead and manage the teams delivering patient care to ensure that staff skills, knowledge and training met national and professional standards of quality (Gray et al., 2020).

The responsibilities of the role included the promotion of children's rights in a healthcare setting and asking the children and their families about their patient experience, and what matters to them whilst receiving healthcare (Health Improvement Scotland, 2020). Patient satisfaction and the quality of service must be continuously monitored to facilitate service improvement wherever possible (NHS Institute for Innovation and Improvement [NHS Institute] 2013). This encourages an engagement cycle which enables a transformation of the patient experience by acting upon feedback, including complaints, from children and families on the healthcare services provided. Service audits were completed but did not provide the depth and breadth of information required to fully understand and appreciate the child and family's journey through the service provided.

This research will investigate whether the healthcare services experienced by children and families meet the standards recommended by RCPsych (2009) and RCPCH (2018). The UNCRC Articles 2, 12, 19, 24 and 41 detailed in Appendix 1 are most pertinent to the motivation for this study. Article 2 is the child's right not to be discriminated against, Article 12

focusses on the child's right to participate, to be listened to and to have their views taken seriously. Article 19 states that all children must be safeguarded, protected from harm, including neglect, violence and abuse. In addition, safe, effective, and appropriate healthcare for children is the aim of Article 24 and governments are reminded that where nations meet, or exceed, the standards in the 54 Articles the recommendation in Article 41 is to maintain those higher standards. The information currently available regarding the lack of progress on the implementation of the child's right to be heard in relation to healthcare service provision indicates that there is a risk that children's health and wellbeing may be negatively impacted. This has strongly influenced the motivation to research this topic and supports the view that children and families' experiences of healthcare service provision warrant further investigation.

Rabiee et al. (2005) state that there are few research studies in the UK which focus on the area of children's experiences of healthcare services and Coad et al. (2019) indicate that there is less research undertaken with children and young people compared to adults. This issue was previously raised by King and Horrocks (2010) who state that the possible reason for this is that there are additional ethical and safeguarding issues that must be addressed in research with children, whilst balancing this against the child's right to be heard and to participate in research. The Communications Trust (2014a) additionally highlight the lack of studies undertaken with children who are diagnosed with SLCN and those living with complex health issues and disabilities. The National Institute of Health Research (NIHR) (2012) project VIPER (Voice, Inclusion, Participation, Empowerment, Research) with young people as joint researchers, found that children with disabilities and SLCN are seldom heard due to the impact of the communication difficulties and the lack of appropriate facilities available to listen to children. The inclusion of children with disabilities is very often dependent on a few interested and supportive individuals within organisations and is not reliant on an established, routine process. This disparity in research practice poses the risk of children with disabilities being omitted from research. Clark et al.

(2014) believe that more studies undertaken in this field would afford all children, regardless of abilities, the right to an opportunity to express themselves and to have their voices heard and this view is strongly supported by Kenny (2016). The proposed novel study will be undertaken with children and their families, who are currently underrepresented in research, to enable further knowledge to be gained in this important, under researched area of children's healthcare and rights (Bercow, 2018). The information gained may add to the body of evidence required by the UNCRC review (Williams, 2021).

1.4.2 Academic motivation

Healthcare practitioners and nurse educators are required to undertake continuous professional development to remain credible, to practice safely and to remain validated by a regulatory body (NMC, 2018), this is achieved through statutory, mandatory, and further education. Taylor et al. **(**2014) advocate undertaking research and implementing service improvements which provide the opportunity to achieve the required academic education in conjunction with addressing practice issues. Health educators must demonstrate contemporary knowledge of the evidence available on the health topics they teach. This can be achieved by implementing theoretical frameworks, for example, PARIHS (Promoting Action on Research Implementation in Health Services) a framework that supports the development of knowledge and skills (Rycroft-Malone, 2008; Bergström et al., 2020).

1.4.3 Personal motivation

My personal motivation for undertaking doctoral studies is the desire to contribute to knowledge in the field of nurse education and to strive to influence positive change in nursing care. Professional development and the achievement of academic qualifications will provide me with personal satisfaction and increase both my self-esteem and confidence. It is accepted that researchers are often reluctant to adopt a confident attitude in relation to their research status due to the perception of imposter syndrome, a

phenomenon highlighted by Gill (2020) and which applies to my situation. My aspiration is to develop and acquire new knowledge, skills, and expertise through conducting this research study and achieve self-actualisation through the model of self-development known as Maslow's Hierarchy of Needs (Aruma & Hanachor, 2017) and to contribute positively to society in my chosen career. The opinions of, and the recognition from my peers is important to consider whilst examining the relationship between my personal goals and my actual achievements. My personal aspiration is to fully understand the concept of self-actualisation and to achieve the maximum potential possible (Bardach et al., 2020).

1.5 Thesis contributions

This thesis will fulfil a key component for the award of a Professional Doctorate in Healthcare. This research presents the opportunity to explore through the lens of phenomenology the children's and families' views on healthcare services and to contribute to new knowledge in this area of investigation. The study is particularly linked with children's rights (UNCRC, 2009) and to the objective of hearing from children whose voices are seldom heard, and who are often excluded from research participation (Murphy, 1998a; Coad et al., 2019).

Contribution of this thesis:

1. The literature review contributes to the thesis by providing current evidence on the topic and was conducted to discover and examine the existing body of knowledge regarding children's rights and how children and families' views are gathered in relation to the health services provided. The research topic is focussed on children living with complex health needs and disabilities, including SLCN. The literature review demonstrated the evidence currently available which helped to confirm the suitably of the research question and the important factors to consider within a research investigation, these issues relate to the confidence the researcher applies to a proposed study at the outset (Aveyard, 2018). The literature review provided

information on the next phases of the research process regarding applying suitable methodologies, methods, and population samples. Knowledge of the limitations of conducting studies on the topic of children and families' lived experiences of healthcare were demonstrated within this thesis. The stages required when undertaking the research process, from commencement with the initial interest in the topic and the search for existing knowledge will be demonstrated in the literature review. A detailed account of the literature review process will be provided in Chapter 2.

2. This thesis further contributes to the research knowledge on the topic by presenting an account of the phenomenological approach employed and the choice to use semi-structured interviews, as opposed to non-structured and structured interviews, as the appropriate method by which to gain the views of children and their families. The value of the case study method and the use of participants' supplementary material in obtaining a rich, deep picture of the participants is explained. Details of the analysis of the participants' transcripts, the themes generated from the participants' first-person narratives and the discussion relating to the findings from the study will provide new knowledge on the topic.

3. The thesis will provide a discussion of the limitations of the study and will detail the recommendations for further research.

4. The thesis will demonstrate the rationale for developing a novel Talking Mats® method applied in this study which removes ambivalence regarding a decision and presents a dichotomous choice to assist with minimising the cognitive load on the children with disabilities. In addition, the thesis will discuss how Talking Mats® (Murphy, 1998a) facilitates communication with children and individuals experiencing communication difficulties (Reitz & Dalemans, 2016) and how this approach could be applied more widely within research. The Talking Mats® method will contribute to ensuring that

there is equity of access to this study and will promote equality in relation to children's communication opportunities. Children who are seldom heard within healthcare provision will be afforded the opportunity to recount their views and first-person experiences and for these to be heard by researchers and service providers. The application of this approach will contribute to the method being recognised more prominently in studies. Talking Mats® is underused in children's research studies due to the lack of opportunity for children who use this method of communication to participate in research (The National Institute of Health Research, 2012; Bercow, 2018).

5. The thesis will contribute to a discussion about the promotion of children's rights in relation to minimising harm and optimising safety, protection and participation, along with maximising opportunities for optimal health and wellbeing.

6. This thesis reflects an analysis of policy context in relation to the application of Articles 2, 12, 19, 24 and 41 of the UNCRC (2009), the legislation within the Children and Young People (Scotland) Act 2014 and the responsibilities to children found in UK government policies. Patient and public engagement, using the model of Information Feedback Engagement Co-design and Partnership (NHS Institute, 2013), is central to the thesis, encouraging NHS staff deliver positive experiences to patients as 'always events' as opposed to negative experiences or 'never events' (Care Quality Commission, 2018). The issues of potential harm to health and wellbeing raised by Bellis et al. (2015) were confirmed by RCPCH & Us (2015). The work of RCPCH (2018) links to this study's objective of gaining the experiences of children and families regarding safety within healthcare services.

7. The thesis will demonstrate the value of using a phenomenological approach and the semi-structured interview and case study method to facilitate the child's right to speak, to enable the child's right to be

heard and to promote the child's right to participate in research which may influence the co-production of future policy development within health service provision (Williams, 2021).

8. The thesis will highlight the importance of engaging with all individuals, groups and agencies when developing sustainable services for children living with disabilities, complex health needs and communication difficulties and their families to ensure the best person-centred and prudent health and social care.

Chapter 7 provides the discussion and study synthesis, along with a conclusion of the research chapters and explores the limitations encountered in the study objectives and the chosen methodology. The study results are compared to the research theory and recommendations for further research are provided.

The references cited within the thesis are presented at the end of the main body of the thesis. The Appendices provide key information and details related to the study including the timeline, the models used in the research process and the details of the studies analysed in the literature review. The Appendices also include the ethics approval letters and the letter to those who could provide access to the participants, known within research as the 'gatekeepers' (Clark et al., 2014). The Appendices also contain copies of the interview schedules, the Participant Information Sheets (PIS), the Participant Consent forms, and the Child Assent forms.

1.6 Chapter summary

This chapter introduced the chapters included in this PhD thesis and provides an overview of the background to the phenomenological study which used semi structured interviews, case study and an adapted Talking Mats® as a novel method due to removing ambivalence from the children's choices.

The child's right to be heard and to participate was explored in relation to healthcare services (UNCRC, 2009; RCPsych, 2009). The aim of the study to address the underrepresentation of children in research was highlighted, building on the argument about this issue which was raised by Clark et al. (2014). Children's rights and safeguards whilst receiving healthcare and as outlined by UNCRC (2009) were explained, especially in relation to disabled children and those diagnosed and living with complex health and communication needs (Bercow, 2018). The concerns raised by RCPsych (2009) regarding the lifelong impact of children's adverse experiences were outlined, and the implications were highlighted regarding future ill-health and psychological distress through trauma as investigated by Bellis et al. (2015) and RCPCH (2018).

The motivation for conducting the research was declared and this reflected three aspects relating to the life and career of the researcher, which are first, the professional interest in the topic of children's nursing and research, second, the continuous academic requirements to enable a practitioner to remain within the dual professions of nursing and higher education. Finally, the personal perspective relating to the aim to contribute positively to society. The aim to maximise full professional, academic and personal potential can be achieved through the use of the model of self-development and self-actualisation known as Maslow's Hierarchy of Needs (Aruma & Hanachor, 2017). In addition, the rationale was presented for seeking the views and experiences of children and their families on the provision of healthcare. The discussion highlighted the impact of failures in care and sub-optimal services in healthcare provision and included the risk of health services causing ACEs and potential harm to children, leading to lifelong consequences (Bellis et al., 2015). This chapter discussed the aims, objectives and timeline of the study and the contribution that the thesis may make to the topic area of research with children living with complex health needs, SLCN and disabilities, and their families.

CHAPTER 2:

REVIEW OF THE LITERATURE

This chapter will explain the rationale for undertaking a literature review (LR) and how the results impacted on the development of the research question and the methodology and methods employed in this study.

2.1 Introduction and chapter overview

The United Nations Conference on the Rights of the Child (UNCRC, 2009) and Bellis et al. (2015) recommend that children's rights should drive policy development and service provision in healthcare and this tenet is a significant foundation for the interrogation of the literature. Aveyard (2018) supports the value of conducting a literature review to assist researchers with the development of a relevant research question on the topic of interest.

This chapter provides the rationale for undertaking a review of the current literature to investigate the factors in relation to children's rights and legislation and regarding children and families' access and influence on the use of healthcare systems. The focus of this literature review centres on gaining insight into the experiences of children living with complex health conditions or disabilities and their families whilst receiving healthcare. The World Health Organisation (WHO, 2010) International Classification of Disability (ICD) coding system defined these children as having additional needs to their peers in relation to development, physical, emotional health and daily functioning and who require support beyond that provided by universal health services.

Chapter 2 will outline the rationale of this literature review. Section 2.1 will introduce the rationale for undertaking a literature review and Section 2.2 will define the aim and objectives of this literature review. Section 2.3 will explain

the literature review process using a systematic approach and the literature search strategy will be discussed in Section 2.4.

The selection of relevant studies to review, including the criteria used for inclusion and exclusion (Long et al., 2020) will be detailed in Section 2.4.1 and the data extraction will be presented in Section 2.4.2.

A quality assessment of the studies will be provided in Section 2.5 and the results of the literature screening and assessment will be detailed in Section 2.6. The selected studies, the quality of the studies and the characteristics identified within the studies will be presented in Sections 2.6.1, 2.6.2 and 2.6.3 respectively.

The analysis and synthesis of the studies within the LR will be provided in Section 2.7 and the coding and thematic analysis will be detailed in Section 2.7.1. The thematic analysis results will be presented in Section 2.8 and the three identified themes which are Theme 1. Cultural influences on Quality of Life (QoL) and emotional wellbeing, Theme 2. Complex Health Needs and Disabilities impact on populations and Theme 3. Research methodologies and approaches are discussed in Sections 2.8.1, 2.8.2, and 2.8.3. This is followed in Sections 2.9 to 2.9.3 by a discussion relating to the suitability of the studies, methodologies, methods and study sample of the three identified themes. The limitations and recommendations for future research are set out in Section 2.9.4. The conclusion is drawn in Section 2.10 and Section 2.11 will provide a summary of Chapter 2.

2.2 Aim and objectives of the literature review

The focus of a literature review is to identify the relevant studies available within the area of interest (Smith et al., 2009). The aim of this literature review is to investigate the current evidence globally relating to safeguarding mechanisms applied to the delivery of healthcare and to define the current knowledge base regarding research with children and families on their lived experiences of healthcare.

The objectives of the literature review:

1. To examine the breadth of studies pertaining to the views of children and their families and relevant information from grey literature found in government sources. Studies undertaken on the topic children living with complex health conditions, including Speech, Language and Communication Needs (SLCN) will be examined.
2. To understand and explore the literature available regarding children's rights and safeguards examining how this knowledge is applied in the delivery of healthcare.

According to King and Horrocks (2010) a thorough search of information available on a subject helps to identify where there may a deficit of knowledge and where contradictory views or results may have been presented. Snyder (2019) states that literature reviews undertaken by any discipline, and using a systematic or semi-systematic approach, provides a useful contribution to what is already known on a topic which can consequently help the researcher to develop a relevant research question or questions. In addition, a literature review is one that interrogates and analyses in depth all the studies found in the search providing a framework that helps researchers build on their knowledge. Machi and McEvoy (2016) suggest that the frameworks enable effective literature searches and the formulation of relevant research questions and projects. Beecroft et al. (2015) describe five key points listed below for finding the evidence required to inform the development of a research question and to conduct a study.

1. Effective literature searching is an essential skill for research, audit and evidence-based practice.
2. The research literature consists of journals, reports, theses, conference proceedings, government publications and Web-based resources.
3. Much literature searching uses electronic databases and the Internet.
4. High-quality sources of evidence include systematic reviews, evidence syntheses and critically appraised topics.

5. Reference management skills are vital for effective research and evidence review.

The information from Beecroft et al. (2015) provides a persuasive argument to augment the views of Machi and McEvoy (2016) and Snyder (2019) that researchers seek practical advice on how to conduct systematic and literature reviews, how to access academic databases to begin the search and how to use validated frameworks to present the information once acquired.

2.3 Literature review process using a systematic approach

The process of a literature review is to identify and examine relevant studies found in the literature search and Schünemann et al. (2014) recommend that optimum frameworks are used for literature reviews, ensuring that the review includes criteria for the inclusion and exclusion of relevant factors. The quality of evidence gained for analysis is believed by Long et al. (2020) to be directly impacted by the suitability of frameworks employed for the review. The literature review process aimed to identify sources relevant to the research interest and to assist the formulation of the final iteration of the research question. Gerrish and Lathlean (2015) state that the importance of conducting this process with rigour is to achieve the stated aim and to produce a credible result.

2.4 Literature search strategy

A framework to conduct a literature search is recommended by Glasper and Rees (2012) and the model PICO (P, Patient or problem. I, Intervention or Exposure. C, Comparator. O, Outcome) provides structure for the search. PICO was applied (see Table 1) in relation to the proposed research question, 'What are the views and experiences of children with complex health needs and those of their families on the provision of healthcare?'

The quantity of material found by researchers often practically cannot reasonably be reviewed within the time frames available for a project or to

complete a programme of doctoral education. Machi and McEvoy (2016) suggest streamlining the process by following a framework where the evidence is collected, examined, and reviewed. The literature search and literature   review were undertaken during the month of February 2019 following the gaining of ethical approval for the study on the 6th of February 2019, reference number 18/WS/0228.

The information gained from undertaking the PICO exercise provided the initial search terms to input into the search databases.

Participants	Children and families living with complex health needs and disabilities.
Intervention/Exposure	Views, experiences and interviews.
Comparison	National surveys, reports and National guidelines.
Outcomes	Services provided, including any designed by those who use the service.

Table 1. PICO applied to the research question

The search for existing evidence was conducted by using the key words 'children' 'health needs' and 'disabilities', truncated phrases, complex health* and Boolean operators (EBSCO, 2020) 'OR 'AND' and NOT in the digital databases. The next step in the process was to enter the key words 'children' 'health needs' and 'disabilities' generated by using PICO (see Table 1) into the CINAHL, PubMed, PsycINFO, MESH (Medical Subject Heading).and Medline database search boxes (EBSCO, 2020), these databases are sources of full text nursing and allied health journals hosted online. The EthOS database (EBSCO, 2020), which hosts published theses online was also used to enable a wider range of sources be consulted. Machi and McEvoy (2016) advise that many studies may be revealed from an initial

search and that a process of reducing the studies for review is required for the manageability of the information returned. This was achieved by using an inclusion and exclusion process (see Table 2) based on the PICO model from Glasper and Rees (2012).

PICO	Include	Exclude
Population	Children, Families, Living with complex health needs, disabilities	No health needs
Focus	Views, experiences gained through interview	No personal experience
Publication date	2000- 2019	Prior to 2000
Source type	Peer reviewed journals, original articles and published theses	Conference papers, books, periodicals, magazines, opinion pieces and editorials

Table 2. Inclusion and Exclusion criteria based on PICO

The initial search yielded 145,652 results which included 176 online research theses and 'grey' literature, which is defined as material that is unpublished but may be of value to the topic. For example, grey literature is a conference presentation, an editorial or legislation (Higgins et al., 2019). The number of items initially returned was unmanageable for review and to address this issue limiting criteria were applied to the search results to help to reduce the number of items to review (Smith & Noble, 2015). The following inclusion criteria were employed; 'original research', 'full text' and 'peer reviewed items' in the 'English language only', this was due to there being no funding available for translation services. The further search yielded 121,633 returns

and a criterion was added of items published during the period 2000 to 2019 which then reduced the returns to 116,738. This number was unmanageable for review and a further reduction was required by including additional limiting criteria were applied. The terms 'complex health needs' 'special needs 'speech and language needs' 'augmentative and alternative communication' and 'experience of healthcare'. The following exclusion criteria were applied; editorials, posters, citations, book chapters, conference programmes, duplicate studies published in a number of different journals and the salami sliced research articles which are articles derived from a single original study, highlighted for concern by Tolsgaard et al. (2019). These actions reduced the returns to 291 which were then manually reviewed for their suitability to the topic being explored. Smith and Noble (2015) explain the significance of finding the existing evidence on a topic and the value of reviewing the literature in relation to gathering high quality information.

2.4.1 Study selection criteria

The evidence that is available on a subject is built from a range of sources and in addition, advises that the search for information is undertaken with caution to ensure the resources consulted are credible and rigorous and to enable credibility and rigour the studies were screened by two researchers. It is important to demonstrate rigour in the selection process applied to the studies and this was enabled by using a two-person process (Machi & McEvoy, 2016).

The lead investigator for the study reviewed the titles, abstracts and relevance and the research supervisor provided independent scrutiny of the studies selected. A contingency was arranged in the event of any disagreement on the proposed studies to include for review and a third researcher was available to assist with any dispute resolution.

The process of discovering existing evidence in relation to healthcare could be improved by following the advice from Khan and Qureshi (2020) who explain the significance of using the Preferred Reporting Items for

Systematic Reviews and Meta-Analysis (PRISMA, see Figure 1) in relation to systematic literature reviews. An accredited system was required to filter and organise the search results, and Moher et al. (2009) advocate PRISMA as a suitable framework to employ to enable the number of studies first returned on data searching to be reduced to a manageable number of studies for review.

2.4.2 Data extraction

The selected studies were consequently examined by using Critical Appraisal Skills Programme (CASP) (Long et al., 2020) and the Grading of Recommendations, Assessment, Development and Evaluation GRADE framework (Schünemann et al., 2014) models. The characteristics and quality assessment of the included studies are detailed in Table 3. Detailed characteristics of the selected studies include the full study title, the research interest, the ethical issues and recruitment, the study population, the key findings, the recommendations, the limitations and the quality assessment of the studies of the included studies are provided in Appendix 18.

Support for confidence in the technique used to select and analyse the studies found is seen in the CASP model recommended by Long et al. (2020) and the GRADE framework (Schünemann et al., 2014).

2.5 Quality assessment

A quality assessment of the selected studies is integral to supporting the validity of the review process (Long et al., 2020). The CASP model was used to screen for quality factors by following the10 questions found in CASP. These are the research topic, the question posed, the suitability of the methodology, the design, the methods, the study population, ethical issues, rigour of analysis, the study limitations and the value of the research.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews)

Quality Assurance: the review was guided the PRISMA checklist (Moher et al., 2009)

```
┌─────────────────────────────┐        ┌─────────────────────────────┐
│ Records identified through  │        │ Additional records          │
│ database searching          │        │ identified through other    │
│ initially = 145,652         │        │ sources ETHoS- Theses       │
│                             │        │ online = 176                │
└─────────────────────────────┘        │                             │
              │                        │ Hard copies of Theses in    │
              ▼                        │ University library = 2      │
┌─────────────────────────────┐        │                             │
│ Records following Limiters  │        │ Total Theses = 178          │
│ added and applied: Full     │        └─────────────────────────────┘
│ text. English language.     │                      │
│ Peer reviewed articles.     │                      ▼
│ Date from January 2000 to   │        ┌─────────────────────────────┐
│ 2020 = 121,633              │        │                             │
└─────────────────────────────┘        │ Further keywords added,     │
              │                        │ total = 112,174             │
              ▼                        │                             │
┌─────────────────────────────┐        │ Records excluded following  │
│ Full-text articles assessed │        │ criteria:                   │
│ for eligibility = 291       │        │                             │
│                             │        │ Editorials, posters,        │
└─────────────────────────────┘        │ citations, reports, book    │
              │                        │ chapters, conference        │
              ▼                        │ programmes                  │
┌─────────────────────────────┐        │                             │
│ Records screened and        │        │ Same study given different  │
│ manually reviewed = 291     │───────▶│ titles and published in     │
│                             │        │ several separate journals.  │
└─────────────────────────────┘        │                             │
              │                        │ 'Salami sliced' research    │
              ▼                        │ articles (original study    │
┌─────────────────────────────┐        │ split into several parts)   │
│                             │        │ = 291                       │
│ Studies included in         │        └─────────────────────────────┘
│ qualitative synthesis = 10  │        ┌─────────────────────────────┐
│                             │───────▶│ Second review of full-text  │
└─────────────────────────────┘        │ articles and those not      │
              │                        │ suitable excluded           │
              ▼                        │                             │
                                       │ One study included from     │
                                       │ previous search 2000- 2020  │
                                       │ = 10                        │
                                       └─────────────────────────────┘
```

┌──┐
│ Studies included in qualitative analysis = 10   │
│ Authors and date of publication listed below: │
│   │
│ 1. Bishop (2017) 2. Davys et al. (2017) 3. Graham (2012) 4.   │
│ Hemsley et al. (2013) 5. Ilkhani (2013) 6. McNeilly et al. (2015) │
│ 7. Misuk & Emmett Gardner (2015) 8. Rabiee et al. (2005) 9.   │
│ Singer (2013) 10. Markham (2008)   │
└──┘

2.6 Results of the Literature Screening and Assessment

The initial results of the literature screening and assessment are presented in Table 3 and the screening and assessment process provide a clear and rigorous review. The suitability is assessed of the methodology, methods, study population, ethical considerations, data analysis and limitations in relation to the questions posed by the researchers.

2.6.1 Selected studies

Ten studies were suitable for analysis and synthesis following the use of the PRISMA, CASP and GRADE models:

Rabiee et al. (2005) Graham (2012) Markham (2008) Singer (2012) Hemsley et al. (2013) Ilkhani (2013) Mc Neilly et al. (2015) Misuk and Emmett Gardner (2015) Bishop (2017) Davys et al. (2017).

2.6.2 Quality of selected studies

GRADE (Grading, Recommendations, Assessment, Development and Evaluation) provides five factors to consider relating to the variation in evidence, these are, limitation of design and execution (bias), inconsistency, indirectness related to PICO and applicability, imprecision of numbers and publication bias and the GRADE technique were chosen due to their credibility with researchers (Schünemann et al., 2014). GRADE was subsequently employed to allow analysis of the quality of the evidence found (see Appendix 18).

2.6.3 Characteristics of selected studies

The characteristics of the selected studies are identified using the following criteria: Author or Authors and date, the country where the study was undertaken in addition to the methodology and method used. The quality assessment regarding the appropriateness of the study to the research question is categorised using High, Moderate, Low and Very Low (Table 3).

2.7 Analysis and synthesis

Analysis and synthesis of the ten selected studies elicited the following themes:

Theme 1. Cultural influences on Quality of Life (QoL) and emotional wellbeing

Theme 2. Complex Health Needs and Disabilities impact on populations

Theme 3. Research methodologies and approaches

2.7.1 Coding and thematic analysis

The coding and thematic analysis of the ten selected studies are presented in Table 4 where each of the studies was examined in relation to a link to the themes identified. This allowed a comparison and a confirmation process be undertaken in relation to the proposed study.

The studies were assessed for the suitability of the chosen approach, methodology, methods, study population, ethical considerations and data analysis. In addition, conducting the process highlighted that further consideration should be given to the identification of obvious limitations, preventing the risk of researcher bias and highlighting the ethical issues that must be addressed to protect the participants (Long et al., 2020).

Selected Study Reference Author and Year	Country	Type of study	Method	Quality assessment
Bishop (2017)	UK	Quantitative	Systematic Review of Primary Care and Health Board data	Moderate
Davys et al. (2017)	England UK	Qualitative Interpretative Phenomenological Analysis	Semi-structured interviews	Moderate
Graham (2012)	UK	Qualitative Grounded Theory	Focus Groups	Low
Hemsley et al. (2013)	Australia	Qualitative Narrative Inquiry	Interviews	Low
Ilkhani (2013)	UK	Qualitative Health Care Research	Nominal Group Technique	Low
Markham (2008)	UK	Qualitative and Quantitative	Mixed methods Focus Groups and Questionnaires	Moderate
McNeilly et al. (2015)	Northern Ireland UK	Qualitative Phenomenology and Quantitative	Mixed methods Interviews, Talking Mats® and Questionnaires	High
Misuk and Emmett Gardner (2015)	Korea	Qualitative Phenomenology	Semi-structured interviews	Low

| Rabiee et al. (2005) | England UK | Qualitative | Talking Mats® Visual Symbols | High |
| Singer (2012) | America | Qualitative Narrative Inquiry | Semi-structured interviews Observational Guides | Low |

Table 3. Characteristics and quality assessment of the included studies

Additional aspects of the studies relating to are presented in Appendix 18 and which includes the full study title, the research interest, the ethical issues and recruitment, the study population, the key findings, the recommendations, the limitations and the quality assessment.

Theme	Paper
1. Cultural influences on QoL, health and emotional wellbeing	Seven of the ten selected papers focus on the cultural influences comprising spiritual, societal and religious aspects of lived experience that impact on Quality of Life (QoL), health and emotional wellbeing. The papers are: Rabiee et al. (2005), Singer (2012), Hemsley et al. (2013), Ilkhani (2013), McNeilly et al. (2015), Misuk and Emmett Gardner (2015) and Davys et al. (2017).
2. Complex Health Needs and Disabilities: the impact on relevant populations	Nine of the ten papers focussed on children diagnosed with complex health needs and disabilities and the families' views on services for disabled children in the UK, America, Australia and Korea highlighted similarities in the lack of understanding of the impact of living with disability by extended family members and care providers. The papers are: Rabiee et al. (2005), Markham (2008), Graham (2012), Singer (2012), Hemsley et al. (2013), Ilkhani (2013), Mc Neilly et al. (2015), Misuk and Emmett Gardner (2015) and Davys et al. (2017).
3. Research methodologies and approaches	All ten papers provided details of the research approaches, methodologies and methods applied within the studies. Rabiee et al. (2005), Graham (2012), Markham (2008), Singer (2012), Hemsley et al. (2013), Ilkhani (2013), Mc Neilly et al. (2015), Misuk and Emmett Gardner (2015), Bishop (2017) and Davys et al. (2017).

Table 4. Themes and relative study findings

2.8 Thematic Analysis results

Three themes were generated from the analysis; 1. Cultural influences on QoL, health and emotional wellbeing 2. Complex Health Needs and Disabilities: the impact on relevant populations 3. Research methodologies and approaches.

2.8.1 Theme 1- Cultural influences on Quality of Life (QoL), health and emotional wellbeing

In order to understand the cultural influences on access and use of healthcare there is a need to examine what are the actual cultural factors that impact on the access to and use of healthcare among populations. The World Health Organisation (WHO, 2010) International Classification of Disability coding system defined these children as having additional needs to their peers in relation to development, physical, emotional health and daily functioning and who require support beyond that provided by universal health services.

There are eight studies from the ten selected for analysis which bring cultural issues into sharp focus and reflect cultural attitudes towards children living with complex health needs and disabilities which are Rabiee, Sloper and Beresford (2005), Markham et al. (2008), Singer (2012), Hemsley et al. (2013), Ilkhani (2013), McNeilly et al. (2015), Misuk and Emmett Gardner (2015) and Davys et al. (2017).

Rabiee et al. (2005) found that negative cultural perceptions pervaded children who are disabled and who are within the social care system. The options for inclusion and participation were 'fragile and fragmented' and not given significance by social care staff.

Markham et al. (2008) identified that the culture of negative perception and underestimation of the abilities of children with SLCN impacts on the quality of life of children and families. Four themes relating to the quality of life experienced were presented:

1. Communication and frustration
2. Relationships and satisfaction with life
3. Support at school
4. Social activities

Positive and negative experiences were expressed within the themes and the possibility was raised that quality of life can be improved for children living with SLCN if suitable assessment and measurement tools were developed, validated and universally available.

Singer (2012) investigated the culture relating to school nurses caring for students with disabilities and found that the staff experienced barriers to optimum care provision due to general attitudes and misconceptions of disability and its impact from educators and clinicians in various fields of practice, including paediatrics, the specific field of childcare.

Hemsley et al. (2013) highlighted a culture in hospitals of staff not recognising the rights of children to use specialist equipment for Augmentative and Assisted Communication (AAC), whether high or low fidelity, and of a reluctance for staff to engage in communication training. Parents developed a culture of avoiding leaving the children alone for short or extended periods because of their anxiety and expressed views that staff undertake training.

Ilkhani (2013) reported that a culture had developed within parents of disabled children that staff delivered sub-optimal care and services to children with disabilities, support was insufficient resulting in life potential not being maximised.

McNeilly et al. (2015) conducted research with disabled children through the lens of social justice, a concept culture of inclusion and found that institutionalised cultures persisted. regarding lack of respect, tendency to view the child and family sub-ordinately or invisibly and the non-recognition of children's abilities.

Misuk and Emmett Gardner (2015) explored the impact of religion and the philosophy of Confucianism in Korea on public and family perceptions, especially grandparents. Confucianism affects most citizens in Korean society who are expected to positively contribute to that society, have high achievements and bring honour to the family. Due to the impediments of disability, many children and young people are unable to fulfil this expectation. This results in family embarrassment and public denial of the child, and this is tolerated in Korean society.

All of the studies identified that extended family members, gatekeepers, researchers, staff in health and education demonstrated little or no understanding of the impact on the quality of life and the health and emotional wellbeing of the children and families. The researchers highlighted negative impacts from not only the primary factors of ill health and disability but also the secondary factors of stigma, discrimination, underestimation of abilities, lack of safeguarding and the denial of children's rights. The study findings raise the awareness of healthcare providers to examine current healthcare services and to avoid significant physical and emotional harm. This can be achieved by improving the patient and family experience through cultural impact awareness, staff education and training. If the findings are not acted upon there is a risk of adverse childhood events (Bellis et al., 2015) increased mortality and morbidity, reputational and financial damage to health services, complaints and litigation similar to the issues highlighted by Frances (2013).

Davys et al. (2017) found that there was a culture where staff and public stereotyped fathers as lacking in interest and abilities to care for their disabled children and this perception resulted in their exclusion from significant discussions relating to the children, their treatment and plans for the future. Fathers reported high levels of stress and frustration with this situation and their lived experiences.

2.8.2 Theme 2- Complex Health Needs and Disabilities: the impact on relevant populations

Nine studies were included in this theme and are concerned with the theme of complex health needs and disabilities and the impact on the populations of children, families, researchers, gatekeepers and staff in health and education. The papers are:

Rabiee et al. (2005), Markham (2008), Graham (2012), Singer (2012), Hemsley et al. (2013), Ilkhani (2013), Misuk and Emmett Gardner (2015), McNeilly et al. (2015) and Davys et al. (2017).

Rabiee et al. (2005) stated that children's disabilities included the need for them to use AAC which are systems and techniques at various technological levels to help speech. An example of AAC is a computer assisted synthetic or digitised voice produced by movement, this purposeful movement can be subtle, such as head pointing, eye gazing and blinking to the more physically active movements of pressing keys on keyboards and electronic touch screen and physical buttons and switches. Without appropriate speech aids the quality of life for those diagnosed with speech and language impairments would be sub-optimal Murphy (1998b). They found that there is a lack of research with this population due to researchers being unfamiliar with alternative communication techniques and the requirement for training in how to use AAC communication methods. The findings that parents and teachers learned new aspects concerning the children's quality of life and likes and dislikes by using AAC were encouraging for the research population.

Markham (2008) explored the population of children living with Speech, Language and Communication Needs (SLCN) through the lens of the Speech and Language Therapy (SaLT) and identified factors of discrimination and higher costs of support required by the population due to needing additional educational provision (Disability Discrimination Act 2005). The research aim was to develop and validate a tool to measure the impact on the population's physical, emotional and educational attainment.

Graham (2012) discussed the population of fathers of children with disabilities and the focus groups' views confirm the lack of studies undertaken with this group. They identified a population of inflexible and restrictive professionals and related agency systems that do not communicate with or respond to each other. The risks and implications for sub-optimal care were magnified in cases where children were transitioning to other services or who required end of life care, problems that have been highlighted by Chambers (2018) and the Royal College of Paediatrics and Child Health (RCPCH, 2017).

Singer (2012) indicated concern regarding the citizen's right to speak which is often denied to populations with communication difficulties, especially for those with limited or no speech. They found that children with developmental and intellectual difficulties are disadvantaged due to School nurses and carers within education having little or no appropriate training in advanced and technological communication. There was also concern that some of the communication aids use by children were expensive pieces of equipment and fear of loss or damage to the aids prevented their use and disadvantaged the children's care and hence the children's educational needs are not met. There was an impact on the confidence of parents who felt unable to leave their children for long periods when inpatients in hospital due to the belief that their children's needs would be met. This situation has major implications for patient safety and wellbeing and risks failings in care through lack of staff training and experience. Similar failings were highlighted in the Mid Staffordshire Health Trust Inquiry into avoidable patient harm and deaths due to the lack of effective leadership and suitably skilled and trained staff (Francis, 2013). Staff were not invited to interdisciplinary meetings which discuss the children's needs and progress therefore denying this population of opportunities for appropriate support and suitable care interventions. In addition, Singer (2012) found that School nurses with the responsibility for children with disabilities did not always have the knowledge and expertise to teach the student nurse and carer populations the care and treatments required by the children. It was recommended that the school

nurse population of schools specialising in education for children with developmental and intellectual disabilities have their experiences or working compared to School nurses working in the mainstream schools provided for children not impacted by disabilities and that the population samples should be increased in future research.

The qualitative study undertaken by Hemsley et al. (2013) explores experiences of children diagnosed with cerebral palsy and communication difficulties and those of their parents during hospital inpatient episodes. This population of children spent longer than average periods in hospital and communication barriers arose because of the lack of staff time, knowledge, skills, experience and equipment, for example, AAC (Clark et al., 2001; CALL, 2020).

Ilkhani (2013) studied the population of children diagnosed with complex health needs and disabilities known to the Health Service because of complaints from parents of poor service delivery. The implications of poor care and unsafe practice to patient death and harm were clearly outlined by Francis (2013) and it was a reasonable decision for Ilkhani (2013) to review the status of services experienced by children and families. The findings confirmed parents reports of sub-optimal leadership, policies, care, lack of suitable care environments, equipment, especially relating to AAC and limited staff education and training. The negative implications of oversight of communication needs is documented in the Long-Term Plan in England (NHS, 2020) which mandates that communication needs are met within health and social care and that appropriate assessments regarding SLCN are required for compliance with the legislation and recommendations of the Disability Discrimination Act 2005 for all citizens. McNeilly et al. (2015) explored the independence, social justice and participation as their research topic, believing in the rights of citizens to be heard found that children and young people with communication needs are seldom heard due to a lack of participation, primarily because they are not invited to give their views. Findings from the study have implications for service providers due to the realisation that children and young people do not receive the appropriate

support and information required to enable their right as a citizen and a child to the best quality of life possible, an aim advocated by UNCRC (2009) and WHO (2010).

Misuk and Emmett-Gardner (2015) acknowledged researcher bias with the study population recognised as those with protective factors (Disability Discrimination Act 2005). This was due to their preconceived ideas about the strengths and vulnerabilities of children and families coping with disability. Issues of discrimination and the denial of a disability were identified where the study population is in the minority for example, due to ethnic diversity. Misuk and Emmett-Gardner (2015) noted limited generalisability of the cultural issues in the Korean population compared to peers in the UK. The findings from the Korean population have resonance within minority groups of UK citizens with Black, Asian and Minority Ethnic groups (BAME) populations that are negatively labelled and who are recognised as requiring additional support from statutory services, for example, displaced people from all populations, minority ethnic groups and refugees who are seeking asylum in the UK.

Davys et al. (2017) considered the negative impact of public perception on the population of fathers whose adult children were living with a learning disability and of how males are stereotyped as being strong and insensitive to emotion. The needs and concerns of fathers as a population were not considered and the differences perceived in the roles of mothers and grandmothers to that of fathers regarding the provision of appropriate care for significant periods were highlighted. The importance of understanding of people's perspectives in relation to the actions taken was discussed by O.Nyumba et al. (2018).

2.8.3 Theme 3- Research methodologies and approaches

This theme included all the selected papers which examine the research approaches, methodologies and methods applied within the studies. A wide range of approaches were applied within the studies, quantitative, qualitative, mixed methods and the novel Talking Mats® approach (Murphy, 1998b). The

methodologies applied were phenomenology, Interpretative Phenomenological Analysis (IPA), Grounded Theory, Narrative Inquiry, Health Care research, Talking Mats® and non-commercial picture card tools depicting life events and emotions. The methods used were focus groups, nominal group technique, interview, semi-structured interviews, AAC techniques, observational guides, questionnaires, systematic review and audit.

The papers are: Rabiee et al. (2005), Markham (2008), Graham (2012), Singer (2012), Hemsley et al. (2013), Ilkhani (2013), McNeilly et al. (2015), Misuk and Emmett Gardner (2015), Bishop (2017) and Davys et al. (2017).

Rabiee et al. (2005) first piloted their interviews with children who were living with complex needs and had ability of speech within their sphere of communication. It can be seen from the discussion of Rabiee et al.'s (2005) results that this research issue is complex one, requiring careful consideration and critical thinking by the researcher. Findings which are perceived as less than rigorous, or appear to have little generalisability, or both, may not be accepted or explored further by the research community (Machi & McEvoy, 2019). Rabiee et al. (2005) were aware of the risks to the rigour of their study due practicalities of developing a new, untested tool through the work undertaken by Murphy (1998a) who developed a visual communication aid using a small floor mat and picture cards. The exclusion of deaf children may raise questions, particularly in relation to the aim of the right to inclusion and participation (UNCRC, 2009) and especially because the data gained was to inform the development of a relevant tool for the next stage of the study which conducted interviews and was sensitive to the non-verbal behaviour displayed by children with no speech or limited speech.

Markham (2008) developed a research interest in children diagnosed with complex health needs, speech impairments and disabilities due to working in the discipline of Speech and Language therapy. A qualitative approach was used with mixed methods for the study with the aim to discover the quality of life experienced by children and young people diagnosed with speech

impairments. Information from 13 Focus groups helped the development of a reliable measure which was used to survey 303 children and young people with speech impairments about their health experiences. It is interesting to note that Markham (2008) was concerned about the validity of the newly developed quality of life measure and its application to clinical practice but the findings from the use of the measure concurred with those of UNCRC (2009) that children diagnosed with complex health needs, speech impairments and disabilities are disadvantaged in health, education and leisure provision settings. Further studies are recommended due to limitations found in using the quality-of-life measure.

Graham (2012) used grounded theory as the methodology and Focus groups with Field notes as the method to obtain data on the way agencies from education, health and social services coordinate provision for children diagnosed with complex health needs and disabilities. Constant comparative analysis helped shape the findings regarding the value of an identified person or key worker to coordinate the range of services children diagnosed with complex health needs and disabilities require to achieve an acceptable quality of life.

Singer (2012) used Narrative Inquiry and semi-structured interviews to gain in depth information from experienced nurses caring for children diagnosed with complex health needs and disabilities.

Hemsley et al. (2013) used the Focus Group methodology and used Narrative Inquiry for participant interviews. Hemsley et al. (2013) expressed disappointment and concern that each Focus Group could only recruit the minimum of three participants per group allowed in their ethics approval. The low number participating may not be an indication of a lesser value of the data received or this would call into question the validity of the one-to-one interview in research practice.

The description of Focus Groups as a methodology, and not as a method, may be supported by researchers O.Nyumba et al. (2018) but challenged by other researchers like Parahoo (2014) who describe Focus Group interviews

as a research method for data collection. The optimum number for an effective Focus Group is currently debated in research and contested by O.Nyumba et al. (2018) who reviewed 170 papers on this topic. They found that Focus Group discussion was rarely used as a unique technique and noted the absence of reasoning for choosing Focus Groups as a methodology.

There was minimal consensus on the number of participants for an effective Focus Group with suggestions of between 3 and 21, 7 to 12 and a median of 10 participants. Half of the studies reviewed by O.Nyumba et al. (2018) did not detail the numbers of participants who attended the Focus Groups. Hemsley et al. (2013) were limited by the small number of participants recruited and the diversity of the chosen population which restricts the generalisability of their findings.

Ilkhani (2013) that interviews were conducted with 14 members of Health Staff and an unconfirmed number of students using the Nominal Group Technique method. It was established on review of the thesis that the study was categorised as an audit which had received approval from the Health Board. Service evaluation by audit may be contested as a true research methodology but it is clear from the findings that valuable data can be gained which informs future service delivery and quality.

McNeilly et al. (2015) recruitment of 18 children and young people to their study was low due to the reluctance of gatekeepers regarding recruitment and their perception that children diagnosed with communication needs could not relate their views and experiences and it was futile to ask them. McNeilly et al. (2015) were concerned that the 24% response rate from the parent survey, 77 in total, limited their analysis of findings, the transferability and generalisability of results.

Findings from the study have implications for service providers due to the realisation that children and young people do not receive the appropriate support and information required to enable their right to the best quality of life possible, an aim advocated by UNCRC (2009).

An important note from Hemsley et al. (2001, 2013) and McNeilly et al. (2015) for researchers with an interest in the experiences of children and young people diagnosed with complex health needs and disabilities is the difficulty in first accessing this research population, due to ethical and gatekeeper issues, the uniqueness within diagnoses and the range of methods of communication children use which reduce transferability and generalisability of results gained.

This system was categorised as a low technology aid and the system was subsequently enhanced to allow a high technology version to become available through computer software (Communication, Access, Literacy and Learning (CALL), 2020). The low technology visual aid tool developed by Rabiee et al. (2005) following their first interviews built on Murphy's (1998a) work, but the newly developed tool had no guarantee of credibility.

Misuk and Emmett Gardner (2015) employed a phenomenological approach to gain the lived experiences of six mothers caring for children with severe disabilities. The use of semi-structured interviews, audio recordings and field notes enabled a comprehensive picture to emerge from the research regarding the mothers' roles, the support obtained and the perception of the roles of grandparents, both positive in reducing parental stress and negative in their becoming over-involved and undermining parental care.

Bishop (2017) was involved in a large-scale cohort project looking at children born in the city of Bradford, Northeast England to mothers over the age of 34 years and the incidence of congenital abnormality within 13,857 births reviewed via medical records, the Primary care database and questionnaires completed by mothers following birth. The early identification and classification of the children's health needs and disabilities using the World Health Organisation (WHO, 2010) International Classification of Disability coding system would assist in planning health, education and social services and provide an integrated approach to care. This approach is one advised by the Royal College of Paediatrics and Child Health (RCPCH, 2017) in improving health outcomes for children and ensuring resources are efficient

and appropriately targeted. The limitations of current coding systems in recognising the extent and complexity of disability and complex health needs in children is prohibitive and could lead to underestimation of the finance required to provide adequate services.

Davys et al. (2017) chose the qualitative approach of IPA (Smith et al., 2009) and semi-structured interviews to gain in depth information from seven fathers whose adult children had a diagnosis of learning disability. They found that few studies were undertaken with fathers and underrepresented groups are described as seldom heard by organisations who have raised their concerns on this issue (WHO, 2005). It may remain difficult to generalise findings, despite participant numbers being increased, due to practical difficulties, for example, fathers' working patterns or the generally accepted reluctance of men to be recruited to research studies (Mueller & Buckely, 2014). The choice of IPA is appropriate when considered against the aim to comprehensively investigate deep feelings from emotional experiences.

2.9 Discussion

The review of the ten included studies explored the evidence relating to research undertaken with children living with complex health needs and disabilities, the families who care for them and the teams involved in providing health care, social care and education. The methodologies, methods, study sample, ethical issues, limitations and recommendations evident in the ten included studies provide significant information to add the body of knowledge on the topic and this will be discussed in relation to the themes and sub themes elicited from the studies.

2.9.1 Theme 1- Cultural influences on Quality of Life (QoL) and emotional wellbeing

The multicultural issues raised within the study, the barriers to care and the variation in attitudes of young people, families, staff, carers, healthcare providers and gatekeepers are detailed in Appendix 18. The studies used

qualitative approaches and found factors that raised the predominantly negative impact of the lived experiences of children with disabilities and their families. Little evidence was seen in the included studies regarding the healthcare providers awareness of children and families' involvement in policy making and in the recognition of children's rights and safeguards. There is no acknowledgement of the negative impact that Adverse Childhood Experiences (ACEs) (Bellis et el., 2015) has on children's physical health, emotions and mental wellbeing throughout the life course and into adulthood.

2.9.2 Theme 2- Complex Health Needs and Disabilities impact on populations

Nine of the studies used qualitative methodologies with three using mixed methods, Rabiee et al. (2005), Markham (2008) and McNeilly et al. (2015). The mixed methods studies provided credible results which may encourage further research on the topic and promote the use of mixed methods. The methods used were focus groups, nominal group technique, interview, semi-structured interviews, AAC techniques, observational guides, questionnaires, systematic review and audit. Two studies, Rabiee et al. (2005) and McNeilly et al. (2015) chose the novel method Talking Mats® (Murphy, 1998b), a resource that aids and improves communication. The participants demonstrate whether they like, do not like or are impartial to a particular phenomenon depicted as a picture symbol and the picture cards are placed by the participant on a fabric mat resulting in a visual, pictorial representation of the participant's story.

The researchers would have required accredited training to use Talking Mats® to ensure the credibility and consistency of the Talking Mats® method and the necessity for this may deter researchers from using the method or for seeking funding to employ a trained practitioner to undertake the interviews and interpret the completed picture.

The quantitative study (Bishop et al., 2017) reviewing data from a multi-ethnic population regarding children born with congenital abnormalities is valuable to the topic evidence base because it provides information about

860 children aged up to five years whereas the other nine studies, as is appropriate for the qualitative methodologies chosen, have small number of participants. There is a paucity of evidence on this research top because only a few opportunities have been taken by researchers to address questions relating to the lived experiences of children diagnosed with complex needs and disabilities and how this affects families and healthcare providers.

The staff and carers' views presented in the studies by Markham (2008), Singer (2012), Ilkhani (2013) and McNeilly et al. (2015) highlight suboptimal experiences and barriers whilst working with the populations impacted by complex health needs and disabilities (Theme 3). The lack of training and equipment available to carers was a significant factor in the reporting of negative experiences and cultural barriers. The duty of care placed on nurses as carers to practice safely with the appropriate skills and knowledge is clearly stated by the Nursing and Midwifery Council (NMC, 2018) and this correlates the findings in Themes 1, 2, 3. The families' views on services for disabled children in the UK, America, Australia and Korea highlighted similarities in the lack of understanding of the impact of living with disability by extended family members and care providers.

2.9.3 Theme 3- Research methodologies and approaches

The qualitative methodologies of Phenomenology, Narrative Inquiry, Grounded Theory and Interpretative Phenomenological Analysis used within nine of the studies were suitable for the research questions posed. Appropriate methods were employed, and these were focus groups, nominal group technique, interview, semi-structured interviews, AAC techniques, observational guides, questionnaires, systematic review and audit.

Ilkhani (2013) found that the choice of the Nominal Group Technique (NGT) method, which gathers groups together to encourage spontaneous opinion or brainstorming, usually in response to an identified issue requiring action for improvement. NGT enabled Health Care Support Workers have more confidence in expressing views about the nursing care delivered, particularly

in relation to care that was considered suboptimal quality. NGT could be used more widely in health services because it complements Health Action Research and would suit research questions seeking to address service delivery issues and the identification of training needs. The five studies which interviewed healthcare staff found that there were training needs to address to enable the children receive appropriate safe care to avoid possible risks of harm clearly identified within the Francis (2013) report. The fact that in Bradford alone 860 children will require additional healthcare and support from multi-professional teams across the life course (Bishop et al., 2017) would alert healthcare providers to assess service provision for suitability to meet the children's healthcare needs.

2.9.4 Limitations and recommendations for future research

All the included papers recommend that further research should be undertaken with children and families who are living with the impact of complex health needs and disabilities. The researchers also recommend that cultural, spiritual and religious issues are considered when developing and providing health and education services in addition to acknowledging the public's negative perception of populations living with disabilities (NHS, 2020).

Rabiee et al. (2005) and McNeilly et al. (2015) recommend that more novel approaches are employed to address the issues of intentional or non-intentional exclusion of this population from research, for example, Talking Mats® (Murphy, 1998a) a resource that aids and improves communication. The participants demonstrate whether they like, do not like or are impartial to a particular phenomenon depicted as a picture symbol and the picture cards are placed by the participant on a fabric mat resulting in a visual, pictorial representation of the participant's story. The researchers must acquire accredited training to use Talking Mats® to ensure the credibility and consistency of the Talking Mats® method and the necessity for this may deter researchers from using the method or for seeking funding to employ a

trained practitioner to undertake the interviews and interpret the completed picture.

In addition, the misconception that children are unable to contribute because of their disability or speech, language and communication needs must be removed to ensure that children's rights are upheld as stated by the United Nations Conference on the Rights of the Child (UNCRC, 2009). Singer (2012) recommended the improvement of training and education of staff working with children diagnosed with complex health needs and disabilities. Further recommendations from the studies are that suitable safe services are provided to prevent harm (Bellis et al., 2015). In addition to specialist training regarding the care of disabled children being provided during staff orientation to roles caring for children.

2.10 Conclusion

Chapter 2 examined the breadth of studies relating to the views of children with disabilities and their families and included an exploration of grey literature found in government sources. Current literature was explored relating to children living with complex health conditions and disabilities, including Speech, Language and Communication Needs (SLCN). The objective of the LR was to understand if children's rights to participate were upheld and safeguards applied whilst receiving healthcare.

The findings from the LR, the semi-structured interviews, case study and from Talking Mats® raised the following key points:

1. The LR demonstrated that children with disabilities experience stigma, discrimination and exclusion and that parents require support beyond the universal services available to uphold human rights and to experience an optimum quality of life (WHO, 2010). Healthcare providers should also address the health literacy (Public Health England, 2015) of children and families to enable their effective participation and contribution to the development of policy and

services, helping eliminate the risk of child and family participation becoming a token gesture or non-existent.

2. The semi-structured interviews found that children and parents were tired and frustrated living with disabling conditions, diabetes, respiratory disease, cardiac illness, cognitive and developmental impairments, speech, language and communication needs and regressive illness. Quality of life was negatively impacted particularly where the child could no longer achieve milestones in development that were previously met.

3. The Talking Mats® method demonstrated the abilities of the researchers to communicate effectively with children living with SLCN, complex health diagnoses and disabilities and to gain the children's views. The qualitative and quantitative methodologies demonstrated within the review were appropriate for the topic and the novel methods employed, for example, Talking Mats® added another valuable dimension to the research studies.

Each of the three research methods employed in this study identified that more research is required with children living with disabilities whose right to speak is seldom acknowledged (NHS, 2020). The LR found that research can be undertaken with a wider range of study populations and that the issues raised regarding access to the participants due to reluctant gatekeepers must be addressed. The findings highlight the importance of further exploration of the views of children with disabilities, complex health and communication needs and their families.

The exploration must extend to healthcare service providers, educationalists and staff with caring responsibilities to gain a broader perspective of the lived experiences of the participants. Addressing the perceived and actual multi-cultural issues and barriers would be instrumental in enhancing the patient experience (RCPCH, 2018) and in preventing the negative impacts of Adverse Childhood Experiences highlighted by Hardcastle et al. (2019).

The use of the Nominal Group Technique (Ilkhani, 2013) has merit for health staff who have identified service issues regarding quality of service or staff training needs and this technique could result in the development of an Action Plan for Improvement.

The result of the LR confirms that the most suitable approaches for the data collection to apply to the proposed study are qualitative, using semi-structured interviews, case study and novel using Talking Mats® which best fit the research question. Suitable frameworks to analyse the qualitative data gained in this study are Interpretative Phenomenological Analysis (IPA) and the Effectiveness Framework of Functional Communication (EFFC) as detailed in Chapter 3.

In seeking to explore children and families' views on health services it is evident from the LR that the most appropriate methods to employ for the study are interviews which are semi-structured and Talking Mats® techniques. These methods aid the participants stay guided on the topic but provides the flexibility required for the participant to further explore their unique lived experiences.

2.11 Chapter summary

This chapter summarised the rationale for undertaking the review of the literature regarding children's rights, safety and the legislation available in relation to children and families' experiences of living with disabilities complex health conditions.

The impact of policy, legislation and the quality of the service provision in healthcare were significant to the literature being sought and was explored. Due consideration was paid to the ethical considerations required for each of the studies. The discussion detailed the literature search, the process of selecting relevant studies to review, including the PRISMA criteria (Moher et al., 2009) used for the inclusion and exclusion.

This chapter described the frameworks employed for analysis and the quality of evidence gained (Long et al., 2020; Schünemann et al., 2014). In addition to how this approach enabled a credible literature review to be undertaken along with the analysis of the selected studies.

The results provided an evidence base on which to draw a conclusion which relates to several factors. These are the suitability of the studies, the

methodologies, methods, study sample, limitations and recommendations for future research.

Examining the evidence within the literature review strongly suggested that two qualitative approaches are best suited the proposed study, phenomenology influenced by Interpretative Phenomenological Analysis (Smith et al., 2009) and the novel approach of Talking Mats® (Murphy, 1998b). In addition, the population sample became evident (Smith & Noble, 2015) based on the findings of the literature review and the methods cited. The semi-structured interview method with purposive samples of children of living with a complex health condition and disabilities, including those of their parents, would best suit the research question being proposed.

The limitations encountered in undertaking the literature review process were highlighted within this chapter and this provided guidance in relation to conducting the proposed study. Listening to the seldom heard voices of children and families living with disabilities, complex health and communication needs aims to enrich the body of existing knowledge on this topic and to provide insight into the lived experiences of those children and their families who are often marginalised within health care systems (Davys et al., 2017).

CHAPTER 3:

RESEARCH METHODOLOGIES AND METHODS

This chapter will provide details of the research methodologies and methods used to conduct this qualitative study and to explore the research question: 'What are the views and experiences of children living with disabilities and complex health needs and those of their families?'

3.1 Introduction and chapter overview

Carter et al. (2016) explained that children with complex health needs and disabilities live with one or more health diagnosis which require a high level of nursing and medical care. The children's health conditions are often unstable and can result in repeated and protracted hospital admissions which Whiting et al. (2019) believe impacts on the children and families' quality of life and coping skills.

This study aims to add to the evidence available relating to the impact on children and families of living with complex health needs and disabilities through qualitative research.

Qualitative research will be outlined in Section 3.1 and will be discussed as the chosen approach for this study. In addition, the influence of qualitative phenomenological methodologies employed by Smith et al. (2009), and the qualitative research methods applied by Coad et al. (2019) and Murphy (1998a) will be explored in this section.

Section 3.2 will introduce the research theories that are examined within this thesis, in addition to the methodological approaches selected and applied to the study. The reasons will be provided for the use of the qualitative approach applied to this study and for the qualitative methods employed for the data collection. The research design will be presented in Section 3.3 and the reasons will be provided in Sections 3.3.1 to 3.3.2 for using interviews in qualitative research, including the choice of semi-structured interviews to

collect rich, deep information from the participants in this study (Dearnley, 2005). The argument will be presented, supported by the work of McNeilly et al. (2021), that participants of all ages and abilities can be invited to explore their lived experiences, provided that a suitable approach and method are employed. Murphy (1998a) developed Talking Mats® as a method of communication and inquiry to use with participants of all ages who are living with disabilities, complex health conditions and SLCN. The reasons will be presented for applying an adapted Talking Mats® within this study to provide a dichotomous choice for the participants on the concepts and domains of daily living presented to them during interview. The use of Word Cloud (Sellars et al. 2018) is discussed as a useful service quality feedback method and as an adjunct to the data collection within this study.

Section 3.4 to 3.4.2 will explain the ethical considerations for this study and will outline the practical issues involved with the ethics process, including how the ethical approvals for this study were sought from the three relevant ethics committees, the University Ethics Committee, the Regional Ethics Committee, and the Health Board Ethics Committee. Section 3.5 will present the recruitment process and Section 3.5.1 will discuss the sample selection. The research process will be discussed in Section 3.6 to 3.6.1.3 and the data collection through a phenomenological approach and the semi-structured interview method. The Talking Mats® method will also be detailed within this chapter.

Section 3.7 to 3.7.5 will outline the data analysis process and will present a discussion on rigour, transparency, validity, reliability, and credibility. The choice of analytical approaches, including Narrative Analysis, Interpretative Phenomenological Analysis (IPA) developed by Smith et al. (2009) and the World Health Organisation (2001) Effectiveness Framework of Functional Communication (EFFC) are presented in Section 3.8 to 3.8.3.

The six steps of analysis of IPA (Smith et al., 2009) will be introduced in Section 3.8.5 of this chapter and will be used to present the analysis of the data collected during the case study and the semi-structured interviews.

A timeline of the study will be provided in Section 3.8.6 and this chapter will conclude with a final summary in 3.9.

3.2 Qualitative research

Aveyard (2018) discussed the value of qualitative research and the various methods available to researchers when conducting a study, and the relevance of these in relation to this study are outlined in this section. Matto (2021) argues that philosophical paradigms are crucial to understanding the quality of research and that they provide a pedagogical or academic value to the science of research, a point which is relevant to the academic purpose of this study. Mackenzie and Knipe (2006) extol the value of the sets of beliefs, theories and models known as philosophical paradigms, from which qualitative research approaches, methodologies and methods are developed and implemented. Parahoo (2014) defines qualitative methodology as research that encompasses several approaches of inquiry, and which explores human experiences and behaviour.

The value of qualitative studies in gaining rich, in-depth information about personal experiences is highlighted by Seale et al. (2007) and Coad (2020) who advise that qualitative approaches and qualitative methods of data collection can extend existing knowledge in an area of specific interest. Qualitative approaches describe and explain relationships within phenomenological experiences, relating to the familiarity of something, and aims to understand them (Smith et al., 2009). Qualitative studies, including the individual case studies presented in Section 3.6.1.2, use a qualitative approach and a qualitative method to explore the personal stories from similar groups of people, known as participants. The personal, lived experience is defined as a phenomenon (Hammersley, 2013) and the qualitative methods applied to this study incorporate the concept of interpretivism which seeks to interpret, and to understand the meaning that the participants attach to a phenomenon, and their personal experiences of a phenomenon (Gerrish & Lathlean, 2015). The issues and benefits of drawing on a range of philosophies in modern research and adapting qualitative approaches to target the focus of the research question were raised by

Mitchell et al. (2021). An example of this was illustrated by Menage et al. (2020) who used the underpinning of interpretive phenomenology and guidance from Appreciative Inquiry (AI) to provide a blended qualitative approach to explore compassion in maternity care.

An adapted approach was applied by Dewar et al. (2020) to reframe a qualitative approach to gain the positive, lived compassionate experiences from women's maternity care rather than seeking the women's negative experiences on the lack of compassion in maternity care. This study used an adapted qualitative approach to enable the study to be conducted with children who required a flexible, individualised approach to their participation in the study. Punch (2014) explains that whilst each participant's account of their lived experience is unique, there are similarities and differences within the experiences, known as themes, that become evident during the interviews and following the data analysis. This study used an adapted qualitative approach, and this will be explained in Section 3.6.1.3 Talking Mats®.

It is argued by Menage et al. (2020) that historically qualitative researchers encountered difficulty in enabling the scientific community to recognise qualitative research as credible and valuable, or as having the replicability and rigour attributed to quantitative approaches. In addition, the scientific community have held quantitative methodologies and methods as the gold standard in research for validity and credibility of design, rigour and results, for example and particularly, the Randomised Controlled Trial (RCT). Mitchell et al. (2021) provided evidence that qualitative approaches used in research demonstrate rigour, validity, transparency, reliability and produce credible results. According to Oflazoglu (2017) the tenets of the qualitative approaches are opposed to those of quantitative methodology which are centrally concerned with providing scientific fact which has roots in hypothesis testing. The numerical and objective measures within quantitative research may manipulate or control events and incidences to produce statistics that can be generalised to the same or similar experiments (Donaldson et al., 2009). It is acknowledged that both qualitative and

quantitative methodologies provide the means of obtaining research data and each is used in relation to the suitability of the approach to the research question being posed. Cohen et al. (2011) believe that the contributions from researchers who used qualitative methodologies and methods across the last four decades, and the publication of the research studies, have helped establish qualitative research as a legitimate form of inquiry. Hammersley (2011) highlights the increasing acceptance of mixed, multi-method or combined methods studies in research where researchers use both qualitative and quantitative methodologies. To enable improved confidence and familiarity in qualitative research techniques Hammersley (2013) advises that researchers search for the relevant tools to help conduct qualitative studies as a credible, rigorous and valid exercise. Clark et al. (2014) support this view and provide the frameworks to support the promotion of qualitative research into questions that are relevant to address within the field of health and social care sciences. The intent of qualitative research is the exploration of cultures and sub-cultures, and this is enabled by using the most suitable qualitative approach and the employment of the most appropriate methods for the research question (Holloway & Galvin, 2017). The suitability to this study of the approaches discussed in this chapter was considered in relation to the proposed research question to enable the most appropriate qualitative methodology and relevant methods to be selected.

3.3 Methodologies

Bordogna (2021) advises that several qualitative methodologies can be considered when proposing a qualitative study and each methodology enables rich personal data of lived experiences to be obtained from participants. The qualitative approaches predominantly applied in qualitative research are Ethnography, Grounded Theory, Phenomenology, Action Research and Health Care Research (Howlett, 2020). The important stage of method selection within the research process is explained by Gerrish and Lathlean (2015) who state that the data collection method must be the correct fit with the methodology and be relevant to the research question being asked. This study is led by phenomenological principles which have

informed the choice of methodologies. Phenomenological methodologies seek rich, deep information from the lived experiences of participants (Bordogna, 2021) and this study aims to gain a wealth of in-depth views and experiences from children and their families about the healthcare they receive. This chapter explores the suitability of the qualitative methods employed in this study in relation to the research question being asked.

Gerrish and Lathlean (2015) advise that following the selection of an appropriate methodology, a suitable method or methods of data collection must be chosen, for example, interviews. This study applies three methods of data collection, semi-structured interviews (Smith et al., 2009), case study and Talking Mats® (Murphy, 1998a). These are considered as the most appropriate methods for the data collection in this study and are discussed within this chapter.

According to Flewitt (2006), interviews can be unstructured, structured and semi-structured. Unstructured interviews allow the participant or interviewee the freedom to speak for the length of time desired, structured interviews enable data collection whilst guiding the participant through the interviewer's questions, and semi-structured interviews afford the participant the flexibility to answer the researcher's questions from personal experience, whilst they remain focussed on the researcher's topic of interest.

Dearnley (2005) advocates semi-structured interviews as enablers of confidential discussions within a flexible framework that provides an accurate representation of the participants' views. Preece and Jordan (2010) recommend that the methods and interview techniques selected by researchers to elicit authentic and credible data must provide equity and parity of access for the participants. BERA (2018) advise that equity is an important factor to observe true diligence in the researcher's ethical duty of care and that the participants may have a range of communication abilities and disabilities to consider. In addition, communication issues must be acknowledged by researchers to enable ethically informed actions and the required adjustments to be made to the research proposal.

3.3.1 Methodology: Phenomenology, Interviews and Case study in Qualitative Research

Holloway and Galvin (2017) explain that phenomenology is a qualitative, philosophical approach which stems from the hermeneutic paradigm attributed to the philosophers Husserl and Heidegger. The hermeneutic paradigm and the concept of phenomenology aim to widen the understanding of the impact of phenomena, which is something that is experienced, on human thoughts and behaviour. Phenomenological inquiry is centrally concerned with a person's view of the phenomenon and, according to Gerrish and Lathlean (2015), the interpretation of the individual's unique experience. The phenomenological approach seeks rich deep information from individuals on their experience of something that has happened to them, the phenomenon. Bordogna (2021) states that phenomenology is a suitable approach for an inquiry about being in the world and experiencing the world and this is appropriate when seeking the views and experiences of a person or a group of people who have undergone similar, but unique, experiences. An interview schedule is used to gain data from a small number of participants, for example, those who have received healthcare services or are living with the same clinical condition. The data collected is reviewed and synthesised to produce themes, followed by further review to elicit sub themes until the significant facts and issues are identified and the findings can be presented. A phenomenological approach enables participants relate their unique, rich, deep experiences and the process of analysis extracts the themes relevant to the research interest facilitating the formulation of findings.

The use of a phenomenological approach for qualitative studies, as supported by Bordogna (2021), is suitable for the proposed study because the principles, framework and methods fully meet with the proposed study aim and objectives. The qualitative data gained will enable themes and sub-themes to be generated which will enable the presentation of the study's findings (Holloway & Galvin, 2017). Interviews may then proceed in the knowledge that an equitable process has been followed for all participants.

The importance of participants living with SLCN being supported to communicate effectively in research was also raised by Preece and Jordan (2010). Participants may be fully able to answer questions posed during interviews, but some participants may require support with communication, for example, those living with SLCN. The advice from the National Institute for Health Research (NIHR, 2019) is that effective participation must be enabled to uphold the rights of a person to be heard. Researchers should become familiar with examples of supportive communication systems used by people living with SLCN to enable them to meet their ethical and moral obligations to participants. Stans et al. (2019) state that the communication aids frequently used by people living with SLCN are Augmented and Assisted Communication (AAC) systems. These are based on symbols and pictures such as Makaton or Talking Mats® (Mundt, 2020) and on hand gestures as used sign languages, for example, British Sign Language (BSL) (Riley, 2017).

3.3.2 Methodology: Phenomenology and Talking Mats®

The influence of a phenomenological approach when using the Talking Mats® method will be examined in this section. Wojner and Swanson (2007) explain that the concept phenomenology was drawn from the original teachings of philosopher Edmund Husserl (1859-1938). The tenets of Husserl's work, which include accepting the participant's 'lifeworld' as their personal, concrete perception of the things, the phenomenon, experienced are discussed. The term Descriptive Phenomenology (DP) was applied to Husserl's concept and describes studies which investigate the perspectives and experiences of the lifeworld of the participant independently to that of the researcher. A feature of DP is 'bracketing', which is the technique of suspending the researcher's perception and lifeworld from the lifeworld of the participant. In addition, Wojner and Swanson (2007) outlined the further development on Husserl's seminal work by philosophers Heidegger, Kierkegaard, Sartre and Merleau-Ponty who engendered the concept of Hermeneutic (Interpretive) Phenomenology (HIP). The difference between HIP and DP is that the researcher's background and worldview is accepted

as an influence on the study and combined with that of the participant gains a blended perspective of the phenomenon during the research interaction.

Table 5 details the comparison of DP and HIP conducted by Wojner and Swanson (2007) and the key distinctions noted within the two approaches. Reviewing the table enabled the selection of the most suitable approach to best inform this study and to the application of Talking Mats®. Descriptive Phenomenology was chosen as the best fit to influence and inform Talking Mats® which was applied in this study to seek the views of child participants living with disabilities and SLCN.

Descriptive Approach	Interpretive Approach
1. The emphasis is on describing universal essences	1. The emphasis is on understanding the phenomena in context
2. Viewing a person as one representative of the world in which he or she lives	2. Viewing a person as a self-interpretive being
3. A belief that the consciousness is what humans share	3. A belief that the contexts of culture, practice, and language are what humans share
4. Self-reflection and conscious "stripping" of previous knowledge helps to present an investigator-free description of the phenomenon	4. As pre-reflexive beings, researchers actively co-create interpretations of phenomenon
5. Adherence to established scientific rigor ensures description of universal essences or eidetic structures	5. One needs to establish contextual criteria for trustworthiness of co-created interpretations
6. Bracketing ensures that interpretation is free of bias	6. Understanding and co-creation by the researcher and the participants are what makes interpretations meaningful

Table 5. The Key Distinctions Between the Descriptive and Interpretive Approach Source: Wojner and Swanson (2007).

Descriptive phenomenology applied to Talking Mats®

1. The emphasis on describing universal essences; this applies to Talking Mats® through the rights of the child to have their voice heard, Article 12, UNCRC (1989).

2. Viewing a person as one representative of the world in which he or she lives; this will apply to the lifeworld of the child living with a disability or SLCN, this world differs from peers who have no additional health needs but is a distinct environment where the universal principles of disability assessment and treatment apply (Bercow, 2018).

3. A belief that the consciousness is what humans share; this concept may not be apparent due to the ages and cognitive abilities of the children.

4. Self-reflection and conscious "stripping" of previous knowledge helps to present an investigator-free description of the phenomenon; this factor can be applied by the researcher to the topic.

5. Adherence to established scientific rigor ensures description of universal essences or eidetic structures; the study will be conducted following the stringent rules of research of BERA (2018) which will support rigour and the participants' rights.

6. Bracketing ensures that interpretation is free of bias; this will be met by following the code of conduct for nurses undertaking research (Nursing and Midwifery Council, 2018 and BERA, 2018).

The Talking Mats® resource and method

The Talking Mats® method is a low technology, interactive, evidenced based, quality assured, structured resource developed by Murphy (1998a) to facilitate person-centred communication with people of all ages living with disabilities and SLCN, including no speech. Talking Mats® enables the person, known as the thinker, to freely express their feelings about their

experiences of daily life through their consideration of the relevance of the Talking Mats® cartoon style picture symbols presented to them by a Talking Mats® practitioner. The additional advantages of the Talking Mats® method are that the thinker has control over the communication process, with as much time as is needed being given to the thinker to enable the expression of opinions about what matters to them. The use of the short, staged approach to the two-person conversation within the Talking Mats® exercise may be less anxiety provoking for the thinker than a traditional interview method (Murphy, 1998a). The Disability Discrimination Act (2005) and the NHS Health Scotland Delivery Plan 2019-20 (Scottish Government, 2019) mandate that communication needs are met for patients within health and social care. The cited legislation states that it is not acceptable for individuals in society who are identified as seldom heard or hard to reach to be excluded from giving a view on their personal health and social experiences. Light and McNaughton (2014) highlight the development of a new era of AAC for people living with SLCN and indicate that there are barriers preventing effective participation in public consultations held with legislators, policy makers and health and social care service providers. Stans et al. (2019) indicate that appropriate assessments are required regarding SLCN services to measure the compliance with the legislation and the concordance with recommendations on effective communication. It is further noted by Stans et al. (2019) that the responses often offered by health practitioners state that appropriate communication methods are either unavailable, or that there is a lack of trained clinicians to apply suitable communication methods for the individual. McNeilly et al. (2021) dispute this view and present the argument that Talking Mats® (Murphy, 1998a) provides an evidence-informed method of alternative communication for people living with disabilities and SLCN. The Talking Mats® resource (see Figures 2 & 3) was developed by Murphy (1998a) and is a commercially produced package which comprises of a resource bag containing specific bundles of targeted resource packs relevant to life experiences. The picture cards facilitate communication on the domains which relate to health, activities of daily living, emotions, social issues, and relationships. The resource contains the 'Top Scale', a 3-point visual scale which indicates likes, dislikes and an 'undecided or do not mind'

status. The cards relating to a particular topic are known as the 'Central Topic' or domain and a selection of 'Option' symbols relating to the Central Topic enable the thinker, choose a card relevant to their opinion or experience. The topic's option cards are offered by the trained Talking Mats® practitioner to the thinker who places the card without influence from the practitioner onto a textured mat. The mat used is a domestic floormat which is not included in the resource pack and must be purchased separately. The dimensions of the mat are approximately 45cm wide, 75cm in length and 2cm depth and the mat may be folded and carried in the resource bag.

Figure 2. Talking Mats® Top Scale, Topic and Options
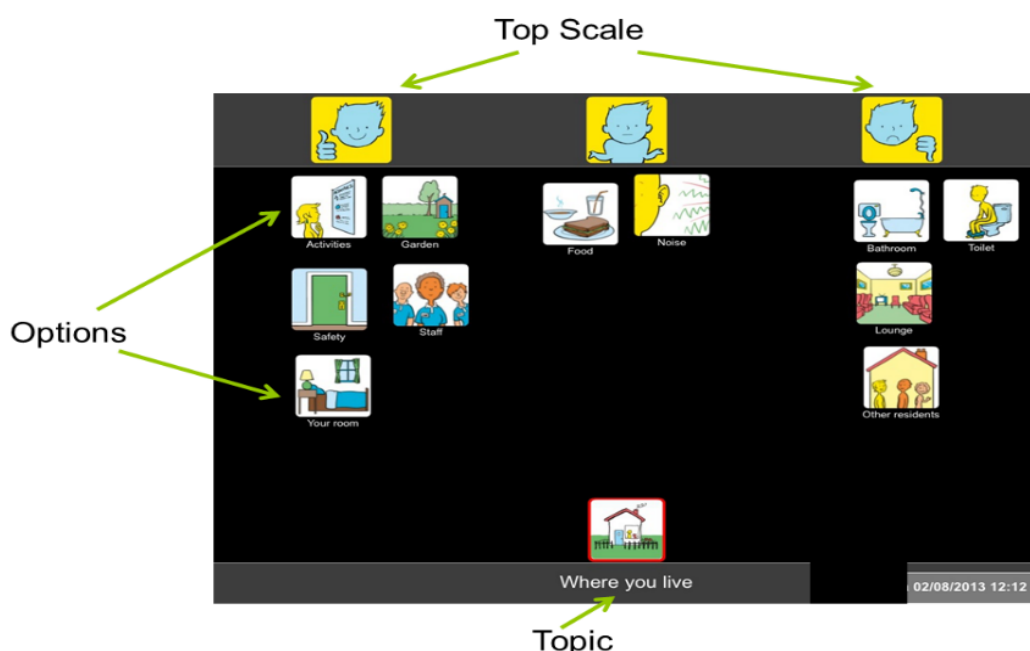
The completed Talking Mat® produced by the thinker can identify their educational needs in addition to their health and social care priorities which can assist with planning services, the monitoring the person's progress and to measure personal outcomes (Murphy & Boa, 2010).

A digital version of Talking Mats® was also developed but the simple, low technology method is often preferred by practitioners because it can be used in any setting and is easily understood by people of all ages and abilities.

Light and McNaughton (2014) advocate the citizen's right to speak through augmented and alternative communication (AAC) systems but highlight

economic factors that influence governments, health boards and social care providers who realise that cost benefits are available by implementing low budget, low technology systems with patients and clients. For example, equipment for individuals using AAC varies from £30 to £18,000 and may need replacing and repairing within 5 years, in addition to the annual servicing costs where applicable (Scottish Government, 2014). The low technology Talking Mats® resource represents an economical option for clinicians, service managers and service providers because the resource requires no maintenance, is expected to remain suitable for use for over ten years and has an approximate equipment cost of £300 with basic training costs of £175 which are not prohibitive for services Murphy (1998a). The Talking Mats® resource is an economical and effective method of communication for people of all ages and Stewart et al. (2018) found that people living with Alzheimer's disease in the Netherlands could successfully use the Talking Mats® method. Reitz and Dalemans (2019) discussed the suitability and versatility of the method across a wide range of populations and the severity of communication disabilities. Talking Mats® enables practitioners in health, education and social care discern an individual's likes and dislikes and how well they are managing to live with a health condition, disability or communication difficulty. The Talking Mats® method merits consideration for its increased applicability by healthcare providers and researchers as a reliable method of communication and to promote participation.

The resource issues, cost implications and the need for financial investment in services were raised by Royal College of Speech and Language Therapists (RCSLT, 2021) who stated that suitable services are not provided to address the communication needs of 14 million residents in the UK who are living with communication disabilities. Bercow (2018) previously stressed the negative impact of unmet communication needs on the physical and emotional development of the 1.4 million children and young people living with SLCN, and the ongoing issue of the lack of delivery of positive changes for this group of children and young people. A further issue was raised that

the services available to support children living with SLCN had not improved in the decade since the prior review conducted by Bercow (2008).

Choice of Talking Mats® as a communication tool with children and young people

The Scottish Government (2014) and Mackay and Murphy (2017) advocate for UNCRC Article 12 (UNCRC, 1989), the right of children under to be consulted about matters that impact on their lives and health. Mackay and Matthews (2020) endorse the Talking Mats® resource pack, containing the children and young people's (CYP) bundle to scope children's views (see Figure 3). This bundle takes account of the physical, cognitive, and emotional changes that occur during the development of a child between the ages of three years and seventeen years. The CYP packs are presented in three categories, Early Years for use with pre-school children, the Primary pack for children aged between five years and eleven years and the Secondary pack for use with children aged between eleven years to seventeen years. It is noted that the chronological age of a child may not equate to their cognitive ability, or the factors impacting on their life experience and understanding of the world around them (Bercow, 2018) and it is believed that this point must be considered when this method is applied.

Figure 3. Talking Mats® resource pack, children and young people's consultation bundle

The Talking Mats® packs for use with CYP illustrate aspects of health and wellbeing through picture symbols which include the concrete elements and the abstract concepts of daily life (see Figure 4).

Figure 4. Talking Mats® Health and Wellbeing symbols
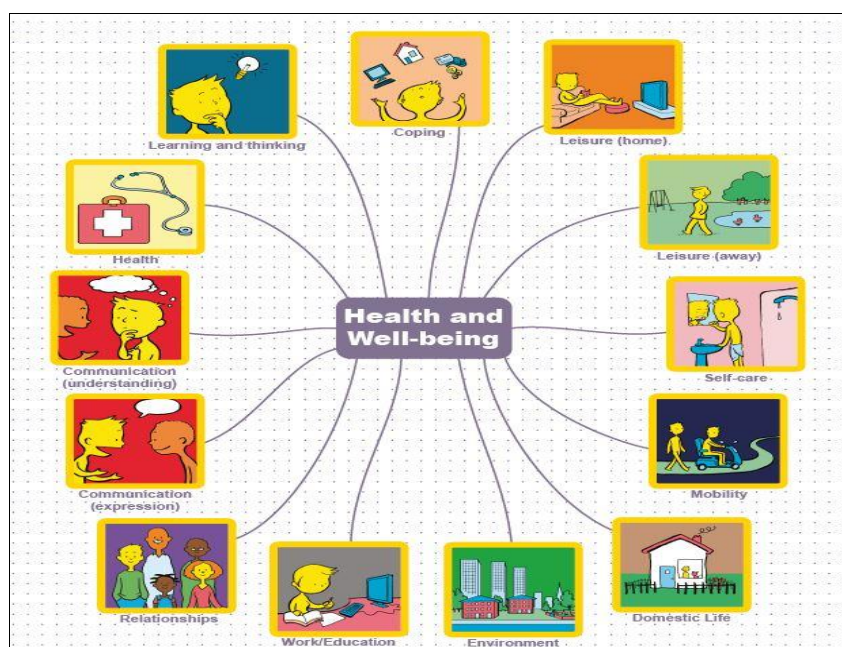
The Talking Mats® picture symbols are brightly coloured squares and each measure 5.5 centimetres. The concrete elements and the abstract concepts depicted on the squares relate to daily living and include pictures of modes of transport, cars, buses, and wheelchairs. In addition, there are pictures relating to health, medications, and the body systems, including the digestive system and their related organs. The abstract concepts relate to emotions which are demonstrated through pictures of faces showing expressions; happy, sad, angry, guilt or puzzlement. An empty speech bubble placed overhead on the symbol indicates that thought processes are required to demonstrate the participant's opinion regarding the concept (see Figure 5). Mackay and Matthews (2020) who are experienced in the use of Talking Mats® with CYP living with disabilities and SLCN advocate using the consultation bundle as an effective communication method.

Figure 5. Talking Mats® concrete elements and abstract concepts

Concrete — Abstract
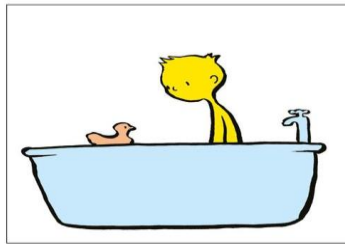
Blank square for adding the thinker's individual ideas

Use of a wheelchair- Thoughts and opinions- Guilt- Other's behaviour

Others' behaviour

Family   Routines

Family

Routines

The resource packs also include blank cards to enable freehand drawing and writing by the Talking Mats® practitioner or thinker onto the cards of anything that is not depicted by the commercial cards. The blank cards provide the opportunity for any issues deemed relevant and important to the thinker to be identified and addressed. This can assist members of their family, or any of the health, social or education teams who are involved with the thinker to understand the views of the thinker.

In relation to this study the ethics committees expressed concern that the cognitive demand on the children living with disabilities and SLCN who use Talking Mats® may be increased if the method was employed in its original form. For example, the Top Scale included the neutral, undecided symbol which provides the option of 'not being sure' or 'do not mind' as discussed in Section 3.3.2 and this layer of decision-making may cause the children additional cognitive stress.

Gerrish and Lathlean (2015) described how a range of options in scientific or consumer research to enable a question to be answered could be presented using a Likert scale. This scale provides the opportunity to submit a graded response to a question from respondents in quantitative research or participants in qualitative research. The Likert scale presents a multi-point visual scale typically up to 5, 7 or 10 points, depicting a range of numbered or attitudinal choices starting from a point zero to a zenith (Bockenholt, 2017). The range is decided by the researcher, for example, from nothing, not at all, strongly disagree to everything, always and strongly agree. A Likert type scale was developed by Wong and Baker (1963) to assess pain (see Figure 6). Following due consideration by the researcher, the use of a Likert scale was not included in this study and preference was given to the relevant Talking Mats® symbols to assess the children's views. Talking Mats® offers a unique, person-centred approach which is targeted to the specific communication and cognitive needs of the thinker therefore an adapted, novel Talking Mats® approach will be applied in this study for children living with SLCN.

Figure 6. Likert type scale to assess pain
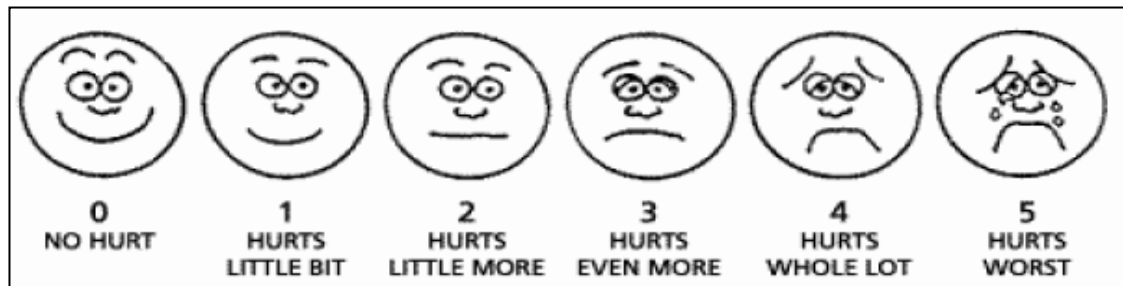
3.4 Research Design

The approaches, method and population sample used in this study were influenced by three factors, first, through an interrogation of existing literature, a Literature Review (LR) of studies conducted with children living with disabilities, complex health conditions and SLCN detailed in Chapter 2. Second, influenced by phenomenology the semi-structured interview method, case study and an adapted dichotomous choice Talking Mats® method. Third, the ethics committees' condition that the participant recruitment numbers must not be greater than twenty to ensure that the study sample was a suitable fit for the qualitative approach.

The decision made regarding the optimal number for the study sample was influenced by published findings from qualitative researchers (Smith et al., 2009) and the ethics committees considering this research proposal. It was agreed following discussion with the research supervisors for the study that the study sample would not exceed the recommendations of expert researchers and the ethics committees. The study cohort would consist of up to eight parents and seven children, with the ages of the children ranging from eight years to fifteen years. Further detail regarding this decision is provided within the discussion on the ethical approval process in Section 3.4.2.

The information regarding the approach, methods and recruitment sample employed within the study design, in addition to the influences that were applied to the decision making within this study are provided in Table 6.

Qualitative approaches	Influences	Options	Parents	Children	Children's ages in years
Semi-structured interviews	Interpretative Phenomenological Analysis	May recruit 1 additional participant to a maximum of 15	Maximum of 7	Maximum of 7	8 to 15
Talking Mats®	Phenomenology	As above	7 +1 optional	**7**	8 to 15

Table 6. Potential sample for semi-structured interviews and for the Talking Mats®

3.4.1 Ethical considerations

Gerrish and Lathlean (2015) advise that ethical considerations commence at the point where the research question is being developed on a topic of interest and where a gap is identified in the body of current knowledge. King and Horrocks (2010) state that the process regarding ethics approval is fundamental to all research studies to ensure that there is maximum benefit to the participants in relation to being involved in the study. The British Educational Research Association (BERA, 2018) and the National Society for the Prevention of Cruelty to Children (NSPCC, 2018) define all research study participants as being vulnerable and at risk of a negative, exploitative research experience during the research process if not protected from harm through a robust ethical approval process. This study aimed to gain the lived experiences of children and their parents and the study proposal for submission to the Regional Ethics Committee (REC) and the University and Health Board Ethical Committees outlined that the participants required a comprehensive assessment of the actual or potential risks of harm that the

study may cause. The strategies to be applied for the mitigation of the identified risks were documented within the research proposal to provide reassurance to the ethics committees. The participants would be protected from harm according to the recommendations on the prevention research harm from BERA (2018) and NSPCC (2018). Ethics committees consist of panels of experts within research and subject experts from science, health, and social care whose remit is to review research proposals and to grant or refuse permission for research to be undertaken (Brown et al., 2020). The members of the ethics panel assess the potential value to research of the submitted research proposal in addition to the perceived benefit, or risk to cause harm, to the participants. The panel may decide that the study is of value to the field of research and to society and will grant permission, described as a 'Favourable Opinion' (BERA, 2018) or the panel may decide that the research cannot be undertaken for various reasons, and refuse to grant permission. This is known as an 'Unfavourable Opinion' and the proposer is informed in writing. A refused research proposal may be allowed a resubmission with the revisions recommended by the ethics panel and the application and assessment process is repeated. The process described relating to the Unfavourable Opinion was experienced during the initial application of this research study.

General Data Protection Regulations (GDPR) 2018

BERA (2018) recommends the strict adherence to data protection policies and security protocols as stated in the General Data Protection Regulations (GDPR, 2018). To protect the confidentiality and rights of the participants and to enable the general standards for data protection, security, and storage to be met, GDPR (2018) was strictly applied in this study. To meet GDPR (2018) security standards, the audio and video recording equipment was provided by the University and the study data collected from the participants was encrypted and password protected. In accordance with BERA (2018) principles for data protection and security standards, the recording equipment, when not in use, and the participant data collected was stored in a locked cupboard within a locked room and was accessed only by

the researcher and the research supervisors. Once the data was analysed and no longer required it was disposed of following the University process for data protection and GDPR (2018).

3.4.2 Ethical approval process

Clark et al. (2014) state that the benefits to the participants and the scientific, health and social communities must be demonstrated within a research proposal and must provide a coherent argument of its relevance to research if the study is to be approved by the appropriate Health and Academic Ethics committees. The process of gaining ethical approval is described within this section and includes the issues raised by the ethics committees that were addressed prior to ethical approval being finally granted.

The background to the process of the first ethical approval submission in February 2018 is detailed below:

Applications for the proposed study were made to the following relevant Ethics Committees:

1. IRAS (Integrated Research Application System)
2. The Regional Ethics Committee (REC)
3. The University providing the award
4. The Research and Development department at the NHS Health Board

The research application was made online to the required ethics committees by the designated dates. The process of research application was a complex one and required strict adherence to each of the committees' guidelines. Several supporting documents were required, the Curriculum Vitae (CVs) from the applicant and the research supervisors, along with electronic signatures to verify the submissions as genuine. This process supported the submission and validity of the Research Proposal, the Gantt charts (proposed and amended timescales for the study, Appendices 6 and 7 respectively). The Participant Information Sheets (PIS) (Appendices 8, 9 and 10, Letters to the Gatekeepers (Appendix 11), the Assent Letter for Children under thirteen years (Appendix 12), the Consent forms for Parents and Children (Appendices 13, 14 and 15), the Thank you letter to participants

(Appendix 16) the Interview schedules (Appendices 19, 20 and 21). The Appendices 1, 2, 3, 4, 5, 17, 18 and 22 cited within the list of appendices but not detailed within this section were not required as part of the ethics application.

The process of gaining ethical approval was protracted and difficult due to the naivety of the researcher and the first application being over ambitious in relation to several factors now discussed.

The attendance of the researcher was required for an interview at the Regional Ethics Committee (REC) approvals panel and the research proposal was examined. Several issues were identified, first, the number of participants stated for the population sample, up to fifty, with the reason being given to the REC panel that this number would enable a wealth of data be gained. The panel deemed that a qualitative study with fifty participants to be unmanageable for a novice researcher, especially within the timeframe of one year allocated for the collection and analysis of the data. The number of participants was stated as unsuitable also for the qualitative design and methodologies proposed for this study. The panel pointed out that the proposal aimed to use Interpretative Phenomenological Analysis (IPA) and indicated that researchers who are experienced in this approach such as Smith et al. (2009) advocate that small participant numbers, no greater than twenty are recruited. Seale et al. (2007) raised the issue of recruiting small participant numbers in qualitative research stating that the rich deep data generated from a sixty-minute participant interview about their lived experiences can amount to around sixty A4 sized pages of transcript.

The second point raised by the panel related to the intended age range of the study sample which was from three years to eighteen years. Panel members stated that children of three years should not be included due to a concern that the children's cognitive abilities and their understanding of research process instructions would not be sufficient to enable valid participation in the study. The panel also suggested that the parents of the youngest children may present their views as the children's views, resulting in an unauthentic, invalid process. A response was given by the proposer

that research studies have been undertaken and findings published where pre-school children successfully participated in studies using methods based on pictures (Twycross et al., 2008; Mackay & Matthews, 2020).

The panel additionally pointed out that children over sixteen years of age in Scotland would be regarded as adults within health settings and would be in receipt of adult health services, with perhaps the exception of cancer services and some aspects of disability care. At the time this study was proposed, children aged up to their fourteenth birthday and requiring hospital care in some regions of Scotland, would receive care in adult wards due to the fact that regional children's hospitals did not admit children over the age of fourteen years to children's wards (Action for Children Scotland, 2015). A discussion ensued which suggested that a separate ethics application would be required for children over fourteen years who had received healthcare in adult health settings. This situation has now changed due an increase in age-appropriate provision and the building of new regional children's hospitals where the age of admission has been raised to the child's sixteenth birthday (Children's Health Scotland, 2019).

A panel member whose professional role was a Speech and Language Therapist expressed concern that children living with speech, language and communication difficulties would not have the ability to participate in this study using the methodologies within the proposal and that this issue must be addressed. The third issue raised was about the unsatisfactory quality of the participant documentation proposed for use within the study and this required to be resolved. The REC also required more information regarding the ethical care and safeguarding arrangements planned for the participants. Due the unsatisfied concerns of the REC panel a refusal of permission was decided, and an Unfavourable Opinion letter was received which contained detailed recommendations and advice of how to improve the application for a resubmission. Reflecting on the advice from the Research supervisors and the REC panel, particularly that given from the REC member whose expertise was speech and language therapy, an amended proposal, which

demonstrated the recommendations of the REC, was prepared and then submitted.

The preparation of the new research proposal focused on the most suitable methodology and methods for the research question, the age range and abilities of the child participants, the optimum number of participants for the study and the arrangements for the safety and security of the participants. Additional information to support the development of the new proposal, and to provide strong evidence informed the argument for undertaking this study. This was gained by undertaking a literature review whose details are provided in Chapter 2. Evidence was obtained from studies conducted with children living with SLCN and disabilities as defined in The Disability Discrimination Act (2005) and in the NHS Health Scotland Delivery Plan 2019-20 (Scottish Government, 2019).

Further detail relating to the renewed research proposal was provided to the REC panel regarding the measures taken for the safeguarding and comfort of the participants, gaining permission from the gatekeepers and process to access the participants. An explanation was provided regarding the process required for the procurement of encrypted equipment for the data collection and for managing the equipment and data security.

The following factors were addressed in the new submission for ethical approval:

- Justification for the study sample of children and their families as participants.

- The age range of the children in the study was changed to children aged between eight years and fifteen years from children aged three years to eighteen years.

- Safeguarding and protection arrangements to enable the child and family's consent and participation be gained ensuring full regard to participants' health and wellbeing.

- Contingency plans to stop the interview and to provide emotional support if a child and family are showing signs of discomfort, illness, or stress.

- Amended documentation including the removal of ambivalence, neutral options, from the accessible formats and new versions of documentation. This related to the Participant Information Sheet (PIS), the Consent forms for Parents and Children, the Assent Letter for Children under thirteen years and letters to the Gatekeepers.

- Support to encourage and document children's own views which may be different to the views of their parents and guardians.

- Demonstrate that the data reflects the authentic opinions of the child to ensure true participation.

- Action to ensure that parents and guardians' views are not presented as the children's views, particularly where the children have cognitive difficulties.

- Expertise in analysis was required for the interpretation of the child's answers.

The amended proposal was presented to the REC and the other two Ethics committees in February 2019, and this resulted in a Favourable Opinion, the ethical approval for the study (Appendix 17). The approval contained the condition of minor amendments to wording within the documents and to meet these recommendations the recruitment packs prepared for the study participants provided information in plain English. In addition, documents were developed in accessible formats for those participants with SLCN and learning differences. The final copies of the study documents meet the requirements of the ethics committee and are provided in the appendices (see Appendices 8-16). Equity and parity for all participants was fully employed by applying the principles of BERA (2018), NSPCC (2018) and the Ethics committees who approved the study. Ethical approval for the study

was gained on the 6th of February 2019. REF number 18/WS/0228 IRAS project and protocol number 253492.

3.5 Recruitment

Recruitment of participants for this study was undertaken following the guidance of BERA, (2018), the NSPCC (2018) and the ethics committees. The process of recruitment involved contacting the gatekeepers who could advise about the children and families who may be interested in taking part in the study and who could facilitate access to the potential participants. McFadyen and Rankin (2016) explain the role of gatekeepers in relation to granting permission to researchers to access relevant population samples within services. Gatekeepers are crucial to facilitating access to participants and the relevant gatekeepers who were identified and approached about this study were colleagues who were known and accessible. This was due to the researcher's employment within children's integrated health and social services and the fact that the gatekeepers all attended the same multi-professional meetings for children's integrated health and social services. The gatekeepers were the Associate Nurse Director for Nursing and Midwifery, the Children's Specialist Nurses for the Health Board and the Headteachers of selected schools attended by children living with disabilities, complex health needs and SLCN. The gatekeepers were able to identify prospective participants to receive the initial information about the study and to then grant access to the study sample. A detailed account of the recruitment process and the study sample will be presented in Chapters 5 and 6.

3.5.1 Sample selection

Participant numbers in qualitative studies vary from single case studies to multiple participants (Gerrish & Lathlean, 2015). Due to the amount and depth of data that can be obtained through the interview method Smith et al. (2009) recommended limiting participant numbers up to a maximum of twenty, especially where there are restrictions on the time available for the study. Shenton (2004) suggests that to overcome the issue of finding optimal

sample numbers, researchers can employ purposive or targeted sampling of a particular group and this strategy is useful for this study. In addition, this helps the researcher focus on the topic of research interest and assists with meeting research timelines which often dictate the actual sample number recruited. Gerrish and Lathlean (2015) indicate that caution is required regarding setting realistic timelines for the successful completion of a study.

Wanat (2008) states that the access to the study sample may be impacted due to the beliefs and attitudes of the gatekeepers, for example, the gatekeepers hold a position of power and can accept or reject a request of access to potential participants. In some circumstances, the gatekeepers may have little or no understanding of the importance of this step in the research process (McFadyen & Rankin, 2016). In relation to this qualitative study, the Regional Ethics Committee stated that small numbers of participants should be recruited for optimal results when using a qualitative approach. The Regional Ethics Committee directed that a maximum of fifteen participants should be recruited to the study, this recommendation was followed, and fifteen participants were recruited (see Table 7).

The next step was to approach the Headteachers and the Associate Nurse Director to request that detailed information about the study was given to potential child and adult (parent, carer, guardian) participants. This comprised of the aim and objectives of the study, the Participant Information Sheets (PIS), consent and assent forms and the detail of ethical considerations to protect the participants. Following this process, a purposive sample of fifteen participants was sought and that would consist of a balance of parents, carers, guardians and children.

BERA (2018) support the UNCRC articles (UNCRC, 1989) and advise researchers to allow adequate time for the recruitment of participants to minimise the risks of undue pressure and coercion. BERA (2018) also suggest that potential participants are given a reasonable time period in which to make a voluntary and informed decision of whether to participate in a study to ensure the consent to participate is not coerced and is valid. Taking BERA's (2018) advice into consideration the potential participants

were contacted two weeks after receiving the information pack for consideration to ask whether more information and time was required to consider whether they wished to take part in the study or not. If the decision had been made by the potential participants to participate, an offer to meet the researcher was made to confirm their decision and to discuss the process of gaining consent for the research study.

The recruitment of participants took place over an eight-week timeframe which enabled sufficient time for an ethical decision-making process for the gatekeepers and the potential participants to be applied. In addition, this helped to gain the reach and spread of participants required for the study. The study participants comprised of seven children plus their one significant other who was a parent or a guardian, resulting in a total of fourteen participants. An opportunity arose to interview an additional parent bringing the number of participants up to the maximum of fifteen participants, the optimum number agreed with the ethics committees.

Chapter 3 details the process undertaken to develop and provide information to gatekeepers and potential participants. The letters to the gatekeepers, the Participant Information Sheets (PIS) and the consent and assent forms are discussed in relation to the instructions given from the ethics committees about document development for participants and the suitability of documentation in research studies.

3.6 Research process

The research process was guided by information from Green and Thorogood (2018) and the frameworks developed by Smith et al. (2009) for the semi-structured interviews and Murphy (1998a) for the Talking Mats®.

3.6.1 Data collection

According to Gerrish and Lathlean (2015) the method or methods for data collection must be clearly described within the research proposal and must be suitable for the chosen methodology to enable credibility. The methods applied in the study were semi-structured interviews influenced by

Interpretative Phenomenological Analysis (IPA), case study informed by the supplementary material provided by Lily aged 15 years and Amber aged 8 years and their emotional discussion of the impact of their lived experiences and Talking Mats® influenced by phenomenology. The cohort number for the study was agreed during the ethics approval process (Section 3.3.2) and eight parents and seven children, with the ages of the children ranging from eight years to fifteen years were recruited (see Table 7).

Semi-structured interviews	Male	Female	Parent	Child	Boy	Girl	Child's Age in years
	1	**7**	8	5	3	2	8 to 15
Talking Mats®							
			In attendance	1	1		8
			In attendance	1	1		9
Total	**1**	**7**	**8**	**7**	**5**	**2**	

Table 7. Gender and ages of the child and adult participants

3.6.1.1 Semi-structured interviews

The types of interviews that are suitable to undertake with qualitative studies are outlined in Section 3.2 and the optimum interview method for the proposed study is semi-structured interviews to enable the participants flexibility to answer the researcher's questions from personal experience, whilst remaining focussed on the study topic. The participants in the proposed study had a range of abilities relating to communication, from full verbal ability to requiring communication support and aids to communication,

for example, Talking Mats® (Mundt, 2020). Equity and parity for all participants during interviews were fully employed as recommended by the British Education and Research Association (BERA, 2018) and the relevant ethics committees who approved the study. Data was collected by semi-structured interview from the participants who had full verbal ability and this method provided flexibility for both the researcher and the participant. To promote the participants' safety and security, and to meet the ethical standards advised by BERA (2018) and NSPCC (2018), the interviews were conducted at the participant's preferred environment of home or at school. The participants' preferred communication method was used to enable full understanding of the process and to ensure inclusion (BERA, 2018). The interview guide was developed by taking into consideration the risks and benefits of semi-structured questions. The decision was taken to employ the semi-structured interview method to best elicit the participants' views and experiences about the following areas of research interest (Appendix 18):

1. Healthcare services.
2. Living with a complex health need.
3. The age appropriateness and suitability of the healthcare information in relation to formats for children with a range of conditions, and their families.
4. The health condition affects the child or young person and their family.
5. Treatments, and the outcome of treatment, if any.
6. Issues relating to the diagnoses of complex needs, including disabilities, speech, language and communication needs.

Gerrish and Lathlean (2015) support the view that semi-structured interviews provide the flexibility required to encourage participants tell their unique story whilst keeping within the essence of the topic of interest. The experiences of health services are to be shared through individual interviews that are audio or video recorded with the participants' and participants parents' permission. A choice is offered for interview notes (also known as field notes) to be taken, if participants prefer.

3.6.1.2 Case study

Sheridan and Chamberlain (2011) outline the value of enabling participants to explore and demonstrate their feelings and experiences through personal tangible, material objects. They describe the significance of including the information gained within the research interview to simultaneously depict an enhanced view of the lived experience from the encoded memories that the objects provide. The benefit of this first-person, phenomenological approach is supported by Boden (2019) who explains that the participants' use of objects, drawings, photographs and written accounts or poems composed by the participants provide researchers with enriched data and a powerful, visual ethnographical perspective of the participant. The case study data obtained from two of the children, Participant 1 Lily, and Participant 5 Amber provided insight into their unique view of living with their condition. The supplementary information provided had significance to their lived experiences and was offered unprompted by the researcher, demonstrating the emotional importance that Lily and Amber placed on the information. Lily was aged 15 years and was living with Cystic Fibrosis, repeated infections, and panic attacks. Lily's written personal story was a biography which highlighted her deep feelings about the impact of living with a respiratory disease that was similar to but not formally diagnosed as Cystic Fibrosis, a respiratory condition affecting the lungs which is life changing and life threatening if not carefully clinically managed (Chang & Bilton, 2008).

3.6.1.3 Talking Mats®

The child participants who routinely used the low technology version Talking Mats® for daily communication provided their experiences of health services through an adapted novel Talking Mats® method. The typical Talking Mats® approach was considered for the study but the expert advice received during the ethics process regarding the children's cognitive abilities led to the decision that this study would apply an adapted, novel Talking Mats® approach. For this study it was crucial that the risk of cognitive overload for the child participants must be avoided. A possible solution to this issue was to ensure that the option design would be a forced, dichotomous opinion between a positive or negative

option choice and that no graduated choices would be offered. Further consideration of the value of removing the neutral option and forcing opinion within this study resulted in the removal of the neutral choice. This would help safeguard the children from avoidable stress (NSPCC, 2018) and would resolve the concerns of the ethics committees. The neutral option was removed from the Talking Mats® thinker's choice options with intention of lessening ambivalence and the cognitive load on the child participants. The aim was to enable the children to clearly demonstrate their views on daily life experiences. Edwards and Smith (2014) reported that research studies which presented a neutral response option found that the neutral option was selected rather than a positive or negative opinion being expressed. This is an important point to consider in relation to this study which seeks to gain the authentic views of the child during the Talking Mats® intervention, and where the comfort and safety of the child participants is paramount (BERA, 2018). The Top Scale with the neutral option removed, as explained in Section 3.2, was applied to provide the optimum interview experience to the child participants and to minimise the cognitive load required for the Talking Mats® intervention. Due to reflecting on the evidence and arguments provided by Edwards and Smith (2014) and BERA (2018) the adapted, novel Talking Mats® was developed. The new Talking Mats® Top Scale method applied within this study is depicted in Figure 7.

Figure 7. Talking Mats® Top Scale, dichotomous forced choice, neutral option removed
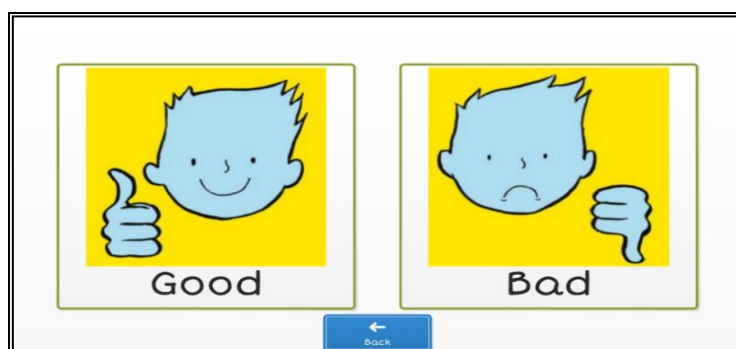
The Talking Mats® interactions

The novel Talking Mats® interactions were conducted by following the approved study protocol and the recommendations for the care and safeguarding of the child participants (NSPCC, 2018). The choice of audio or visual recording of Talking Mats®, or by taking field notes was offered for participants who were not comfortable with the audio-visual technology being used. The Talking Mats® were video recorded in accordance with the parents' consent and the child participants' assent. Encrypted and password protected equipment provided by the University was used for the audio and video recordings which enabled the standards for data protection and security to be met (GDPR, 2018).

3.7 Data analysis

Green and Thorogood (2018) advise researchers of the duty of care to participants and the requirement for a study to demonstrate rigour, transparency, validity, reliability and credibility and the importance of these research elements is now discussed.

3.7.1 Rigour

Qualitative studies often involve small participant numbers and depict research that is not easily replicated. To address any questions about the rigour or quality of evidence produced by the study researchers can demonstrate the rigour of their studies by ensuring the data analysed and themes generated are checked by individuals with accredited research process knowledge, skills, and experience. To provide rigour within this study the principles of research outlined by BERA (2018) were followed, particularly relating to the process undertaken to gain ethical approval for the study design, explained in Section 3.2.

3.7.2 Transparency

Transparency of the research process is important to enable the readers of a study believe that the process was undertaken with integrity and that the researcher or research team are honest. This study process was transparent due to being conducted by researchers who provided credentials relating to

their personal and professional honesty and integrity for inspection and approval by the ethics committees, the gatekeepers, and the participants.

3.7.3 Validity

According to Long et al. (2020) the critical appraisal of studies (CASP) is a crucial part of establishing the validity and reliability of a study and advise that a range of critical appraisal tools have been developed by the research community for this purpose. For this study, the principles within the framework of the CASP tools were followed to demonstrate that an academic, reliable, and valid process was applied. Research findings whose validity or truthfulness are doubted by the research community and the general public may have ethical implications (BERA, 2018) and this can result in harm being caused to the reputation of researchers and to the credibility of the research process. Confidence in the research process and results, especially where the research is conducted in health and social care is important to enable research studies to be undertaken (Nursing & Midwifery Council, [NMC], 2018). Information about how the participants received ethical care and consideration adhering to the recommendations of the NSPCC (2018) will be presented in this thesis. The contact information for participants to receive emotional support during or following the study, or to register a complaint about the conduct of the study, was placed within the Participant Information Sheets (see Appendices 8, 9 and 10) and the Cover letter for the research project (Gatekeepers) in Appendix 11.

3.7.4 Reliability

Confidence in published researched is required to enable researchers in the field of healthcare to replicate the findings of studies and to build on current work to promote evidence informed practice (NMC, 2018). The principles outlined by the NMC (2018) and BERA (2018) were followed during the conduct of this study. Reliable evidence was considered and applied to this study and was informed by undertaking the LR presented in Chapter 2.

3.7.5 Credibility

Discredited research reduces confidence in the science of research and Offit (2020) examined the negative and perverse impact on the research community and potential researchers. The untruthful research undertaken by the discredited researcher Andrew Wakefield raised a perceived but mistaken connection of childhood autism to the measles, mumps, and rubella (MMR) vaccine. To avoid any debate regarding the credibility of this study the recommendations from BERA (2018), NSPCC (2018) and (NMC (2018) were followed, in addition to the strict adherence of the stringent guidance of the ethics committees who had approved this study (Section 3.3.1). To demonstrate and to ensure that an honest, regulated, and rigorous research process was conducted in relation to this study, routine monthly and ad hoc research supervision was attended, and this was evidenced within a research diary and through the six-monthly progress reports written by the researcher for review and comment by the internal and external supervisors.

3.8 Analytical approaches

King and Horrocks (2010) advise that there are several analytical approaches which may be used by the researcher to analyse and to make sense of the information, the data, received from the participants in a qualitative study. The analytic approaches selected for this study will be discussed in this section. Gerrish and Lathlean (2015) list several of the choices available for qualitative data analysis which include, Critical Discourse Analysis, Grounded Theory Approach to Analysis, Narrative Analysis, Framework Analysis and Template Analysis. Smith et al. (2009) present Interpretative Phenomenological Analysis (IPA), an approach which uses a six-step framework for data analysis in qualitative studies. Murphy (1998a) outlined the Effectiveness Framework of Functional Communication (EFFC) (WHO, 2001) as a relevant analytical approach to use with Talking Mats® and from which to develop themes from participants' data gained during a Talking Mats® interaction. Sellars et al. (2018) advocate the application of the Word Cloud method (Atlas, 2002) to use with staff and patients in clinical areas to help gain feedback on the quality of health

services provided. Atlas (2022) suggests that electronic, commercial programmes such as ATLAS.ti.8, formulated by technical data corporations, can be effective and supportive as an adjunct to qualitative analytical approaches. The respondents' comments are digitally processed through computer software which generates a Word Cloud, a pictorial representation of the submitted words. The significant words or phrases that are meaningful and important to respondents are depicted in the Word Cloud (see Appendix 22) and can inform further actions or improvements required for the service. The rationale for the choices of the analytical approaches, the semi-structured interviews, case study, the novel Talking Mats® and the ATLAS.ti.8 adjunct used in this study are now considered, along with the value of the analytical approaches employed within this study.

3.8.1 Narrative Analysis

Gerrish and Lathlean (2015) explain that Narrative Analysis is concerned with extracting themes from a participant's story and situation, drawing out results that may inform the planning of services and service delivery. This analytic approach has relevance to this study because the experiences of participants were required to understand the impact of disability, SLCN and complex health conditions which result in the requirement to attend health services. The tenets of Narrative Analysis helped influence the final choice of approaches explained below.

3.8.2 Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) is an approach developed by Smith et al. (2009) that uses a six-step framework (see Table 9) to develop themes from the personal accounts given by participants on their lived experiences of a phenomenon or issue. The emergent themes can highlight current experiences of services and inform the quality of future services. This analytical approach resonates with the aim of this study and the six steps of analysis will facilitate the generation of themes to reflect the participants' opinions and to inform future services in healthcare. Sinkovics and Alfoldi (2012) and Woods et al. (2016) advocate the use of CAQDAS (Computer

Assisted Analysis Software) for the analysis of qualitative data within transcripts or audio-visual recordings. The convenience of this technology is appreciated but the resource was not known to the researcher at the time of the data analysis.

3.8.3 Effectiveness Framework of Functional Communication (EFFC)

The Effectiveness Framework of Functional Communication (EFFC) (WHO, 2001) provides an analytical approach to support the analysis of the data gained from the Talking Mats® (Murphy, 1998a) method (see Figure 8). Health and Wellbeing categories are presented for consideration which relate to aspects of daily living. These are coping, learning, and thinking, health, relationships, and communication, including understanding and expression. Factors which are central to a person's self-care, mobility, domestic life, the environment, leisure at home and away, work and education are depicted within the framework. The framework enables the individual to give an opinion on the impact of the factors relevant and important to the person's daily living experiences and helps to identify any issues that would need to be addressed to maintain or improve the health and wellbeing of the individual.

Figure 8. The Effectiveness Framework of Functional Communication (EFFC) Incorporating the Health and Well-being (ICF Framework)
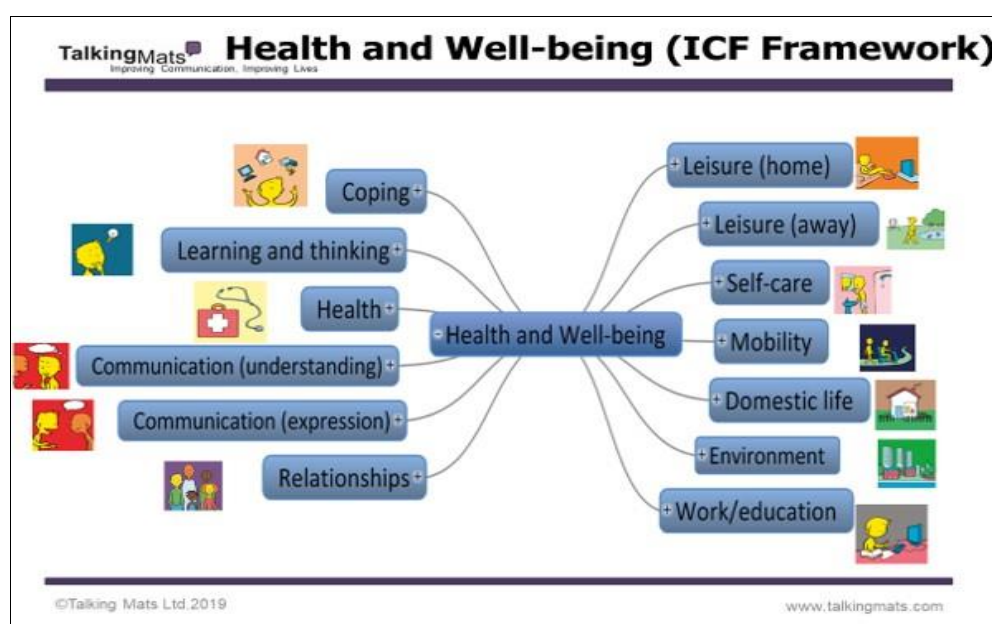
3.8.4 Choice of analytical approaches

The range of analytical approaches explored to conduct this phenomenological qualitative research will be explained within this section. The approaches are the Effectiveness Framework of Functional Communication (EFFC) (WHO, 2001) which relates to the Health and Well-being Framework (ICF Framework, 2019), Talking Mats® (Murphy, 1998a) which supports communication with people who are living with speech, language and communication difficulties (SLCN) and includes a discussion regarding a supportive adjunct, Word Cloud developed by ATLAS.ti.8 (2002) which is applied to qualitative analysis (see Table 8).

Sellars et al. (2018) advocate the use of the Word Cloud method (Atlas, 2002) to gather words and phrases important to the participants in healthcare to present an immediate visual representation of the views of participants on the quality of services. This study seeks the views of participants on the quality of health services experienced and World Cloud appears a suitable adjunct to include as an initial scoping of the children's and families' opinions, along with SSI, and the novel Talking Mats® approach selected. The findings from the Word Cloud exercise (see Table 8) demonstrated a snapshot of the participants wider concepts and produced both positive and negative expressions about people, places, emotions, and factors that impacted on the participants' daily life and healthcare experiences, for example:

Word Cloud: Positive expressions	Word Cloud: Negative expressions
Confidence, safe, understanding, great, good, kind, accept, understood, settled, support, answers, favourite, doctor, dentist, nurse, professional, mum, daddy, husband, teachers, friends, school, scouts, football clubs, sailing, beads, play.	Upset, awful, worry, fear, lying, illness, hurt, bad, angry, hospital, clinic, appointments, antibiotics, hard, wrong, bloods, issues, disability, sputum, nebuliser, never.

Table 8. Positive and Negative expressions from the Word Cloud

3.8.5 The six steps of analysis of IPA

The interviews are analysed using the six steps of Interpretative Phenomenological Analysis (IPA) developed by Smith et al. (2009).

The participants' first-person idiographic findings and their collective findings, from the analysis of the participants' semi-structured interviews and case study will be presented in the findings Chapter 5 of this thesis.

Each of the six steps and their relevance to the data analysis is now explained (see Table 9). The application of this framework will be illustrated in sections 3.8.5.1 to 3.8.5.6.

The six steps of analysis of IPA interview data (Smith et al. 2009)
Step 1: Reading and re-reading
Step 2: Initial noting
Step 3: Developing emergent themes
Step 4: Searching for connections across emergent themes
Step 5: Moving to the next case
Step 6: Looking for patterns across cases

Table 9. The six steps of analysis of IPA interview data (Smith et al., 2009).

The data analysis follows the IPA approach which demands that transcribed data is interrogated repeatedly in the iterative six steps for analysis. This allowed for a deep and exhaustive interpretation of the data, the process explained by Smith et al. (2009). Emergent themes were developed from the repeated actions taken in steps 1 and 2 and examples of the developing emergent themes from this process are detailed in Table 11 and subsequent emergent and super-ordinate themes presented in Tables 12 and 13.

3.8.5.1 Step 1: Reading and re-reading

The qualitative data collected by means of semi-structured interviews was crucial to the completion of the analytical process to become familiar with

each of the participants' interviews (Seale et al., 2007) and this was enabled by listening intently and repeatedly over a period of two weeks. Undertaking of this intense process enables the data to become more familiar by the time the transcripts were received from the contracted transcriber.

Step 1 involved reading each of fifteen transcripts and simultaneously listening to the original recordings of the interviews. This enabled a physical and psychological transportation back to the original researcher- participant interaction and allowed deep reflection on the sense and tone of the interviews, as Voutilainen (2011) may have contended, with the aim to confirm or refute first impressions and to promote understanding of the participants' perspective.

Smith et al. (2009) describe this as the development of an emergent theme and emergent themes are discussed in detail in step 3. The first reading, in conjunction with listening, promotes familiarity with the data but according to Smith et al. (2009) in order to become totally immersed in the data, the transcriptions must be re-read, usually several times, to become an effective activity. The reading and re-reading activities were undertaken several times over a period of two weeks to ensure complete familiarity with the participants' verbal and visual responses. This process enabled knowledge of the participants' world and the interviews' key phrases and sentences to be quickly and effortlessly recalled, skills deemed useful by Seale et al. (2007). The reading and re-reading the transcripts establishes the rhythm required to move the interviewer from the status of generalising the data to the honing of specific detail. This process elicits deeper meaning from the data and allows synthesis or bringing together of all the participants' ideas into a whole. This process is emphasised as essential for the effective transcription and the credible analysis required (Voutilainen, 2011).

3.8.5.2 Step 2: Initial noting

Smith et al. (2009) inform researchers that initial noting allows a first attempt to discern important words, phrases and information and to make a note for further consideration. Practical advice is also given on the most effective way

to set out the hard copy, paper, transcript page assists the organisation of the task. They recommend preparing three columns on a page orientated to a landscape design and which includes a column on the left for noting initial comments and emergent themes. The central column is to display the original transcript and a wide right-hand margin is provided for the continuous detailing of exploratory comments as the process is repeated. The process of initial noting produced thoughts about the participants' responses and the words and phrases of interest enabling significance to be drawn out of the page. The initial noting process, coupled with the time spent intensely listening to the interviews, was a reminder of, and re-lived to some extent, the original interaction and conversations experienced at interview, an acknowledged phenomenon in research (Goldstein, 2017). Initial noting produced a jumble of words and phrases which had no obvious, distinct links or connections and the transcripts were further scrutinised to discover the first exploratory comments. The risks of lack of clarity and understanding of an initial noting process on first review is highlighted by Peat et al. (2019). The words and phrases developed a deeper meaning when synthesised, or combined, with the memory of events from the participants' interviews and this echoed in the points relating to practice made by Smith et al. (2009). Researchers are encouraged by Peat et al. (2019) to distinguish where the words and phrases exhibit a phenomenological, or remarkable focus and that can be categorised in three distinct groups of comments known as descriptive, linguistic and conceptual. The categorised groups of descriptive, linguistic and conceptual are now explored in relation to this study.

It is appreciated that it is unusual to present findings within a chapter to discuss research methodologies and methods but examples from actual findings from a selection of the semi-structured interviews are detailed here to illustrate how the data analysis was completed and to support the transparency of the study.

Exploratory comments

Exploratory comments are defined by Smith et al. (2009) as the first comments made by the researcher on reading the transcripts and immersing

themselves within the data. The initial noting (see Table 10) demonstrates the mechanisms used in this study to recognise the exploratory comments. The process helps identify the descriptive, linguistic and conceptual text and to subsequently develop and synthesise the participants views and experiences. Examples of the actual exploratory comments in the findings have been included in this chapter to illustrate how the analysis was undertaken.

Examples of Exploratory comments from actual transcripts

Child 5 aged 8 years

"…some stuff" "new beads of courage" "the black ones are for having bloods taken."

Parent 2

"For me personally it has a been a lot…my whole life is planned around (child)*"*

Descriptive text

Descriptive text is defined as the key words and phrases used for the explanation of objects, events and experiences (Smith et al., 2009). It was important to consider the descriptive text and to match this to the participants' narrative from the transcripts of their experiences, actively seeking to establish this link.

Examples of Descriptive text from actual transcripts

Child 5 (Table 10)

"beads" "necklace"

Parent 6

"…about 2 years ago, just before epilepsy was diagnosed (child) *was having muscle spasms…I kept being told it was muscle spasms."*

Linguistic text

Linguistic text is defined by Smith et al. (2009) as the functional aspect of the comments, tone, repetition and fluency. The participants' linguistic comments were identified which demonstrated evidence of an exploration of their experiences in addition to the description (Smith et al., 2009).

Examples of Linguistic text from actual transcripts

Child 7 aged 12 years

"…if people judge me then well it doesn't matter cause we're all the same, but we have different qualities."

Parent 2

"A lot of promises that have given to us has never been followed through" *"I'm not coping very well with stress"* *"The doctor was lovely….trying to show* (child) *different things…"*

Conceptual text

Smith et al. (2009) explain that conceptual text provides an element of reflection from the participant's abstract ideas arising from the participants' experiences. Conceptual comments were represented within the transcripts of this study and the skill of interpretation was a crucial factor in ensuring the accuracy of this representation. Smith et al. (2009) liken this skill to the art and strength required and used in the methods of formal interrogation.

Examples of Conceptual text from actual transcripts

Child 7 aged 12 years

I just thought it was something in my body but didn't know what it was."

Parent 2

"Horrendous…exhausted…horrible" "this loopy mum again…making an issue when there's nothing there" "Angry…….I do get angry…..I think they're missing something"

3.8.5.3 Step 3: Developing emergent themes

Original transcript	Exploratory comments	Descriptive	Linguistic	Conceptual
Child 5- aged 8 years 'I can get some stuff to show you, some stuff about me' **Researcher** 'And do you want to tell me what that would be, what is it you want to show me?	'some stuff' 'new beads of courage' 'The black ones are for having bloods taken'	'necklace' 'beads' 'Numbered' 'I like them' 'new beads of courage' 'bravery, brave and scared' Number of blood tests	'to show you' 'very pretty' 'and I can play with them' 'I like looking at them'	'about me' 'whenever I want' Each bead represents an experience Does the participant know what courage means?

Table 10. Initial noting from the original transcript, examples of descriptive, linguistic and conceptual text from actual transcripts

3.8.5.4 Step 4: Searching for connections across emergent themes

Emergent themes are developed as the process is conducted of separating the participant from the data and including the researcher as self who searches for expression and interpretation within the text (Smith et al., 2009). The themes emerged for both the children and parents and some of the participants perceptions were similar but there were also differences. This demonstrated that the method facilitated the authentic voices of the children were being heard as intended (UNCRC, 1989) and that the views of the parents were not presented as the views of their children, a concern raised by the ethics committees during the study approval process. The impact of

disability and its management were significant in the lived experiences narrated by the participants and the daily challenges and victories experienced began to emerge and examples from emergent themes are presented below.

Examples of Emergent themes from actual transcripts

Parent 8

 "I just couldn't think about myself, I had to be practical."

Child 7 aged 12 years

"Well just a check up to see how I'm doing and how I'm coping and if I like it or not, it's just like a wee (little) *visit.I would miss it a bit. You know there would be some good parts and some bad parts."*

Emergent themes	Original transcript	Exploratory comments
The impact on the family Scale of 1 to 10	I'd say a 10. Pretty full on- about 5 now	Family adjustment once familiar with child's needs
Emotionally prepared	We really can't recharge our batteries we just need to carry on	Amount of information received and its accuracy

Table 11. Developing emergent themes

Emergent themes	Original transcript	Exploratory comments
Bravery and courage	'I just like looking at them and I hope I get another bead and I	Associates a hospital visit with the necklace, beads and new beads of

	hope I will get new beads of courage from the hospital'	courage. Does the participant know what courage means? Not knowing the meaning of courage. Try to establish the meaning and significance of the beads to the child

Table 12. Emergent themes

Smith et al. (2009) advocate the use of several processes to develop super-ordinate themes. The development of super-ordinate themes allows the data to be brought together for further scrutiny because the super-ordinate themes are the essence of IPA and assist elicitation of the deeper meanings from the participants' stories.

Using abstraction, subsumption, polarisation, contextualisation and numeration to bring it all together in a super-ordinate theme.

Smith et al. (2009) outline the processes of abstraction, subsumption, polarisation, contextualisation and numeration to produce super-ordinate themes (see Table 13) which are the result of identifying patterns between the emergent themes. Smith et al. (2009) provides the following definitions of the terms, abstraction, is pattern identification, subsumption, is described as collection of similar themes, polarisation is defined as looking for connections that display an opposite position to each other. Contextualisation is looking intently at the participant's narrative or story and seeing meaning beyond the words. Numeration is assessing how many times a theme emerges, function, or applying specific criteria to the participant's narrative and bringing it together or utilising each of the processes to recognise patterns in the participant's responses that enable the super-ordinate themes to develop.

Super-ordinate themes generated by this study

The tenets of the IPA analysis model are promoted by Peat et al. (2019) and implementing the IPA steps 1, 2 and 3 in this study assisted the move from the connections across the emergent themes to the development of super-ordinate themes.

Applying step 4 (Smith et al., 2009) generated the super-ordinate themes presented in Table 13. Emotion, Choices and Control, Intuition, Denial and preferring not to know emerged from this exercise.

Emotion was a central theme and feelings of bravery, courage, fear, being scared and crying were discussed by child and parent participants during interviews.

Choices and control were significant to participants and featured in the digitally recorded interviews.

Intuition about disease and deterioration was a feature of the narrative from an older child participant and parent participants.

Denial and preferring not to know were raised by all participants.

Super-ordinate themes	Emergent theme	Original transcript
Choices and control	**Information**	We didn't get a huge amount of medical history, that made us very unsure. That was all that was available and it was completely inaccurate.

Table 13. Super-ordinate themes

3.8.5.5 Step 5: Moving to the next case

It is important to consider the super-ordinate themes emerged from one participant be compared against the next participant and to repeat the steps 1 to 4 of the six steps (Smith et al., 2009) to elicit further themes.

3.8.5.6 Step 6: Looking for patterns across cases

Smith et al.'s (2009) six steps process became cyclical and intense, producing a deep focus on each narrative and cross narrative until new themes formulated. The new themes identified on completion of the six steps are discussed in Chapters 5 and 7.

3.8.5.7 Semi-structured interviews: Results

The aim of the study was to gain children's and families' views in relation to the impact of living with complex health and disabilities and the impact on their quality of life, including their experiences of health services. The study employed a phenomenological approach and used the semi-structured interview method with the thirteen participants. Two participants presented supplementary information, and this is presented as a case study. First-person accounts were obtained using audio-recordings stored on encrypted equipment provided by the research department at the university. The results of the participants' rich, deep, lived experiences were documented and the original transcripts were analysed using the six steps of IPA analysis (Smith et al., 2009).

The participants' key issues were identified during the six-steps analysis, and five themes emerged which are Theme 1. Choices and control, Theme 2. Relationships, Theme 3. Living with my condition, Theme 4. Living with my child's condition and Theme 5. Bringing it all together. The themes divided into two aspects, the challenges faced by the participants and the resilience the participants developed to meet the challenges. The idiographic and collective findings from the children and parents will be presented in Chapters 4 and 5 and discussed in Chapter 7.

3.8.6 Timeline

The data collection through interviews and Talking Mats® was undertaken between April and June 2019 and all the interviews were conducted in Scotland, UK. All the children and families were offered the choice of their home or school as the setting for their interviews. One family, comprising two

parents and one child chose a community clinical setting for their interviews and the other twelve participants chose their homes, rather than their schools as the interview setting.

3.9 Chapter summary

Chapter 3 introduced information regarding the methodology utilised in this thesis and Sections 3.2 and 3.3 discussed the methods in general and in relation to this study. The research design used in this study was explained and linked to the philosophical approaches and methods which draw on phenomenology, influenced by Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009), case study and Talking Mats® (Murphy, 1998a). In addition, the reasons for selecting the qualitative approach, guided by phenomenology, IPA and Talking Mats® were discussed and explored and the application of the novel Talking Mats® with the neutral option removed was explained. The use of the Word Cloud method (Sellars, 2018) was explored to help gain an overview of the views of children and their parents prior to conducting the qualitative interviews where the participants' stories would be recounted in more depth. The Word Cloud (see Appendix 22) provides a guide to the initial thoughts of the participants and can help inform the interview questions, the value of the Word Cloud as a study adjunct was explained. The ethical considerations required for the study and the ethical approval process were explored in Section 3.4. The journey taken to demonstrate the rigour, validity, and credibility of qualitative approaches to the scientific community was explained. The ethics discussion focussed on the participants' health and wellbeing, the ethical and moral duty to cause the participants no harm and to safeguard the participants during the study process (BERA, 2018). The arrangements were explained to obtain the child and family's consent with full regard to participants' health and wellbeing. Contingencies were detailed to cease the interview and to provide emotional support if a child and family showed signs of discomfort, illness, or stress.

The data collection methods utilised were chosen to encourage and document children's own views, which may be different to the views of their parents and guardians, and to demonstrate that the data reflects the

authentic opinions of the child to ensure true participation (Mackay & Matthews, 2020). The proposed action was discussed to ensure that the views of parents and guardians were not presented as the views of the CYP, particularly where the CYP have cognitive difficulties, and when more care is required with the interpretation of the answers from the CYP. The researcher's obligations in applying the GDPR regulations for the study were also described. Information was provided regarding the practical considerations in relation to data storage, security, encryption, equipment, access to the data and the destruction of the data following the completion of the study to meet GDPR (2018). Section 3.5 outlined the practicalities of the recruitment and sample selection process and justified the study sample choice of children and their families as participants. The research process was detailed in Section 3.6, the data analysis process, along with analytical approaches and the choice of analytical approach were presented in Section 3.7. This section included a discussion about the importance of validity, transparency, rigour, reliability, and credibility in research. Analytical approaches and the analysis of the participants' transcripts using the six-steps analysis of IPA were discussed in Section 3.8 which included the data collection by semi-structured interviews, along with novel Talking Mats® interaction methods. The timeline for this study is presented in two Gantt charts (see Appendices 6 and 7). The research methodologies and methods presented in Chapter 3 were summarised in Section 3.9.

CHAPTER 4:

ANALYSIS

4.1 Introduction and chapter overview

Chapter 4 will provide an analysis of the data generated by the three qualitative methods applied within this study which were influenced by a phenomenological approach which is valued by qualitative researchers to gain rich, deep data on lived experiences from participants (Coad et al., 2019). The chosen mixed methods are semi-structured interview (Smith et al., 2009), case study and Talking Mats® (Murphy, 1998a). Section 4.2 will discuss the analysis of the information gained from the participants' semi-structured interviews and Section 4.3 will detail the analysis from the case studies provided by Lily aged 15 years and Amber aged 8 years. Section 4.4 presents an analysis from the Talking Mats® produced by Jack aged 8 years and John aged 9 years. Section 4.5 will synthesise the information to provide an account of the value of using the three chosen methods to obtain the rich, deep information and personal stories from the participants to add to the body of current knowledge on the healthcare experiences of children living with disabilities and complex health needs, and those of their families. The chapter will be summarised in Section 4.6.

4.2 Information gained from the participants' semi-structured interviews

To achieve the objective of gaining the rich, deep, first-person accounts of children and their families on their health experiences a phenomenological approach was taken. The process of the analysis of the qualitative data obtained through semi-structured interviews will be influenced by Interpretative Phenomenological Analysis (IPA) developed by Smith et al. (2009).

Two children from the original seven recruited, Participant 10 aged 8 years and given the pseudonym Jack, and Participant 12 aged 9 years and given the pseudonym John, provided their lived experiences through the method most suited to their needs, novel Talking Mats®. The findings from Jack's and John's Talking Mats® (TM) will be presented in Chapter 6. In addition, the verbal contributions of the parents offered during the Talking Mats® exercise with their children will be included in Chapter 6. The study sample presented in this chapter are five children, whose details are presented in Table 14, and eight parents whose details are presented in Table 15.

Child participant number and pseudonym	Age in years	Gender	Disability/ health diagnosis	Siblings Y/N and number of siblings	Type of school
1 Lily	15	Female	Cystic Fibrosis Repeated infections Panic attacks	Yes-1	Mainstream
3 Matthew	11	Male	Respiratory disease Multiple Allergy Syndrome	Yes- 2	Mainstream
5 Amber	8	Female	Heart disease, epilepsy, and a stroke	Yes- 2	Mainstream
7 Mark	12	Male	Type 1 Diabetes	Yes- 1	Mainstream
13 Luke	13	Male	Gaps in medical history. Learning disability Fetal Alcohol Syndrome Disorder	Yes- 2	School for children with Additional Educational Needs

Table 14. Demographic details of the child participants

Parent participant number	Mother/ Father of Child Participant (CP) number Adopted (A) Fostered (F) Talking Mats® (TM)	Employed	Undertaking further education	Own health needs
2	Mother of CP 1 Lily	No	No	Yes
4	Mother of CP 3 Matthew	Yes	No	No
6	Mother of CP 5 Amber	No	No	Yes
8	Mother of CP 7 Mark	Yes	No	No
9	Mother of CP 10 (Jack, TM)	Yes	Yes	No
11	Mother of CP 12 (John, A) (TM)	No	No	No
14	Foster Father of CP 13 Luke	Yes	No	No
15	Foster Mother of CP 13 Luke (F)	No	No	No

Table 15. Demographic details of the adult participants

King and Horrocks (2010) warn of the potential risk of breaching data protection faced by over enthusiastic researchers who are keen to discuss their work and who unwittingly may not meet the obligation of confidentiality. This statement is contestable because researchers must declare their intention to protect participants' identities in their signed research protocol (BERA, 2011). Research protocols are presented to the relevant Ethics Committees, and following the granting of ethical approval, confidentiality and data protection must be adhered to (Brown et al., 2020). This study aims to capture information from children and families who have the lived experience of the impact of living with disabilities, which include SLCN, and complex health needs. The children defined by The Disability Discrimination Act (2005) and The Equality Act (2010) as the most vulnerable in society and whose health conditions necessitate the need to use specialist healthcare services.

The ethical duty of care to the vulnerable participants detailed by the Nursing and Midwifery Council (NMC, 2018) applies to all research, and to this study. Participant confidentiality and the protection of the participants' research data will be implemented as mandated by BERA (2011). In addition, the requirements for safeguarding the participants within the study will be paramount (NSPCC, 2018). The relevance of assuring participants' confidentiality and the protection of the data gained was discussed in Chapter 3, Ethical Considerations, and as detailed in Section 3.4.

4.3 Analysis from the case studies provided by Lily aged 15 years and Amber aged 8 years

The case study method findings, the supplementary information offered at interview by two participants Participant 1, Lily aged 15 years and Participant 5, Amber aged 8 years revealed the significant impact that their complex health conditions had on every aspect of their lives, Lily's personal, poignant account 'Just Breathe' provided a vivid, rich picture of her daily struggle with the tasks of daily living, complex medication regimes, family relationships and friendships and repeated hospital admissions. The six steps process of analysis developed by Smith et al. (2009) were applied to the information

provided by Lily and Amber. Directly using the findings from the case study illustrates the analysis and support the context of the participants' experiences.

4.4 Analysis from the Talking Mats® produced by Jack aged 8 years and John aged 9 years

This section explores Murphy and Boa's (2012) recommendation that the Effectiveness Coding Framework, which is shown in Table 16, is undertaken during the analysis of a participant's Talking Mats®, a score of 15 or more out of 20 indicates validity of the results. The model inspects five important indicators of effective communication which are:

1. The participant's understanding of issue for discussion, including verbal and nonverbal cues
2. Engagement with process
3. Keeping on track
4. The participant's confidence level in responding
5. The researcher's understanding of the participant's views, including verbal and nonverbal cues

Communication Indicator	4 Always	3 Often	2 50:50	1 Occasional	0 Never
Understanding the issue					
Engagement with process					
Keeping on track					
Confidence level of response					
Researcher's understanding of views					

Table 16. Effectiveness Coding Framework Scoring template (Murphy & Boa, 2012).

Jack's abilities to communicate were assessed using the Effectiveness Coding Framework Score prior to conducting the Talking Mats® interview.

Communication Indicator	4 Always	3 Often	2 50:50	1 Occasional	0 Never
Understanding the issue Researcher asked if Jack used Talking Mats® in school		✓			
Engagement with process Jack was keen and excited	✓				
Keeping on track Parent asked child about a symbol chosen but not placed on the mat		✓			
Confidence level of response Jack mostly demonstrates understanding of the use of the mat and symbols		✓			
Researcher's understanding of views Appropriate communication tool chosen	✓				

Table 17. Effectiveness Coding Framework Score for Jack aged 8 years living with a complex health need and cognitive impairment. Talking Mats® topic Health and Wellbeing and domains of daily living. Participation score: 17 out of 20

The significance of Jack's Effectiveness Coding Framework Score to the Talking Mats® results

Jack's Effectiveness Coding Framework Score (ECFS) of 17 out of the possible 20 (Table 17) indicated that Jack had understood the innovative Talking Mats® tool and therefore was suitable to use with Jack. This process affords confidence in the validity of Jack's Talking Mats® results and that the choices and views demonstrated on Jack's mat presented in Figure 9 represent his authentic voice. Jack's mother, Participant 9 in Chapter 5, was present throughout the Talking Mats® intervention and stated that she had understood and valued the process. Jack's mother was satisfied that the information gained was a true reflection of Jack's views and experiences and that the Talking Mats® results recorded on a still photograph and given to Jack and his mother, would be useful information to add to Jack's GIRFEC educational, health and social care assessments.

John's life profile will be outlined in Section 6.2.2 and John's abilities and suitability to undertake the Talking Mats® process will now be demonstrated through the score that John obtained during the ECFS assessment. John's abilities to communicate were assessed using the ECFS prior to conducting the Talking Mats® interview.

Participant's Communication Indicator	4 Always	3 Often	2 50:50	1 Occasional	0 Never
Understanding the issue Researcher asked if child used Talking Mats® in school	✓				
Engagement with process	✓				

Demonstrates understanding of mat and symbols					
Keeping on track		✓			
Confidence level of response Understands the use of the mat and symbols		✓			
Researcher's understanding of views Appropriate communication tool chosen	✓				

Table 18. Effectiveness Coding Framework Score for John aged 9 years living with a complex health condition and autism. Topic Health and wellbeing and domains of daily living. Participation score 18 out of 20.

The significance of John's ECFS in relation to Talking Mats ®.

John's ECFS of 18 out of the possible 20 (Table 18) indicated that he understood the innovative Talking Mats® and that it was a suitable tool to use with John. This process afforded confidence that the choices and views demonstrated on John's mat presented in Figure 5 represent his authentic voice and that the interview was valid.

John's mother, Participant number 12 in Chapter 5, was present throughout the Talking Mats® intervention and stated that she had understood and valued the process. John's mother was satisfied that the information gained was a true reflection of John's views and experiences and that the Talking Mats® would be useful information to add to John's GIRFEC educational, health and social care assessments (Scottish Government, 2014).

John's completed novel Talking Mats® related to the central topic of daily living and the Domain option symbols which are concerned with Leisure and hobbies, Transport, Health and Wellbeing and Relationships. John's Talking Mats® is the original image and is of poor quality due to the equipment used

but clearly demonstrates the dichotomous choice option offered within the Top Scale.

4.5 Synthesis of the three chosen data collection methods of Semi-structured interview, Case study and Talking Mats ®

The value of applying the three chosen methods was to enable in depth information, personal stories and rich pictures be obtained from the participants, The aim was to add to the body of current knowledge on the healthcare experiences of children living with SLCN, disabilities and complex health needs, and those of their families. By employing the qualitative analysis techniques provided through the six steps framework (Smith et al., 2009) and the Effectiveness Coding Framework template (Murphy & Boa, 2012) themes could be generated from the range of participants living with diverse abilities. The results gained and the themes identified from the participants were reviewed and compared to develop a synthesis of the collective perspective of the participants' lived experiences who may not routinely, if ever, be enabled to tell their stories. Further detail of the synthesis is provided in Chapter 6, Section 6.6.

4.6 Chapter summary

This chapter has explained the rationale behind the application of three methods of data collection, semi-structured interviews, case study and Talking Mats ®. Synthesising the data generated from the three methods to produce themes which demonstrate the impact of living with disabilities, complex health needs and SLCN adds new knowledge to the current understanding and gives a voice to seldom heard groups on the lived experiences within healthcare.

CHAPTER 5:

FINDINGS FROM THE QUALITATIVE METHODOLOGY SEMI-STRUCTURED INTERVIEW AND CASE STUDY METHODS

This chapter will present the findings from the research process and analysis which were described in Chapters 3 and 4. The findings will be presented under the themes developed through the phenomenological approach applied to conduct the study with children and their families living in the demographical area of southwest Scotland. This region is served by the NHS Ayrshire and Arran Health and Social Care Integration Partnership which is detailed in Appendix 2.

5.1 Introduction and chapter overview

Children living in Scotland have the right under the Children and Young People (Scotland) Act 2014 to be consulted on all matters affecting them and to influence the development of health and social care policies and services through the Getting it right for every child (GIRFEC) National Practice Model (Scottish Government, 2014) which is presented in Appendix 3. Children living with disabilities, complex health needs and Speech, Language and Communication Needs (SLCN), as defined by the Disability Discrimination Act (2005) and The Equality Act 2010, have the right to have their needs assessed and to receive additional help through the GIRFEC process (Scottish Government, 2014).

This chapter will present a detailed account of the findings from applying a qualitative, phenomenological approach, semi-structured interview and case study method within this study to explore the question 'What are the views and experiences of children living with disabilities and complex health needs and those of their families?'

The findings from the application of the qualitative methodology semi-structured interviews will be detailed in Section 5.2 and 5.3. The findings from the case study method will be discussed in Section 5.4.

The anonymity of the research participants is essential to meet General Data Protection Regulations (GDPR, 2018) and to ensure confidentiality, pseudonyms will be used. Section 5.4 will present the case study method findings, the supplementary information offered at interview by two participants Participant 1, Lily aged 15 years and Participant 5, Amber aged 8 years who provided supplementary information which they explained had significance to their lived experiences. Boden et al. (2019) and Sheridan and Chamberlain (2011) found that the value placed by participants on objects, written narrative and photographs in qualitative methodology can produce an increased depth to their narrative, is able to expand the concept of hermeneutic phenomenology and can deepen the ethnographical perspective of participants' lived experiences. Section 5.4.1 will discuss Lily who had requested that the contents of her written personal story should be included as part of her interview, and this request was agreed to by the researcher and the research supervisors. Section 5.4.2 will detail how Amber, during the semi-structured interview, reflected on the experiences that were important to her through her physical handling of each individual bead on a string of beads whilst illuminating the personal story attached to each one. Section 5.5 will present the findings from the semi-structured interviews and the case studies from Lily and Amber which produced individual demographic findings and idiographic findings. The collective, shared findings from the participants' lived experiences provided during the interviews and case studies are presented in Section 5.6. The findings presented within Section 5.7 are the five themes generated from the analysis of the semi-structured interviews which were Theme1. Choices and control, Theme 2. Relationships, Theme 3. Living with my condition, Theme 4. Living with my child's condition and Theme 5. Bringing it all together. The idiographic and collective findings, which include the similarities and differences between the children and their parents' perceptions of living with a disability, complex health needs and SLCN, and their experiences of

healthcare, will be identified in Section 5.8. The similarities of the participants' opinions are discussed in 5.8.1 and the differences in 5.8.2. Reflexive accounts will be provided within the chapter to explain the development of the researcher's decisions during the interview process. The chapter will be summarised in Section 5.9.

Adherence to confidentiality and data protection through Data Protection Act [DPA] (DPA, 2018) was enabled in this study by anonymising the interview information in the transcripts and by allocating a unique identifier to each participant. This met the data protection requirements of the Ethics Committees who approved this study (Appendix 17) and provided assurance that participants' identities were protected. The information is detailed within the Participant Information Sheets presented in Appendices 8, 9 and 10.

5.2 Supplementary (additional) information offered at interview by two participants

During the semi-structured interview process, two of the child participants, both girls, Participant 1 Lily aged 15 years living with Cystic Fibrosis, repeated infections and panic attacks and Participant 5 Amber aged eight years living with heart disease, epilepsy and a stroke offered supplementary (additional) information, through personal objects which were of significance to them. This visual data provided information which enabled a deeper insight into the impact on the girls of their living with their complex health conditions. In this study, the enriched data from Lily and Amber strengthened the relationship with the detail gained from their semi-structured interviews and also informed the subsequent final analysis of their data.

Sheridan and Chamberlain (2011) outlined the significance of including the information gained through exploration of participants' personal material objects and advocate conducting a research interview to simultaneously depict an enhanced view of the lived experience from the encoded memories that the objects provide. The participants' use of objects, drawings, photographs and written accounts or poems composed by the participants provide researchers with a powerful, visual ethnographical perspective of the

participant and enriched data. Boden (2019) advocates the inclusion of the participants' views of the meaning of their personal objects and written accounts to expand the concept of hermeneutic phenomenology. The enriched data can strengthen the relationship with the data gained from the participant's semi-structured interview and inform the subsequent final analysis using IPA.

In this study the supplementary information explained the participants' perceptions of what the impact of living with complex health means, not only to the child themself, but to those who were significant others in their lives. The positive and negative impacts of living with complex health conditions was highlighted by Teuma (2013) who found that feelings of anger felt by the participant regarding their condition were counterbalanced with positivity and a desire to achieve the maximum life potential possible. A similar paradox was demonstrated by the two participants within this study through the supplementary information they provided. The idiographic, or personal findings, along with the collective findings from the exploration of the visual objects, and the connections to the relative memories of both children will now be presented.

5.2.1 Idiographic findings from supplementary information presented by Participant 1 Lily aged 15 years living with Cystic Fibrosis, repeated infections, and panic attacks

Lily had written a first-person account of her life experience for a school project. At Lily's request and with the support of her mother, a copy of the essay was offered and accepted by the researcher as a supplement to the verbal, recorded semi-structured interview. Lily read aloud an emotional account of her life story which she had entitled 'Just Breathe' and her narrative account commenced with:

> *"It's not easy being me. It never will be. They say I'm a mystery that is still waiting to be solved".*

"I don't want to get out of my bed". "This genetic inherited condition that I was born with is part of me and will be forever more. There is no cure".

Lily explained that it had been easier to write down her feelings and experiences than, at emotionally difficult times to speak about them. Lily's narrative account of living with Cystic Fibrosis, the repeated infections which necessitated hospital admissions and the sudden onset of intensely frightening panic attacks had profoundly and adversely impacted on the quality of Lily's and her family's life. Health professionals who care for children living with long-term health conditions would benefit from understanding the additional health risks and psychological impact caused by the negative, adverse childhood experiences (ACEs) of living with disease and its treatments (Bellis et al., 2018). The disease, and her understanding of living with it, had a profound impact on her both physically and psychologically as illustrated by Lily:

"The clear mask suffocates my face whilst I breathe out a transparent gas, with yet another antibiotic rammed down my throat".

Lily narrates a vivid, first-person account of her thoughts, feelings, and physical appearance at the times when her disease was either within a stable period or was within episodes of exacerbation. Lily recounted the realities of the disease and its treatment:

"But nothing will take this pain away; no drug on earth".

"Bronchoscopy, PH study (by far the worst thing I have ever experienced), tonsils removed, lung function tests, a month in hospital, countless bouts of pneumonia, cameras and tubes down my nose, the list goes on. You name it. I've had it".

"This condition slowly shuts the lungs down one day at a time.

This reality was often punctuated by using a metaphor and simile, providing a greater insight into Lily's perception of her lived experience:

"I can remember having pneumonia, very vividly, my lips as blue as sea water, struggling to breathe".

"My lungs are scarred but sometimes it feels like a piece of my heart is too".

"This thick mucus also stops the digestive system and I struggle to digest nutrients required for my body. My body burns with acid, and it feels like I've swallowed fire".

"Saying this condition is draining is an understatement…another chest infection, doped up on medication and feeling like the walking dead".

"That breath you just took, that's a gift".

There were several aspects to Lily's perception of her disease and her response to living with her condition. The dark humour within Lily's story was evident in her first-person account of living with the lifelong uncertainty of an unpredictable disease whose treatment required multiple hospital admissions and recurring treatment interventions:

"It is like I have a season ticket to the hospital, minus the excitement."

"There's been some entertaining times in the hospital which I wasn't fully aware of 'till the morphine and anaesthetic wore off".

"I must apologize to the doctor who got a mouthful of abuse from a five-year-old me".

The personal and professional relationships encountered by Lily were perceived by Lily as being critically important. Lily's quotes demonstrate her ability to reconcile being diagnosed with her condition, living with Cystic Fibrosis disease, the treatment regimens essential to maintain her health and wellbeing and the cumulative, negative impact of her situation on her whole family.

"I've been told some nasty things in my life, things that could bring the strongest of people down to their knees".

"I saw my mum as a living, breathing angel that made everything more bearable……gripping my hand that didn't have the needle in it ...she whispered softly to me, 'I love you' ...her voice faint but warm and crystal clear over the beeping monitors…she looked after me better than any doctor could".

In addition to the impact on the teams involved in Lily's care, her peers, and her social circle:

"…not to forget the nurse who got slapped in the face and was kindly told to 'shut up and leave me alone'."

"Take care of your loved ones…when the dim yellow hospital lights turn off, they were the people who stuck by you no matter what".

Lily's recognition of the impact of her disease and her considering how to cope with her condition culminated in Lily writing her first-person account of her life and in her asking peers, teachers, and others to read it. The writing of the account, and the responses that Lily had received from those who read it, had made a positive difference to Lily and had helped her develop a degree of resilience to her situation, as illustrated in the following quotes:

"It's unfair but then no one has ever said life is fair, have they?"

"I'm allowed to cry; I'm allowed to get frustrated but one thing I am not allowed to do is give up. I will continue to fight this battle every day".

"I'm determined to prove anyone wrong".

The 'Just Breathe' first-person account concluded with Lily's philosophical view of her life and health experiences clearly demonstrating a child's ability to understand and explain the impact of their health condition and treatment:

"I know that the journey of battling this condition does not get any easier, only harder, Disappointment no longer comes as a shock. I will never use it as an excuse but a reason to take advantage of any opportunity. I will battle it for myself and the other ten thousand, four hundred people living in the UK. This is my battle. This is Cystic Fibrosis".

5.2.2 Idiographic findings from supplementary information presented by Participant 5 Amber aged 8 years living with heart disease, epilepsy, and a stroke

Amber's provision of supplementary information differed from that presented by Lily because Amber asked immediately before the semi-structured interview commenced if she

"could get some stuff to show you"

 (a physical object of a necklace to show to the researcher and to tell a story about it). The request was affirmed, and Amber brought a little bag into the room, the item of importance to Amber was a necklace. The necklace consisted of beads, hearts, a 'kitty' (bead shaped like a kitten) and several oval shaped black beads. During the interview Amber explained that the necklace was 'beads of courage'.

"The black ones are for having bloods taken...since I was a baby".

"The hospital chose them".

"I just like looking at them and I hope I get another bead and I hope I will get a new beads of courage from the hospital".

"The beads help me because I like them and I can play with them whenever I want".

Amber further explained that the black beads represent each blood test undertaken and then the child counted out loud, sequentially for each bead,

arriving at the number 14. Amber was asked if she knew what courage meant but she replied that she did not know.

5.2.3 Collective findings of Lily and Amber

The 'Just Breathe' school essay, written and shared by Lily and the 'beads of courage' verbally explored by Amber demonstrated the depth of both positive and negative experiences felt by the girls whilst living with their health conditions and receiving their treatments. The importance to Lily and Amber of being enabled to explain what the personal objects meant to them enriched their interview experience. The importance of supplementary evidence to the quality of data collection is highlighted by Sheridan and Chamberlain (2011) and Boden et al. (2019). Both girls knew that the hospital visits and clinical investigations were an integral part of their lives and that these had a physical and an emotional impact on them. The interactions with Lily and Amber clearly demonstrate their health literacy and portray the belief stated by Public Health England (2015) that children of all ages, stages of development and abilities must be assisted to understand and explain about their health diagnoses and to convey the impact of living with their condition and treatments.

5.2.4 Reflexive account

This unexpected interaction created an emotional impact on the researcher and Collins and Cooper (2014) raise the issue that unexpected events and unintended consequences, like this experience, may happen during participants' interviews. In addition, they explore the concept of emotional intelligence (EI) as a beneficial characteristic for researchers to develop prior to conducting qualitative studies. The acquisition of positive emotional intelligence as an ability, or as a natural trait in research, can assist with demonstrating empathy and a greater understanding of the participants' culture according to O'Connor et al. (2019). EI can help the researcher to recognise the significance of emotions, positive and negative, unconscious bias and any unequal power relationships between the researcher and the participant and enable the issues to be addressed.

5.3 Theme 1. Choices and control

Theme 1. Choices and control, presents the interpretation by the participants of their daily living experiences. The five children, Lily, Amber, Matthew, Mark and Luke expressed that their choices were often limited or restricted, either by their condition, their families or by service providers.

Challenges were raised by the participants in relation to choices and control and with daily living. They experienced the negative aspects of choices and control because the children and their families could not choose their activities, or reliably control how to spend their time. In relation to the children, this was due to the unpredictability of the status of their disability, or the symptoms of their health condition, and in respect of the parents, to the changing needs of their child.

The main challenges arose from the severity of the child's disability or health condition, and the intensity of a relentless daily routine involving medications, feeding and other regimens which removed the prospect of making any firm choices or exercising control in relation to planning family celebrations, events, and holidays. The implications of being restricted in choices and control are highlighted in the participants' quotes which demonstrate the impact of loss, fear, barriers and feeling judged:

The children and the parents spoke about what they had lost due to their situation, taking away their choices:

> *"I loved gymnastics, I was very active. I did 12/13 hours of that a week but I struggled a lot and I couldn't really go places and stuff so I had to stop but I did really enjoy it" (Lily).*

> *"I would love nothing more than to be able to go to bed at night, shut off my mind and be able to relax but I know that's never going to happen" (Lily's mother).*

"I stopped getting invited to places cause people knew I wouldn't be able to go" (Jack's mother, own semi-structured interview following Jack's Talking Mats® interview).

"Everything has changed, you don't look at a plate of food the same anymore, you don't shop the same anymore…it's so much more expensive" (Mark's mother).

These losses were also characterised by participants not only as elements that had been lost due to disease but also a sense that they were being prevented from engaging in activities by other people's decisions:

"I had work experience (police service dog handling) *….it was really good….but they don't know if I would get in to that because of all the running and that"(Lily).*

"If I have a cannula in I might miss out on some activities like sports day…I miss out on a lot a stuff, my football…I play all the time…it's really annoying me I'll just watch it" prevented (Matthew).

"My mum will probably want to drive me (to school) *but I would like to go on the bus" prevented (Matthew).*

The ability of the participants to maintain control, overcome fear, judgement, and barriers, or to have choices was characterised by situations where others assumed control or the ability of the person to maintain resilience and autonomy:

"…I don't stay at people's houses I'm terrified……when I'm there it's fine it's just the thought of going somewhere "(Lily).

"We didn't get a huge amount of medical history…that kind of made us very unsure about simple things like vaccinations…. could be a risk to (child's) *life you know" (Luke's foster mother).*

"It won't stop me from saying things but you feel as if you're viewed very much as a difficult parent… extremely anxious and paranoid…you're not heard" (Mark's mother).

"At first I used to ask them justify but now I just ignore it because I've got bigger battles to deal with and you can't argue with everything. So now I let them think what they want" (Mark's mother).

"Planning a holiday is not as easy cause you can't go somewhere that's got a thousand steps…organise extra medical allowance… flight etc" (Matthew's mother).

The participants' demonstrated their ability to adapt and build resilience in response to the challenges the faced daily and to the uncertainty within their lives.

"We made it clear that when we go in (to hospital) *I say we're only staying over if we really need to" (Matthew's mother).*

"We did get trained then and it did make it easier cause dad could still go to work, we could still get on" (Luke's foster mother).

"I used to sit by the phone for them (school) *to ring…come and get him…now I'm looking at going back to college" (Jack's mother, own semi-structured interview following Jack's Talking Mats® interview).*

"It's just for us to try and keep as much normality as possible…it's about getting the balance of the right kind of support…it's trusting somebody else, it's difficult when you're not there and in control" (Amber's mother).

"I'm mostly very shy but then can fit in with other people once I know how to control. I take a little notepad...what I can and can't do...I would feel more in control" (Mark).

The participants experienced few instances of being in control or feeling that they had choices. Where the children and parents had experienced several years of living with disability or complex health needs there was evidence of some adjustment and acceptance of their situation.

5.4 Theme 2. Relationships

The five children discussed the impact of their relationships in their daily lives, mothers' presence was significant to the children managing their conditions and central to the administration of complex dietary and medication routines. Health and education professionals made an impact on the children's experiences of school, activity clubs and hospital or other care environments. Lily's 'Just breathe' essay account demonstrated how the risk of trauma from adverse childhood experiences can affect the child's ability to cope.

The parents' relationships with their ill and disabled children took priority over other children in the family, their personal relationships, including wider family members and friends. Several family members, including siblings were informal carers and this help was invaluable to the children and their families. The relationships that were developed with the wide range of team members around their child graduated from negative to positive, some staff were seen as 'excellent', 'amazing', and going 'above and beyond'. The challenges in relation to personal and professional relationships were raised by the participants.

> *"I've had friends come in* (to hospital) *to keep me company but they can't keep them too long cause it's very contagious" (Lily).*

A sibling was showing signs of stress and anxiety:

> *"We actually paid someone privately just because it was getting to the point of her being physically sick going into school. The lady from CAMHS* (Child and Adolescent Mental Health Services) *gave us reassurance but said there's absolutely no way CAMHS would even look at her. School tried a few things as a whole class…mindfulness, but*

yeah, she never really got any support…they never really took it on board at all, even though it was written down" (Amber's mother).

"There is a doctor who is a little bit more abrupt…there's two consultants…it's bad for a parent to see the conflict between them" (Matthew's mother).

"Well he's got a lead professional but she has not supported in any way, the named person would be the headteacher …we haven't had a lot of support from them either recently. We have three children, two of who are adopted…biological siblings...bit of sibling jealousy and attention seeking" (Luke's foster mother).

Participants demonstrated their ability to adapt and build resilience in relation to the challenges faced within their personal and professional relationships.

"I like going out with my friends…..it's good that they just kind of accept me as one of them. My mum was always there…my dad's got a gene…my Mum doesn't. I really love my dog…and I really enjoy animals. I've got Dr (name withheld to protect identity) *and nurse* (name withheld to protect identity) *...it's good"* (Lily).

"She's my life…even though my husband is her dad it's always been me and her, I have my other daughter, I can rely on her" (Lily's mother).

"All my friends are good there and the teachers are good" (Matthew talking about school).

"We're a family of five…he keeps us on our toes…we've got gran" (Matthew's mother).

"Two sisters, one's younger and one's older" (Amber).

"The nurse (epilepsy specialist) *has been very good…and has been coming to meetings at school… We have the cardiac liaison nurse now…I wish she had been there at the beginning; it would have*

been brilliant. My sister is very good but she has just had a baby…things have got a little bit trickier for my husband and I to get any time" (Amber's mother).

"As always my dad would set out my breakfast…my mum and sister help me" (Mark).

"The diabetes specialist team are excellent…the teachers need training" (Mark's mother).

"The biggest source of support was the physiotherapist, he was amazing" (Jack's mother, own semi-structured interview following Jack's Talking Mats® interview).

"His headteacher goes above and beyond what we would ever expect a headteacher to…the hospital teachers are really good, they are getting a rapport…the play leader does more…has a better relationship, he knows her more and she is able to do more age-appropriate things" (John's mother, own semi-structured interview following John's Talking Mats® interview).

"We've got an occupational therapist, consultants, specialist nurses, probably dealt with hundreds of nurses…it's positive, some much more than others" (Amber's mother).

"We have our own older children, my sister, and a babysitter…" (Matthew's mother).

"We have friends, grandparents, dentists, nurses, teachers, social work, Scouts and community clubs" (Luke's foster mother).

"You think I don't want them all (health staff) *to just put us* (parents of children diagnosed with disabilities) *together like that…and now, well I'm friends with everyone" (John's adoptive mother, own semi-structured interview following John's Talking Mats® interview).*

5.5 Theme 3. Living with my condition

The participants experienced a wide range of emotions regarding living with their condition, some participants had hardly known life without their diagnosis, routines, and treatment regimens whilst others were newly diagnosed and were adjusting to living life differently. Amber's mother stated that prior to the semi-structed interview Amber had not looked for a long period of time at the 'Beads of courage' and felt that Amber was trying to demonstrate what she had been through by bringing them as an object to explore during the interview. Three of the children, Lily, Matthew, and Mark understood their condition and how it impacted on their daily lives. They were mostly accepting of the restrictions placed on them by their conditions, themselves, their families, friends, health and social care, education professionals, and the wider society. Lily, Matthew and Mark were positive about their futures and philosophical about living with their conditions.

The participants raised the challenges they faced in relation to living with my condition:

> *"I need to get up earlier '…cause I've got antibiotics to take and you can't eat at the same time…I need to wait half an hour then I can eat. It's a routine I need to have. I've had PH studies, bronchoscopy, cameras, and things… Scared...the PH study was by far the worst…the tubes they put them in the wrong place …made me sick so it's given me a big fear of sick. I'm terrified of sick, I do remember that and hated it. The psychiatrist has got me on medicines…but I'm going to try and lower the dose" (Lily).*

> *"I've not been keeping very well myself...stress can aggravate it...I'm not coping very well with stress" (Lily's mother).*

> *"She finds it difficult to verbalise…I think it's quite interesting because we haven't brought them out* (Beads of Courage) *in a good while. It's not like I mentioned them to her…she associates them with the hospital and maybe thought that was a way of her showing you what she'd been through" (Amber's mother).*

The participants demonstrated their ability to adapt and build resilience in relation to living with my condition:

"Well just a check up to see how I'm doing and how I'm coping and if I like it or not, it's just like a wee (little) *visit" (Mark).*

In addition, ambivalent feelings were raised by the participants in relation living with their condition:

"It would be a bit odd if it all stopped (his condition and treatment routines) *I would miss it a bit. You know there would be some good parts and some bad parts" (Matthew).*

5.6 Theme 4. Living with my child's condition

The eight parents interviewed had both unique and universal experiences of caring for their children with complex health needs and disabilities. Parents often had to deliver complex dietary and medication regimes and required training to do so, often needing to train others to enable them to receive some respite from their duty of care. Lily, Amber, Matthew, Mark, Jack, and John's mothers' physical and psychological health was affected, due to the energy needed to provide the best outcomes possible for their children. Luke's foster parents indicated that they were not adequately informed by statutory services in relation to Luke's needs and did not receive the support expected under the Named Person service (Scottish Government, 2014). Family finances were affected, and Amber's mother felt obliged to pay for psychological support for Amber's sibling to mitigate the deterioration she had witnessed in her child, no statutory service was available despite a recognition by school staff that a CAMHS (Child and Adolescent Mental Health Services) assessment and further help was required.

The participants experienced a range of emotions and impacts, including financial and limitations on education and careers. Additional issues were raised in relation to families that contained siblings, parents felt guilty and ashamed that they could not provide equitable care attention to all their children due to child with the illness or disability needing priority. There was

also tension within parental partnerships and for the lone parents, a conscious choice was made not to enter into any relationship that would make demands on their time or energy which they stated was in short supply.

The parents raised 'loss' as a challenge in relation to living with my child's condition:

> *"For me personally it has been a lot…I'll be up at 5…horrendous no sleep…exhausted horrible…my whole life was planned around hers…here comes this loopy mum again…and it was hard telling kids no, you can't come and see her" (Lily's mother who has her own health problems and was worried about an infection risk).*

> *"There are some clothes that I'll not wear either cause it just automatically reminds me or takes me back. Like the pyjamas I'd be wearing on the day we got the 2222 call* (life threatening emergency call to alert the resuscitation team to immediately attend) *…they're in the bin. There are pyjamas he wore down there* (Specialist Children's Hospital) *I can't put them on him anymore" (Jack's mother, own semi-structured interview following Jack's Talking Mats® interview)*

> *"Was just toilet trained when* (child) *came to us but reverted a bit overnight…took at least 2 months to be dry and clean" "they* (child and siblings) *have been through foster care…"(Luke's foster mother).*

The parents raised 'being judged' as a challenge in relation to living with my child's condition:

> *"I still cry now…I just couldn't think about myself I just had to be practical…I think people's answer is if you're upset then you need psychology and they don't" (Mark's mother).*

"When you have a child that has a number of conditions it's hard to just fall into one category" (Amber's mother).

The parents raised 'facing barriers' as a challenge in relation to living with my child's condition:

"Probably not being the person that has to go and seek things out…would need to offered things to take them up rather than ask for it" (Amber's mother).

The ability to adapt and build resilience was demonstrated by the parents in relation to living with my child's condition:

"We got in touch with the Heart Association charity and went to a family weekend…she loved it, we all loved it" (Amber's mother).

Ambivalent feelings were raised by the parents in relation to living with my child's condition:

"It is full on, particularly when the children are awake because of their disability and of course their attachment, it's not so bad now but you know first 3 or 4 years…"(Luke's foster father).

"In the beginning it was frustrating…we didn't know anything…we plodded on…it's easier to manage now we're trained, we kinda pushed to be trained to do it (intravenous medications) *at home…we've wanted to go to Florida for years…so planning a holiday is not as easy as we're led to believe…going out for the day…make sure you've got every medicine" (Matthew's mother).*

"When you go into hospital again it comes down to you know your child, the staff don't know them initially, don't be frightened to speak up and say no, this is not what I would do they are learning from you and you all want to work together" (John's adoptive mother, own semi-structured interview following John's Talking Mats® interview).

5.7 Theme 5. Bringing it all together

The children and their parents were living with the impact of complex health needs and disabilities and were in receipt of services from health and social care, education, third sector and voluntary services. The experiences demonstrated a wide-ranging impact on their physical, emotional, social and financial status and a variable experience of statutory and voluntary help available to them and the rest of their families. The role of support groups and voluntary agencies is appreciated by children and their families, providing a lifeline for respite from the anxiety of responsibility and the duty of care. The participants stated that they were trying to make sense of their situation and to adjust to any event encountered within their daily lives and routines. The participants accepted the intensity of their emotions as normal reactions to the unpredictability of their situation and not being able to plan with reliability any days out, family events or holidays, guilt and blame were emotions experienced by all of the parents and by some of the participants. The parents felt that they should be able to control every aspect of their lives but rationally accepted that they could not. Parents had a range of views on accepting the help and expertise from the teams involved with their child and, at times, wished that they did not have to go through their experiences, whilst knowing that there was no alternative.

Challenges were raised by the participants in relation to bringing it all together:

"I was always thinking I'll go back to work but no, you never ever go back to work" (Matthew's mother).

"The focus now is on the epilepsy and trying to get it under control because it's just having such a massive impact on what we can do as a family and on her" (Amber's mother).

"I think you will never be told enough information; you will have to do a lot of finding out for yourself…so patience is the overriding thing. The fear of the unknown is quite strong…" (Luke's foster father).

"Well, I get annoyed about it (inequity of activities) *cause the children are missing out on opportunities which should be available to them…the children who are more able get more cause it's much easier to take them" (Luke's foster mother).*

"It's just to have the feeling that someone's got your back. You just feel very isolated…fighting every step of the way. I dread putting in a repeat prescription every month cause every month it's wrong, they take things off…they say no, you don't need it". "Every time he has a school dinner something goes wrong. Every Friday he has a hypo (lower than acceptable blood sugar) *they say* (the catering staff) *that they weigh and measure* (the fish) *but they don't" (Mark's mother).*

"There was one day I went in (to hospital) *and had been upset 'cause I said I thought they were getting it wrong and I was polite…but I do feel you're missing something…I know my own child, she is ill. Please can somebody help? If you don't have a doctor out to me in the next hour, I'm putting out a 999. I would love nothing more than to be able to go to bed at night, shut off my mind and be able to relax but I know that's never going to happen" (Lily's mother).*

The participants demonstrated their ability to adapt and build resilience in relation to bringing it all together:

"It's been good to be able to talk about this and without upsetting people..." (Lily's mother).

"I'm a wee (little) *active boy, my health doesn't really stop me. I still get on with life" (Matthew).*

"If we think strongly enough about something we will stand our ground until something's done…9 times out of 10 yeah, it's got resolved" (Matthew's mother).

"I would like to do stuff about the human body. I think I would be good at it '…cause I break bones quite a lot and I'm used to going to hospital" (Lily).

The participants presented mixed feelings in relation to bringing it all together:

"We're very lucky. We weren't aware that we were entitled to apply for an adapted house…we (the family) *really do work as a team…we worry that we will be older parents…what will happen to him, he wouldn't go into a care facility. He'll be cared for by family, but that worry is still there"* (John's adoptive mother, own semi-structured interview following John's Talking Mats® interview).

"…there's just so much to say…I could have gone on and on, so I had to narrow it down" (Lily).

"It's mostly the same old. I would go out and try to test my BM (blood sugar level) *put in my snack cards, have a break then lunchtime I would do the same thing…check my BM. If I'm still under control* (diabetes) *I'm just like everyone else and then if people judge me then well it doesn't matter 'cause we all the same, but we have different qualities"* (Mark).

5.8 Discussion of the collective and idiographic findings from the participants' semi-structured interviews

The discussion will detail the range of perspectives provided by the participants' first-person accounts of their lived experiences. The five themes generated from the participants' semi-structured interviews were: Theme 1. Choices and control, Theme 2. Relationships, Theme 3. Living with my condition, Theme 4. Living with my child's condition and Theme 5. Bringing it all together. There were positive experiences which helped children and their families to build resilience and develop coping mechanisms in relation to the unpredictability of daily living and negative experiences which left children and families feeling undervalued, unsupported, and unsure how to cope with

the demands of daily life. In addition, the children and families had mixed feelings about some aspects of their lives which included feeling fear, being lost, feeling judged, experiencing barriers and the lack of choice. In contrast, this was balanced against an ability to adapt to changing needs and circumstances, taking control and building resilience, learning new skills, increasing knowledge on disability, disease, and treatment (health literacy). The participants had resigned themselves to living with the challenges of ill health, disability and unpredictability and stated that they would find it difficult to adjust to new routines in their daily lives if their situation changed.

5.9 Reflexive account

The experience of interviewing the participants was one of privilege and provided a life-changing impact for the researcher in placing the importance of health and family life in sharp focus and a positive perspective.

The interview process could have been improved with Participant 13, a boy aged 13 years living with a learning disability and Fetal Alcohol Spectrum Disorder (FASD), which impacted on his ability to communicate. This child gave mostly one-word answers during his interview and as such, the sentences were difficult to place in context, for example, *"Dunno"… "yes"… "good"… "for an eye test"… "it's good"… "I got a wetsuit"… "wash"… "ok"* and on reflection it would have been better for this child to have been offered a Talking Mats® interview. This method may have yielded a clearer view of his daily life experiences, more comprehensive answers and deeper findings relating to his feelings. The child's cognitive abilities were impaired by their condition and the child was very shy, looking towards both parents for approval before offering any answers to the questions about his experiences of healthcare and daily living.

Children and parents articulated the issues in relation to culture, quality of life and emotional wellbeing. Parents and children recounted similar experiences and the themes of fear, uncertainty, bravery, courage, control, and choices emerged. The variations in service and lack of appropriate equipment leading to self-funding or charity funding of essential equipment was noted.

Prescription issues were encountered and added to the stress and frustration experienced by parents. Changes in children's treatment were offered or recommended, sometimes related to the latest technological developments. The relevant training was not always provided, or if provided, was delayed, some parents found themselves in the role of trainers of complex procedures. Parents highlighted their duty of continuous responsibility that once trained in medical procedures there was an expectation placed on them to train the healthcare workers involved with their child. Specialist teams, including nurses, provide services which were appreciated but the times of access to specialist services were not always convenient for parents. Parents valued seeing the same person consistently to build positive relationships, communication, experience, and trust, this illustrated the impact on parents of the unrealistic expectations of health and education staff populations. Moving to high school presented the challenges of not knowing what is in place within school, especially for children who are living with diabetes. How children are supported in school was a priority for parents, written diaries and guidelines assisted the child's experience in school. Parents who were resident in hospital with their children appreciated the care and treatment provided but pointed out the over reliance on the parameters or numbers generated by machines. For example, the use of electronic monitors rather than by physical observations, staff looking at other signs and symptoms, hearing the parents' views and trusting the parents' instincts and judgements on their child's condition. Person-centred care, placing the recipients of services at the centre of care, is seen as essential by McCormack and McCance (2017) who highlighted the significance of person-centred services in minimising potential health risks and the possible subsequent trauma of sub-optimal patient experiences during healthcare.

The findings will generate a greater understanding of the children's and families' daily lives impacted by complex health needs, disabilities and SLCN and will add to the body of current knowledge regarding children's rights and legislation in relation to health, social care, and education. Vennik (2015) advocates the meaningful involvement of citizens and communities in the co-

production of appropriate and sustainable services. The co-produced approach through the provision of integrated health and social services in Scotland can gain results which would improve the experiences of children and families.

5.10 Chapter summary

This chapter explained the research process used within this qualitative, phenomenological study and outlined the findings from the semi-structured interview method applied and which was described in Chapter 3. The results of the literature review presented in Chapter 2 provided the evidence that a phenomenological approach and the interview method were the most suitable mechanisms of investigation for this study. Chapter 4 included an analysis of the practicalities and impact on the study findings by applying the semi-structured and case study methods in addition to the Talking Mats® adapted method in this study.

Section 5.2 discussed the selected method of semi-structured interview and case study and their value to this study. Section 5.3 detailed the participant sample and recruitment process and provided the justification for the inclusion and exclusion criteria used for the participant selection. Section 5.4 Sections 5.4.1 and 5.4.2 detailed the additional contributions to the study from two of the children, Participant 1 Lily and Participant 5 Amber, who provided supplementary information which had significance to their lived experiences. Section 5.4.1 discussed Lily who had requested that the contents of her written personal story should be included as part of her interview, and this request was agreed to by the researcher and the research supervisors. Section 5.4.2 detailed how Amber, during the semi-structured interview, reflected on the experiences that were important to her through a personal object, a string of beads and her physical handling of each individual bead whilst illuminating the personal story attached to each one.

Section 5.5 presents the analysis of the interviews which used the Interpretative Phenomenological Analysis (IPA) approach and the six steps of analysis developed by Smith et al. (2009). The idiographic and collective

findings, including the similarities and differences between the children and their parents' perceptions of living with a disability, complex health needs and SLCN, and their experiences of healthcare were presented in Section 5.5. The interview schedule, the interview questions, and the collective, shared findings from the participants' first-person, lived experiences provided during their interviews are presented under the five themes generated from the analysis of the semi-structured interviews. The negative, positive, and ambivalent perspectives of the participants' experiences were presented in Theme 1. Relationships, Theme 2. Choices and control, 3. Living with my condition, 4. Living with my child's condition and 5. Bringing it all together. A summary of the key aspects of the chapter was provided in this section.

CHAPTER 6:

FINDINGS FROM TALKING MATS®

The purpose of this chapter is to discuss the use in this study of the Talking Mats® method developed by Murphy (1998a) and to detail why Talking Mats® was used to address the research question in this study, 'What are the views and experiences of children living with disabilities and complex health needs and those of their families?'

6.1 Introduction and chapter overview

This qualitative study was conducted with a targeted sample of children who used the Talking Mats® method for communication and who were living with disabilities and complex health needs, these are conditions which require long term health care (Royal College of Paediatrics and Child Health [RCPCH], RCPCH, 2014).

Participant Information Sheets (Appendices 8, 9 and 10) were sent to the parents of the potential participants by the gatekeepers, who were headteachers and specialist nurses and who had access to the population of children and families required for this study. The final number of confirmed participants using the Talking Mats® method in this study was two children, both boys. Anonymity of the research participants is essential to meet General Data Protection Regulations (GDPR, 2018) and to ensure confidentiality. The pseudonyms of Jack and John will be used within this study to protect the identities of the two boys. Jack is aged eight years and John is aged nine years and both boys are living with Speech, Language and Communication Needs (SLCN), disabilities and complex health conditions.

The assent and consent processes (Appendices 12 and 13) were discussed with the parents and consent was gained from each parent for their child to

participate. The parents each confirmed that their child had some verbal abilities in addition to their communicating through the Talking Mats® method which was used at school. The assent form and the use of Talking Mats® in this study context was explained to each child to ensure their level understanding of the study process and to meet the ethical standards and safeguarding requirements of the British Educational Research Association (BERA, 2018) and the Code: Professional Standards of Practice and Behaviour for Nurses, Midwives, and Nursing Associates (Nursing & Midwifery Council [NMC], 2018). The prevention of adverse experiences and harm (Appendix 4) and the safeguarding of the two participants will be assured through adherence to the recommendations for research with children from the National Society for the Prevention of Cruelty to Children (NSPCC, 2018) and BERA (2018).

Mackay and Matthews (2020) recognise that Talking Mats® (Murphy, 1998a) is an effective communication method to use with children and young people. In addition, they advocate the use of the Talking Mats® consultation bundle detailed in Figure 3 (see Chapter 3) for children who are living with SLCN, disabilities and complex health conditions. This information confirmed that the consultation bundle within Talking Mats® would be suitable for use with Jack and John but would be examined to assess whether an adaptation was required to meet each of the boys' individual needs.

The rationale will be presented for adapting Talking Mats® within this study for Jack's and John's use and for the amendment required to the 'Top Scale', the 3-point visual scale of symbols as detailed in Figure 2 (see Chapter 3). The three symbols depict the Talking Mats® cartoon character 'Matty' who enables the participant, known as 'the thinker', within Talking Mats® to demonstrate their choices. A positive, neutral, or negative choice is offered indicating likes, dislikes and an 'undecided or do not mind' status in relation to a topic, or domain included in the Talking Mats® resource and as seen in Figures 2 and 4 (see Chapter 3). The three symbols demonstrate Matty with a 'Thumbs up', indicating a positive reaction, 'a shrug', which is shoulders raised and arms outstretched at the sides, to depict a neutral or ambivalent

reaction, and a 'Thumbs down' to indicate a negative reaction to a topic and domain. The positive 'Thumbs up' choice relates to the opinion of 'like, enjoy, happy and important', the neutral response symbol of 'arms outstretched at the sides' is interpretated as 'not sure', 'do not know', 'do not mind' and 'not important' and the negative 'Thumbs down' choice relates to the opinion of 'do not like, do not enjoy, not happy and not important', in relation to each domain considered.

The process used to adapt Talking Mats® and to provide the novel Talking Mats® method applied within this study was outlined in Chapter 3. The reason for adapting Talking Mats® was due to Jack and John's health conditions and their impaired cognitive abilities which required that the interview process must be as clear and simple as possible, reducing the risk of confusion through cognitive overload. Edwards and Smith (2014) found that there was a risk of confusion for participants living with cognitive impairments when the choice of a neutral, ambivalent response is presented in the options to questions. According to DeMaree et al. (2014) the consequence of ambivalence can lead to a discrepancy in the participant's attitude and feelings, impacting on the clarity of the actual opinion of the participant and the rejection of the participant's authentic desired choice. The removal of ambivalence, the neutral option in research questions culminates in a 'forced choice' relating to a negative or positive opinion. Smyth et al. (2006) examined the forced choice in comparison to the option for a range of views and found that the forced choice enabled the participant to consider the choice in more depth. For this study, the removal of ambivalence and presenting a forced choice was necessary to mitigate against the risk to Jack and John experiencing cognitive overload and confusion, and to assist them to make clear, authentic choices.

This chapter explains why the neutral, ambivalent symbol depicting 'the shrug' was removed and how this produced a bespoke communication tool with a dichotomous or forced choice for the participants to reduce the risk of cognitive overload and confusion. The amended Talking Mats® provided an innovative and clear research method to apply within this study. The National

Society for the Prevention of Cruelty to Children (NSPCC, 2018) states that children are vulnerable and must be protected in all situations, safeguarding Jack and John from confusion and cognitive overload was an important consideration within this study to ensure Jack and John's health and safety as participants. Section 6.2 will provide the details of Jack and John, including their health, education and social needs which had resulted from their disabilities, their genetic conditions, and the impact of their long-standing chronic illnesses. Section 6.2.1 outlines Jack's life profile and 6.2.2 relates to John's life profile. Section 6.3 will discuss the analysis of the Talking Mats® approach in relation to this study and will introduce the Effectiveness Coding Framework template (Table 16) (Murphy & Boa, 2012) which was used to assess Jack's and John's communication abilities prior to the application of the innovative Talking Mats® and to demonstrate their authentic choices about daily living experiences within their Talking Mats®.

Section 6.4 will discuss how three themes were identified from the exploration of the boys' perspectives on their daily lives and health through the application of the Talking Mats® Health and Wellbeing topic (see Figure 4) and the Talking Mats® domains of 1. Health condition, 2. Ways of coping, 3. Activities, 4. Self-care, 5. Communication, 6. Relationships and 7. Participation, which are depicted in Figure 5, Chapter 3. The three themes generated from the boys' Talking Mats® will be presented: Theme 1. Mobility and transport Theme 2. Activities of daily living and Theme 3. Choices and preferences. The themes were developed by examining the boys' choices presented on each mat in relation to each domain and by noting on Table 19 in relation to Jack and Table 20 regarding John, the frequency of the positive 'Thumbs up' choice relating to 'like, enjoy, happy and important' and the negative 'Thumbs down' choice relating to 'do not like', 'do not enjoy', 'not happy' and 'not important'.

In addition, Section 6.4 will consider the supplementary information offered by the parents regarding the children's daily routines and the impact of illness through the conversations which took place both spontaneously and naturally during the Talking Mats® exercise. The parents' information

correlated with Jack's and John's authentic accounts presented in the symbols that they had chosen to place on their Talking Mats®.

Section 6.5 will detail a reflexive account of the researcher's experience and will explore the use of the innovative Talking Mats® method in this context and Section 6.6 will present an account of the participants' interaction with Talking Mats®. Section 6.7 will provide a summary of the key phases employed within this study to achieve successful and enriched findings from the application of the innovative, non-ambivalent Talking Mats® method. This chapter will demonstrate confidence in the use of innovative Talking Mats® as an effective, evidence-informed communication tool for use with children and for the consideration of its use within health, educational and social settings.

The evidence provided in this chapter contributes to the results from the literature review detailed in Chapter 2, to the findings presented in Chapter 4 of the semi-structured interviews influenced by Interpretative Phenomenological Analysis (IPA), and the case studies from Lily and Amber.

6.2 Participants

The Children and Young People (Scotland) Act 2014 incorporates Getting it right for every child (GIRFEC), the National Practice Model and the Named Person service (Appendix 3), which are centrally concerned with identifying and meeting the health, social and developmental needs of children and young people living in Scotland. The purpose of the legislation and GIRFEC is to ensure that the integrated care agencies for health, education, and social care address the optimum health, safety, and inclusion of all children. The Scottish Government (2019) reported that some differences in children's abilities can be due to various factors related to a disability or impairment, or a physical or mental health diagnosis which results in substantial difficulty with day-to-day living activities. Jack and John were recognised as having additional support needs through the GIRFEC assessment and the Named Person service (Scottish Government, 2014), and under The Education (Scotland) Act 2016, in addition to the recognition of protected characteristics

under The Equality Act 2010. Jack's and John's rights to receive additional support to that of their peers, including help with communication, are inherent in legislation, GIRFEC and Articles 12, 13 and 23 (Appendix 3) within the United Nations Convention on the Rights of the Child (UNCRC, 1989). Jack's and John's abilities to cope with and manage events in their daily lives are impacted by their health impairments resulting in the need for additional help through statutory services. The background to and the impact of Jack's and John's disabilities, complex health conditions and SLCN will now be outlined, for Jack in Section 6.2.1 and for John in Section 6.2.2.

6.2.1 Jack's life profile

Jack was aged eight years and lived with his mother, they both had minimal contact with any family members which led them to feel isolated at times, particularly during episodes of Jack's illness. Jack appeared happy and settled within his home environment and was very proud of his bedroom and the numerous toys he owned. Jack was interested in dinosaurs, animals, and cartoon characters. Jack's mother was proud of the life and home she was providing for Jack and aimed to improve her personal life chances and family circumstances further through undertaking studies at a higher education institute.

Jack's speech and cognitive level were impaired due to the impact of a late diagnosis of a metabolic condition and living with the morbidity, the health issues that this had caused. Jack required an organ transplant when he was seven years old and needed daily medications, including anti-rejection therapy, which is a routine precaution to maintain health stability following organ transplant surgery (National Institute for Health and Care Excellence [NICE], 2017). Jack required a low protein diet and if this was not carefully followed, Jack would become unwell. Jack's energy levels tended to fluctuate, and his level of fatigue was continuously monitored at home and at school. Jack's health was often compromised, and he required several emergency admissions to hospital which both Jack and his mother found distressing. A reason for frustration during hospitalisation was that Jack was

offered foods that compromised his strict diet, and he would become upset when informed that his choice would not be available to him. The episodes of ill health, hospitalisation and denial of preferred choices were categorised for Jack as adverse childhood events (ACEs) by the professional agencies, known as the 'teams around the child', during the mandatory assessments of the GIRFEC process (Scottish Government, 2014) and through The Education (Scotland) Act 2016. ACEs are detrimental to children's health and development (Hughes et al., 2018) and the impact of ACEs on Jack's health and development were monitored during his routine, annual healthcare appointments or more often when required, for example, following an unexpected health event. Jack and his mother had continual involvement throughout Jack's life from several teams within universal health, social care, and education services and from specialist healthcare professionals. Jack and his mother had developed positive relationships with the teams around Jack and this helped to mitigate some of the distress, and to lessen the impact of emergency hospitalisation on Jack and his mother.

6.2.2 John's life profile

John was aged nine years and lived in a stable, loving home with his adoptive parents (parents) and an older sibling. John's home had been assessed by social services under the GIRFEC process (Scottish Government, 2014). Adaptations had been made to his bedroom to provide a comfortable, child-friendly space and an accessible environment to assist John with his limited mobility. No adaptations had been made to the garden and this area was unsuitable for John to play in due to its inaccessibility through uneven ground and several raised areas only reached through negotiating several steps. John liked to be outdoors and his only option to access the garden space was to sit outside the back door and against wall of the house which had a narrow area of paving. John's parents were very protective of John due to the knowledge of how difficult John's life had been since birth. The parents were aware of their reduced privacy and restricted ability to spontaneously arrange family treats and events due to the number of appointments with the GIRFEC teams and agencies that were involved in

John's and his family's life. John had an age-appropriate but limited understanding of his background before his adoption due his parents sensitively explaining some of his personal history to him.

John has a diagnosis of autism, which is a lifelong developmental disability (NICE, 2019) and the features of his condition were episodes of anxiety when there were any changes in his daily routines and if he was exposed to loud noises. In addition, John had a diagnosis of Neonatal Abstinence Syndrome (NAS) or disorder, which is defined by Rees et al. (2021) as a debilitating health condition affecting a child from birth. This was due to being exposed to drugs, predominantly illicit, during the pregnancy, known as the intra-uterine period, where the drugs are transmitted to the foetus via the maternal placenta. The primary symptoms of NAS in the neonatal period which is from birth to one year old are uncontrolled trembling, high pitched crying, inability to settle to sleep, disturbed sleep patterns and the gastro-intestinal symptoms of diarrhoea which impacts on the baby's ability to gain weight and thrive. Aspects of John's background remained confidential due to the stigma that is often attached to children living with NAS and the predominance of the children requiring child protection and safeguarding services. The impact of the birth history of children diagnosed with NAS is outlined in the child protection policy for children affected by parental substance misuse (Scottish Government, 2021), with the acknowledgement that most children living with NAS are safeguarded by the local authority through fostering and adoption services. John was assessed through the GIRFEC process which acknowledged the impact of his birth trauma, the diagnosis of NAS and his adverse childhood experiences (ACEs). The lifelong impact of ACEs is recognised as affecting optimum health, social and psychological development (Hughes et al., 2018) and was explained in Chapter 1. John's adoption into the loving and stable family environment where he had been fostered since birth provided him with the safety and security that he required to achieve his maximum health, educational and social potential despite his health difficulties. John's health was compromised by an inability to eat and a nutritional deficit due to his chronic long-term

illness. This consisted of gastrointestinal, digestive problems which resulted in cyclical severe vomiting episodes. John's condition necessitated his repeated emergency hospital admissions and extended lengths of stay for treatment, which caused ACEs to John and significant distress to his family. Clinical assessments revealed that John's growth was delayed due to his chronic clinical condition and following a dietetic and surgical assessment an artificial feeding tube, defined as a Percutaneous Endoscopic Gastrostomy (PEG) (Ahmad et al., 2020) was inserted into John's abdomen to support feeding and to maintain adequate nutrition to sustain growth and avoid malnutrition. John's health condition and sub-optimal nutritional status caused him ongoing physical weakness culminating in muscle weakness and difficulties with mobility, particularly walking outdoors, resulting in John requiring the continuous use of a walking aid and a wheelchair. Despite the impact of John's medical history and long-term health conditions, John appeared happy and settled with his adoptive family and he was able to express his views and feelings verbally, in addition to the use of Talking Mats®.

The life profiles of Jack and John whilst different resulted in both boys having to face challenges within their daily lives that were different to their peers, and which limited the range and quality of choices they were able to make. The impact on Jack and John of living with complex medical health and SLCN is demonstrated in their individual Talking Mats®.

Jack's choices demonstrated on Talking Mats®

Jack's Talking Mats® (the original image above is of poor quality due to an unexpected issue which occurred with the equipment used). Jack's dichotomous choice option within the Top Scale (see Figures 9 and 10). Jack's choices related to the central topic of daily living and the domain option symbols pictured below which clarify the choices made by Jack.

Figure 9. Jack's novel Talking Mats: Jack's choices demonstrated

Figure 10. Top Scale symbols adapted to enable a clear, dichotomous choice

Like, enjoy, happy, important.   Do not like, do not enjoy, not happy, not important.
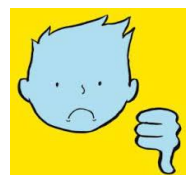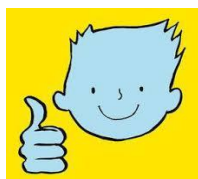
Jack's completed novel Talking Mats® depicted several activities of daily living within the home and school setting. Jack demonstrated his dichotomous choices of what he liked, enjoyed, what made him happy and

was important, and what he did not like, did not enjoy, what he was not happy with and what was not important.

Figure 11. Central topic symbols- Daily living

Coping and stress   **Routines**   **School**   **Making decisions**
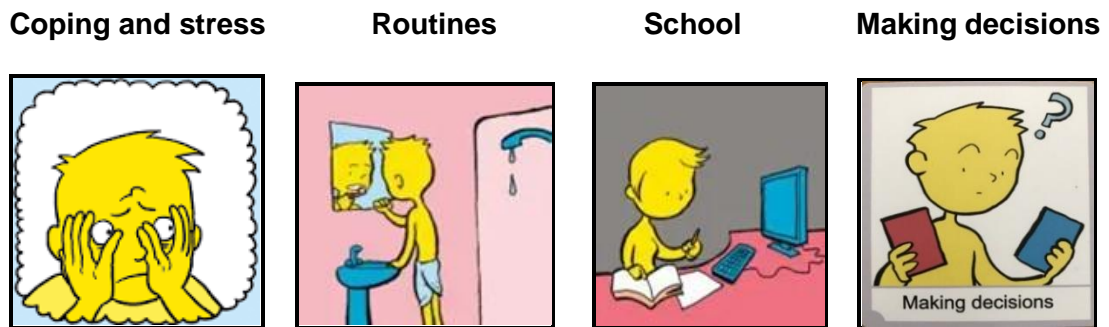
Domain symbols chosen by Jack and depicted on his Talking Mats:

Leisure and hobbies, Transport, Health and Wellbeing and Relationships

Jack was able to understand his daily routines and could undertake some daily living activities such as choosing favourite foods, toys, television programmes and his clothes. Jack liked his bed and sleeping in his bedroom. Jack had some control over his personal care routines and could wash, but not bathe or shower independently. He could brush his teeth and hair with minimal assistance. Jack required help with toileting, dressing and undressing, during his waking and bedtime routines and for preparing for swimming and sports activities.

Leisure and hobbies

Writing   **Reading**   **Numbers**   **Television**   **Playing**
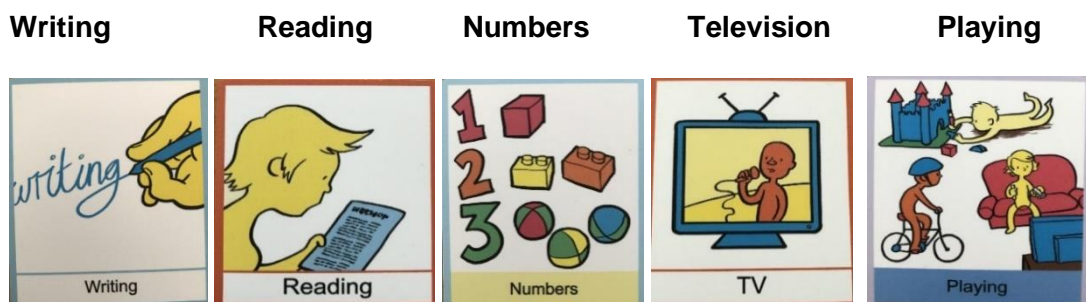
Jack indicated on his mat that swimming and cycling were favourite activities at school and that he enjoyed television at home and when in hospital because his favourite commercial streaming service 'Netflix' was made available to him. Jack enjoyed schoolwork with numbers, and activities and puzzles that included numbers, but did not enjoy reading or any activity or schoolwork that involved writing. Jack enjoyed playing indoors and outdoors with friends in school and within his local neighbourhood. He enjoyed trips out when well but overnight stays with family and friends were not possible due to the complexity of his daily routines.

Transport

Using transport	Wheelchair	Mobility	Travelling	Cycling
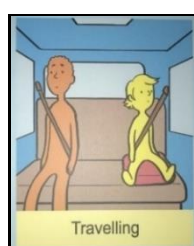
Jack was interested buses and in cars and had toys and models relating to transport. Jack enjoyed cycling when his health and energy levels allowed, Jack understood the need for safety when travelling in the car and getting in and out of the car.

Health and wellbeing

Health staff	Looking after myself	Medications
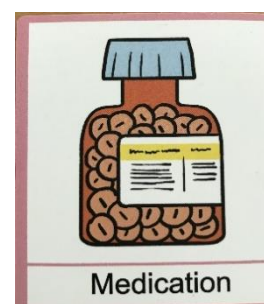
Jack's Talking Mats® demonstrated that he accepted the healthcare teams and carers around him and that his health and his development were regularly assessed. The need for medications was essential to Jack's health and the complex medication routine required amendments to the time needed for Jack to wake up and to prepare for school. Extra time was needed to complete his personal care routine before the school transport arrived to take him to school.

Relationships

Family	**Mum**	**Friends**	**Pets**

Jack was excited and animated when choosing the symbols for family, friends, and pets, indicating that they were important to him. He demonstrated that he enjoyed caring for his pets, being with his Mum, his friends in school, and his friends within the neighbourhood.

Jack's Talking Mats® summary

It was evident from Jack's Talking Mats® that he liked, enjoyed and was happy with most of his daily activities. Jack accepted that his range of medications were an essential routine in daily activity. Jack's mother advised that Jack required a low protein diet and the administration of nine medications first thing in the morning, with one medication taking twenty minutes to dissolve. Jack's mother's opinion was that this complex daily routine was accepted as necessary but was stressful for both. There was clear indication in the 'do not like' column that reading, writing, tidying up and the toileting regime at school were difficult for Jack. The lack of acknowledgement of Jack's preferences and the choices given to Jack

regarding his school activities were highlighted by Jack's selection of the symbols relating to reading and writing. These factors had not been fully identified prior to completion of the Talking Mats® and Jack's mother indicated that she would have further discussion with Jack's health and education providers regarding the findings of his Talking Mats®. The still photograph taken of Jack's Talking Mats® may provide Jack's mother with support at Jack's annual GIRFEC review which is mandated by the Named Person service under the Children and Young People (Scotland) Act 2014.

Figure 12. John's Talking Mats® Top Scale symbols adapted to enable a clear, dichotomous choice
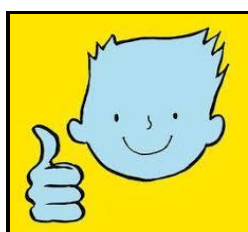
Like, enjoy, happy, important.   Do not like, do not enjoy, not happy, not important.
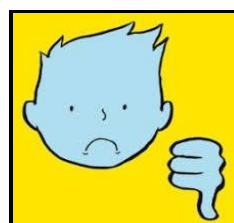
John's Talking Mats® depicted several daily living activities experienced within the home and school setting. John provided his choices of activities that were liked, enjoyed, made him happy and that he saw as important, in addition to activities that were not liked, not enjoyed, John was not happy with and that were not important to him. John duplicated his choices of symbols regarding health and was very concerned and pre-occupied with his body systems, his weight, his mouth and being unable to eat.

John's Talking Mats® choices are pictured in Figure 13 (the original image above is of poor quality, an unexpected issue caused by the equipment used). The choices made by John depict the dichotomous choice option within the Top Scale. John's choices are related to the central topic of daily living and the following domain option symbols; Coping and stress, Routines, Making Decisions and Arts and crafts.

Figure 13. John's novel Talking Mats® John's choices demonstrated on Talking Mats

Central topic symbols- Daily living

Coping and stress	Routines	Making decisions	Arts and crafts
Managing stress	Routines	Making decisions	Arts and crafts
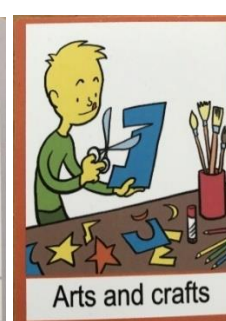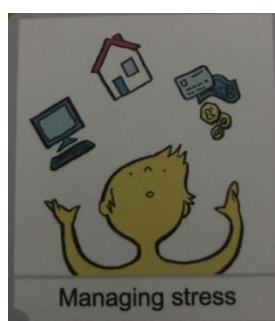
John's completed novel Talking Mats® depicted several activities of daily living experienced at home and at school, and the activities that he was able to undertake independently or with help. John demonstrated dichotomous choices of activities he liked, enjoyed, he was happy with and that were important to him. In addition, John indicated the choices and activities he did

not like, did not enjoy, was not happy with and that were not important to him. John was able to understand his daily routines and could undertake some daily living activities, for example, choosing arts and craft activities, favourite toys, trips out, his clothes and bedtime. John had some control over his personal care routines and could wash his hands and face but could not bathe or shower independently, he could brush his teeth and hair with minimal assistance. John required help with toileting, dressing and undressing, his waking and bedtime routines and for preparing to take part in sports and activities at school.

Figure 14. Option symbols- Domain symbols chosen by John and depicted on his Talking Mats

Transport

| **Wheelchair** | **Mobility** | **Going for a walk** | **Stairs** |

John's mobility was impaired by his muscle weakness, and he had chosen symbols relating to the help he required with his moving and physical activities.

Health
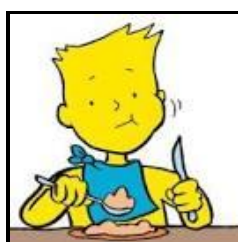
| **Eating** | **Teeth and mouth** | **Loud noises** | **Losing weight** |
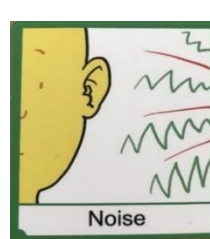
Medication   **Artificial feeding (PEG).**   **Health staff**

Medication

PEG

Health service
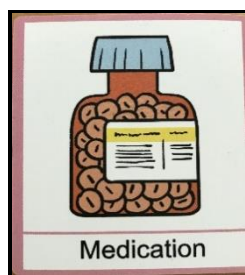
Body systems depicted on John's Talking Mats

Bladder **Stomach** **Skin** **Eyes**

Bladder
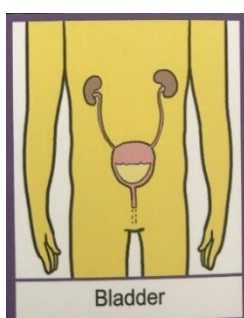
Stomach
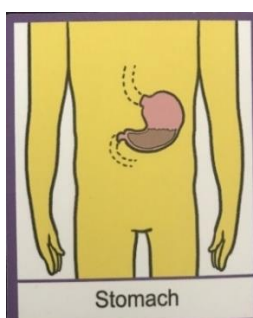
Skin

Eyes
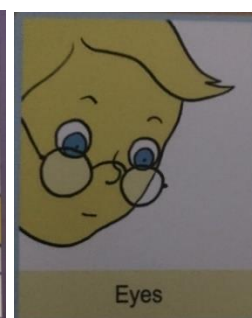
John was eager and excited to choose his symbols and many of choices related to health, body structure and body function. These seemed highly important to John because two identical symbols were chosen and placed on the mat for two of the domains. John was physically unable to eat and demonstrated that his mouth and digestive system were very important to him. John's mat depicts that complex medication and artificial feeding regimes impact on John's ability to complete daily activities. John stated verbally that he knew that the medication and feeding routines were part of his everyday life. John and his family accepted that there were no alternatives to the routines, although these impacted on their ability to organise family events, treats, and holidays. Hospital admissions were a regular occurrence for John and the relationships with health staff had significance for John. The hospital experience was positive for John mainly when the staff he was the most familiar with, and whom he liked, were on duty. John experienced adverse events, ACEs, when he required clinical investigations and interventions such as blood tests and intra-venous therapy during the hospitalisation caused by his clinical deterioration.

Relationships

Mum	Family	Best Friends	Friends
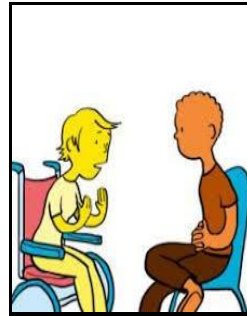
John focussed intently on his relationship with his Mum and John often looked in the direction of his mother before placing his symbols on the mat. John's mother acknowledged John's gesture towards her and verbally responded to John by saying that he should place the symbol wherever he felt best which enabled John's views to be authentic and uninfluenced by his mother. John placed symbols related to relationships at home, school and in the hospital depicting friends, health staff and carers in the do not like, do not enjoy, not happy and not important column.

John's Talking Mats® summary

The adverse factors relating to school and hospital demonstrated by John on his Talking Mats® were of concern to John's mother who had previously raised John's lack of choices in hospital with health staff and in school with education staff. John's mother stated that a further discussion was now required with the health, social care, and education service providers to discuss John's views that were clearly shown within the Talking Mats®. John's mother was satisfied that the information gained was a true reflection of John's views and experiences and that the Talking Mats® results recorded on a still photograph given to John and his mother would be useful information to add to John's GIRFEC educational, health and social care assessments.

6.3 Themes

The mechanism for analysing Jack's and John's Talking Mats® was outlined in Chapter 4 which explained how three themes were developed from the Talking Mats® process. The completed audio-visual recordings of Talking Mats® were rated by three researchers and scores were separately assigned using the Effectiveness Coding Framework template (Table 16).

The scores obtained were averaged and totalled to provide a score out of twenty, with the scores between fifteen and twenty indicating a high level of communication effectiveness to achieve the results presented. A contingency plan was agreed by the researchers and supervisors regarding any discrepancies of the scores to engage a fourth researcher, or practitioner, to adjudicate and to enable a consensus. The reviewers' understanding and experience of research and research processes were deemed the most important factors for the review and scoring process, and the researchers were confident about the use of the Talking Mats® method. No disagreements were encountered in the analysis of the participants' mats in this study which has provided confidence in the rigour of the study.

The analyses were demonstrated in two tables, Table 19, the themes from Jack's Talking Mats® and Table 20, the themes from John's Talking Mats®. The frequency was noted of the positive and negative choices made by 'the thinkers' who were Jack and John, on the central topic and the option domains presented to them during the Talking Mats® intervention.

Supplementary information on the children's daily routines and the impact of illness was offered by the parents through the conversations which took place both spontaneously and naturally during the novel Talking Mats® exercise and this supported the symbols and choices presented on the novel Talking Mats®.

Still photographs of the completed mats had been taken and copies given to the children and their parents. The photographs were examined by the researcher and two supervisors against the original audio-visual recordings

to gain consensus and to enable a rigorous, reliable process to be undertaken. The domains and contextual factors of the International Classification of Functioning, Disability and Health (ICF) listed by the World Health Organisation (WHO, 2001) are detailed in the methods section of Chapter 3 of this thesis. ICF was explored with the children during the novel Talking Mats® interviews and the results were detailed in Table 19 for Jack's Talking Mats® and in Table 20 for John's Talking Mats®.

The findings from the analysis of each of the Talking Mats® will be outlined under the themes generated from the analysis and will include two perspectives relating to both the adverse impact and the constructive effect on Jack's and John's quality of life, and that of their families. Jack's and John's views that were shown through the symbols they chose, and that were demonstrated on their Talking Mats® will now be explored.

Three themes emerged from the domains and symbols selected by Jack and John and demonstrated on the boys' Talking Mats® these were, 1. Mobility and transport 2. Activities of daily living and 3. Choices and preferences.

Table 19 will present the themes generated from Jack's Talking Mats®

Domains- Health condition, Ways of coping, Activities, Self-care, Communication, Relationships, Participation	Thumbs up	Thumbs down	Parent perspective
Mobility and Transport	✓		
Activities- getting around	✓		Agree
Public transport	✓		Likes buses
In the car	✓		
Wheelchair: Researcher observes child's reaction to the repeated question, sees the child smile and look comfortable with the second answer but wonders if there is an additional element to the child's answer	✓	✓	Parent asked child again
Activities of daily living	✓	✓	
Toilet and wash hands	✓	✓	

		✓	
Tidying up		✓	
Writing Child's face demonstrates concern		✓	Parent feels this is difficult for the child and staff have unrealistic expectations of ability
Choice and preferences			
Ability to participate in all activities		✓	
Swimming	✓		School services key to facilitation
Cycling	✓		School services key to facilitation
Watching favourite TV programmes	✓		Hospital staff key to facilitation

Table 19. Themes from Jack's Talking Mats®

John's themes from his Talking Mats® are presented in Table 20.

Domains- Health condition, Ways of coping, Activities, Self-care, Communication, Relationships, Participation	Thumbs up	Thumbs down	Parent perspective
Mobility and Transport	✓		
Activities- getting around Walking indoors	✓		Agree
Walking outdoors		✓	Safety - outdoor environments not suitable for disability
Activities of daily living		✓	
Health staff and carers, variability in carers and standard of care delivered	✓		Relationships vary dependent on who provides care
Body structures and functions	✓		Concerns about health and treatments
Cleaning teeth	✓		Likes to clean teeth
Mouth		✓	Sensitive mouth

Routines in medication, feeding and personal care	✓		Feels safe when daily routines are met
Behaviour, opportunity to give an opinion and to express feelings		✓	Becomes frustrated, not asked for views
Friends		✓	Cannot join in
Choice and preferences			
Ability to participate in all activities		✓	Feels excluded in social situations
Choice of care team with appropriate experience		✓	Staff do not understand the child's condition
Choice of play and leisure activities		✓	Limited services and equipment available

Table 20. Themes from John's Talking Mats®

6.3.1 Themes generated from Table 19, Jack's Talking Mats® and Table 20, John's Talking Mats®

Three themes were generated from Jack's and John's Talking Mats® which were 1. Mobility and Transport, 2. Activities of Daily Living and 3. Choices and Preferences and the elements of these themes will now be discussed.

6.3.1.1 Mobility and Transport

The Talking Mats® results from both Jack and John identified that they had issues with mobility and were unable to access play spaces and communal areas. Both boys had difficulties with walking due to muscle weakness and had general fatigue which necessitated the use of a wheelchair and walking aids.

6.3.1.2 Adverse aspects of mobility and transport

Jack's and John's challenges with mobility and transport had prevented them both joining in sport and leisure activities with their families, as well as in school with their peers. In addition, there were access issues within health services, both in hospitals and at peripheral clinic premises. Arrangements often had to be made to modify planned journeys to school and other destinations to assist both Jack and John to maximise their mobility and to avoid the stigma of being seen as different to their peers.

6.3.1.3 Constructive feedback on mobility and transport

The opportunities for the families to access local authority funded transport from home to school and return for their children was as deemed positive for both boys and their families. The specially adapted vehicles, the availability of 'Blue badges' for the disabled permitting parking and facilitating easier access to buildings were seen as positive factors. The provision of walking aids, equipment and purpose made wheelchairs were acknowledged as essential and as the child's right and entitlement within the Children and Young People (Scotland) Act 2014.

Both Jack and John expressed through their Talking Mats® that transport was important to them. They liked, enjoyed, and were happy with their walking aids and wheelchairs, indicating that these were a routine and accepted part of their lives.

6.3.1.4 Activities of daily living

The Talking Mats® findings indicated that Jack and John were impacted both constructively and adversely by the demands of the activities of daily living, and this was confirmed by their parents during the innovative Talking Mats® exercise.

The children's health conditions were complex, and both Jack and John were recognised within statutory services as requiring additional assistance to that of their peers. Jack and John demonstrated that they required help with their mobility, with their sleep routines, with washing, bathing, toileting, brushing their teeth and with dressing and undressing.

6.3.1.5 Adverse aspects of activities of daily living

John was not happy with his inability to eat and to emulate his peers at school by joining them for meals. John did not like his restricted choice in school of where he could sit at mealtimes. This was deemed as 'not fair' by John and as stigmatising and isolating by John's family. John required the use of specialised equipment for artificial feeding for every meal and the length of time to complete his feeding regime was longer than that of some peers to eat their meals. Mealtimes were stressful experiences because of the complexity of the feeding regime and the equipment used, which restricted John's movement and his ability to play freely.

Both Jack's and John's rigid, complex daily medication routines increased the boy's difficulties to conduct everyday activities and to have a free choice of activity and play times. Jack and John and their parents reported feeling stressed, mainly due to the disruption or cancellation of enjoyable childhood treats, family events, activities, and holidays. The lack of clinical, practical expertise within the children's circle of family and friends meant that full day

trips out and staying overnight anywhere but home was not possible without meticulous planning and considerable additional parental effort. The boys' parents added that when arrangements had been made to attend family celebrations or days out, these may be impacted by a deterioration in the children's health resulting in the abandonment of plans, frustration and family disappointment. Episodes of unexpected illness often required a hospital admission, or repeated admissions and prolonged treatment in John's case. The instability of Jack's and John's health had disrupted all aspects of family life and had caused distress to the children and their families.

6.3.1.6 Constructive feedback on activities of daily living

The Talking Mats® demonstrated that both Jack and John were mostly happy and enjoyed their lives. The children and their parents accepted that diet and medication routines were a necessary component of staying healthy and essential in preventing repeated hospitalisations. The formal and rigid routines minimised the deterioration of the children's health conditions and this impacted positively on the mental health of the parents. The strict routines of daily living were acknowledged by the parents as helping to reduce the children's risks of not maximising their potential, or of achieving their expected physical and psychological development.

The contribution of health and education teams featured highly in the Talking Mats® and the parents relied heavily on the GIRFEC multi-agency teams cooperating to provide smooth transitions and coordinated services, especially at critical stages during their children's lives. School routines, meeting friends, play and leisure time were important to both Jack and John, and the Talking Mats® symbols chosen by the children clearly identified the children's views and their lived experiences.

6.3.1.7 Choices and preferences

The Talking Mats® findings for Jack and John expressed the importance of having their choices and preferences respected and met at home, at school and whilst in hospital.

6.3.1.8 Adverse aspects of choices and preferences

Jack demonstrated the lack of choice offered to him regarding the method used for his writing at school. This was due to Jack being directed by staff to hold his pens, pencils and crayons in a way that felt uncomfortable. Jack's Talking Mats® demonstrated a lack of choice regarding the play activities he preferred at school and during his free time.

John was particularly impacted by having no choice or control regarding which health and play staff provided his care whilst in hospital. John expressed disappointment when the staff with whom he had a trusted, therapeutic relationship were not on duty and when there was a disruption to the continuity of his care. Explanations were provided to John and his family regarding the staff needing to be rostered onto differing shift patterns and in relation to their entitlement to days off and holidays. In addition, there was an ethical consideration regarding the professional boundaries that must be maintained within healthcare (NMC, 2018) and that patients cannot routinely choose the staff caring for them.

6.3.1.9 Constructive feedback on choices and preferences

Both Jack and John expressed their choices and preferences through their Talking Mats® and Jack's Talking Mats® was predominantly positive. Jack demonstrated that he had control over the clothes he wore, the games and toys he played with and the programmes he watched on terrestrial television, or on the commercial streaming service Netflix.

John's Talking Mats® presented his multiple choices and preferences regarding the partial control he had over his health and personal care. John valued his ability to monitor his weight on the scales and to understand his body systems and how they affected his daily life.

6.4 Reflexive account of researcher

The process of using novel Talking Mats® as a method to gather the views from Jack and John was a challenging but positive experience which led to the successful completion of the Talking Mats® of the two boys.

Effective communication skills were required to gain access the children and their families through the gatekeepers in health and education services, and to provide accessible participant information for the study that complied with The Equality Act 2010. Thorough knowledge of the ethical principles within BERA (2018) and NSPCC (2018) was required to gain the initial consent and assent from the participants and subsequently to confirm that the children's assent and parents' consent were still valid.

It was essential to confirm that both boys still wished to engage in the Talking Mats® exercise on the dates arranged for the Talking Mats® interviews and to establish whether their parents would be in attendance at the interview to support, but not influence their child's opinions. In addition, it was of the utmost importance to conduct this study upholding the ethical principles within BERA (2018) and NSPCC (2018) to ensure the comfort and safety of each child and their accompanying parent.

Each family environment needed to be sensitively and tactfully risk assessed to establish safety and privacy and the optimal arrangement for comfortably seating the child participant, their parent, and the researcher, and to suitably place the audio-visual equipment.

The Talking Mats® resource had to be placed in the clear view of the child and the audio-visual equipment positioned to obtain the optimum sound quality and visual results. The practicalities of checking the battery life in the video-recording equipment and completing the recording quality test were addressed to enable a successful interview and to avoid the embarrassment of preventable mistakes.

Despite the careful preparation for the Talking Mats® interviews, and for the separate interviews with Jack's and John's parents scheduled within the

same appointments, there were unforeseen issues leading to rescheduling. The quality of the recordings was impacted by unwanted background noises and interruptions due to dogs barking, a noisy washing machine spinning cycle, an uninvited caller to the family home and unexpected telephone calls received by the parents. This type of practical research issue is highlighted by King and Horrocks (2010) who note that not every eventuality can be mitigated against, however, they advise that planning for qualitative interviews should be meticulous and that unintended consequences are a high likelihood in research.

The interactions between the researcher, the children and their families were emotionally impactful, and this was not surprising due to the sensitive, personal nature of the lived experiences being demonstrated within the novel Talking Mats® and the conversations that took place during the interview visits. This aspect of the Talking Mats® exercise served as a reminder of the risk of researcher bias and its possible impact on the validity of a study if the risk of bias is not recognised and mitigated against (Beecroft et al., 2015).

The ability to be reflective and reflexive was highlighted by Bardach et al. (2020) and using these characteristics enabled the researcher increase self-awareness and enhance the ability to adapt to the changes in expectations which occurred prior to, and during the study.

The personal lessons learned from the Talking Mats® research process will be valuable when planning and progressing further studies and meticulous attention will be paid to emotional preparation prior to the research interviews and to writing a reflective account guided by the reflective template used for revalidation in nursing (NMC, 2018). In addition, careful planning will be important regarding the development and provision of participant information, the consent and assent process and the mechanism applied for participant interviews.

The strict adherence to the ethical principles within BERA (2018) and NSPCC (2018) was crucial to the Talking Mats® process, along with contingency planning for the comfort and safety of the participants should

they become distressed or disclose any information that required escalation to child protection services or the implementation of safeguarding procedures under the Children and Young People (Scotland) Act 2014.

6.5 Participant involvement

Jack and John were enabled to express their views and lived experiences through their taking part in the innovative Talking Mats® exercise. Both children were assessed using the Effectiveness Coding Framework outlined in Table 16 to establish their understanding of the Talking Mats® method and interview process. Jack and John were facilitated to use their voices through an innovative Talking Mats® method and to produce an authentic Talking Mats® picture of their experiences of their daily lives.

Both Jack and John and appeared excited, animated, and comfortable during their interview process. Their completed Talking Mats® clearly expressed the boys' perceptions of the impact of their peers, teachers, parents, family members, health staff and GIRFEC teams on their preferences, choices, and control in relation to their care and education. The results from Jack's and John's Talking Mats® provided a baseline of their views and a barometer of the experience of their daily lives from which to assess any improvements, or deterioration, in their lived experiences. The information from the still photograph of Talking Mats® given to the child and their family at the end of the interview may be used constructively by GIRFEC teams during the children's statutory, annual GIRFEC reviews which are mandated by the Named Person service under the Children and Young People (Scotland) Act 2014.

6.6 Talking Mats® data: synthesis with semi-structured interviews, including case studies

It is interesting to note that the themes generated from Jack's and John's Talking Mats® (TM) which were 1. Mobility and Transport, 2. Activities of Daily Living and 3. Choices and Preferences reflected the views and experiences analysed from the participants' semi-structured interviews (SSI) and the two case studies provided by Lily aged 15 years and Amber aged 8

years. These themes were Theme1. Choices and control Theme 2. Relationships., Theme 3. Living with my condition, Theme 4. Living with my child's condition and Theme 5. Bringing it all together.

6.6.1 Themes of TM1. Mobility and Transport synthesised with SSI 3. Living with my condition and SSI 4. Living with my child's condition

It was significant to this synthesis that both Jack and John had purposefully selected TM symbols relating to transport and mobility which were, a wheelchair, public transport, buses and trains and a car, which represented their school transport provided by the local authority. In addition to this was the car as a family-owned vehicle, along with a mobility scooter and a bicycle, specially adapted for additional safety. Both boys liked to travel and enjoyed the limited freedom that all the forms of transport provided. The participants during SSI also provided examples of the range of transport and mobility options available to them and the advantages, but highlighted frustration in relation to the variation in the level of help and support provided by public transport services for passengers with disabilities. Issues were raised regarding the length of time required for the local authority to agree funding for school transport and, on occasion, the reliability of this service when an assistant, usually termed a school escort could not be recruited to travel with the child in the school transport. The role of the school escort was to closely observe the child, or children, on the journey and to take immediate first aid action should a child have a health event, for example, a seizure or a vomiting episode whilst travelling. Transport was a crucial component for all the participants in relation to a child's attendance to health appointments and for their inclusion within statutory education and have been highlighted as fundamental rights by United Nations Conference on the Rights of the Child (UNCRC (2009) and within the Children and Young People (Scotland) Act 2014.

The points raised by the participants as children and parents regarding living with the conditions that impact on ability and health demonstrated an acceptance of routine procedures for medicine and feeding regimes and the unpredictability that health may deteriorate at any time, culminating in

unexpected visits to hospital by ambulance, school transport or the family's own transport. The reliance and dependence on a range of individuals and organisations was a significant part of the participants' lives.

6.6.2 Themes of TM2. Activities of Daily Living synthesised with SSI 2. Relationships, and 5. Bringing it all together

Jack and John purposefully selected the TM symbols relating to their daily routines and family, both boys were mostly dependent on family members for their hygiene, feeding and medication needs and where Jack and John tried to be independent, for example, washing their hands following using the toilet or having an incontinence product or pad changed. In the majority of daily living activities, the parents in the semi-structured interviews stated that they, or the children's carers in school would need to check whether the standard for optimal care for the children had been met. This was not to undermine the child's ability, the child would be praised for their independent action but to minimise the risk of infection or adverse health incident which Jack, John, Amber, Matthew, Lily, Mark and Luke were susceptible to and predisposed to throughout the lives. The quality and reliability of the relationships were crucial to maintaining a modicum of stability in the participants' lives because unpredictability was a prominent feature in the TM and SSI analyses. The impact of the quality of relationships and the importance of support from a significant adult on a child's physical, mental and emotional health is highlighted by the Royal College of Paediatrics and Child Health (RCPCH, 2018) and Bellis et al. (2015). The parents presented the difficulties during the SSIs on their own physical and mental health of bring it all together, both the positive and negative elements of the demands of daily living and always being prepared for the unexpected events that frequently occur. The child participants, in particular Lily aged 15 years and Mark aged 12 years, were very expressive about the negative impact that the continuous daily routines, repeated invasive investigations and hospital admissions had on their lives. All children stated how illness and disability had an effect on their schoolwork, their aims and ambitions and often the endurance of friendships. Parents and children highlighted that occasionally there was a strengthening

of existing relationships and in forming new relationships, either with others experiencing similar health situations, or the members of the teams around the participants from all agencies and from charitable organisations.

6.6.3 Themes of TM3. Choices and preferences synthesised with SSI 1. Choices and control

All the participants' lived experiences presented within the TM, the SSIs and case studies were coloured by the ability or inability to make choices and to exercise preferences. Where choices were restricted for health and safety reasons there was a reluctant acceptance along with a resignation that this was fact of daily life. When parents had made choices to plan holidays and the holidays then had to be cancelled due to adverse health events or issues with accessing appropriate facilities and health insurance the disappoint regarding restricted or no choices available became very stark and unpalatable. The children were visibly upset when relating their experiences of the choice of leisure activities available to them at home, at school and in clinical settings. John explained how difficult it was for him not to have a choice of the clinical staff caring for him during hospitalisation and providing community nursing support. John's mother explained that whilst she and John clearly understood the reasons for the range of staff involved in care delivery, there was a negative emotional impact on John when the continuity of staff members was interrupted, and new clinicians and carers were introduced. This view was echoed by several participants and a primary reason given was that of the trusting relationship developed between children and families influencing the choice of practitioners they preferred. Matthew vocalised how his choices and preferences had been curtailed due to the dietary restrictions caused by allergies and Mark could no longer eat his favourite foods, particularly in restaurants due to needing to control his glucose levels to safely manage his Type1 diabetes disease. Matthew's and Mark's mothers concurred with their sons' opinions and reflected the practicalities they met each meal and the lifestyle changes that had been imposed on the whole families that had impeded the freedom of choice and preferences that they had previously enjoyed. Lily's ambition to choose

active sports had been curtailed due to her lack of energy and Lily's preference to join the Police service as a career was completely ruled out because of her severe ill health.

The choices made by Luke's and John's birth mothers to misuse alcohol during their pregnancies had severely impacted on the life-choices of their children and on the decisions that that Luke's and John's adoptive mothers were required to make in the children's best interests regarding their adopted children's health and safety. The importance of parental choices on children's health outcomes was raised by all the parents during their SSIs.

The Children and Young People (Scotland) Act 2014, which includes the Getting it Right for Every Child (GIRFEC) national practice model, mandates that children have the right to be heard and their views taken into consideration when making decisions about their future and the services provided for them. The synthesis of the TM, SSIs and case studies eloquently and comprehensively demonstrates the importance of choice and preferences for children and families impacted by disability and complex health needs.

6.7 Reflexive account of the synthesis

It was important to consider the relevance of the qualitative data gathered by the TM, SSI and case study methods because of the variance in the participant population which ranged from the youngest participant aged eight years to the oldest adult being over forty years old. The was also a difference in the cognitive abilities of the children and the adults and the ability of two of the children to communicate verbally. Researchers must be confident that all study participants consent to the research and comprehend the questions being asked during a research interview to enable reliable data to be gained. The data generated from the range of participants in this study was synthesised or examined informed by investigating the data to find both patterns and anomalies that must be considered prior to reaching a conclusion on the meaning of the data (Smith et al., 2009). The aim of the synthesis was to provide reassurance, first of research reliability and second

of any congruence or disparity of the individual and communal experiences of the participants. The application of the synthesis process was challenging due the requirement to view the collective data from several perspectives, generate themes which may present opposing views and finally to draw everything together to reach a coherent and valid conclusion that would be recognised and supported by the study participants.

6.8 Chapter summary

This chapter has detailed the use of the Talking Mats® (TM) method and has extended and expanded on the findings from the literature review presented in Chapter 2 which indicated that qualitative methodologies and interview methods would best suit this study. In addition, this chapter explored to the results presented in Chapter 5 which generated the five themes of 1. Relationships 2. Choices and control, 3. Living with my condition, 4. Living with my child's condition and 5. Bringing it all together from the SSIs and case studies provided by Lily and Amber.

This chapter's introduction restated the research question and explained why and how a targeted study sample was used for this study. The practicalities were outlined of using ethical principles to gain access to the participants through the gatekeepers in health and education, along with the additional considerations and safeguards that were required for the participants both boys who use the TM method, and who were given the pseudonyms of Jack and John.

The rationale was provided for the use of the Talking Mats® communication method and the 'children and young people's consultation bundle' to gain the views of Jack aged eight years and John aged nine years. Jack and John were children living with complex health needs, disabilities and SLCN. In addition, the reasons were given for the development of the novel Talking Mats® method applied within this study. The amendment of Talking Mats® to provide a communication method suitable for Jack and John involved the removal of the choice of ambivalence, leaving either the option of a positive or negative response to be given. The novel Talking Mats® provided a forced

choice between a positive and a negative response and this action intended to mitigate against any confusion and cognitive overload that Jack and John may have experienced during the Talking Mats® interviews.

Section 6.2 explained the recruitment of Jack and John and how the study sample was finalised. The background to and the impact of Jack and John's disabilities, complex health conditions and SLCN, resulting in the need for additional help through statutory services were outlined. In addition, Jack's and John's abilities to cope with and manage events in their daily lives were explained. Jack's life profile was detailed in Section 6.2.1 and John's life profile was provided in Section 6.2.2.

The analysis of the chosen approach was outlined in Section 6.3 which included the assessment through the Effectiveness Coding Framework of Jack's and John's understanding of the innovative Talking Mats® process. In addition, the findings of Jack's and John's completed Talking Mats® were presented in Section 6.3 and these findings indicated that children of differing backgrounds and cognitive abilities can participate in research when provided with the appropriate tools to do so. The findings demonstrated that when suitable research approaches and methods are applied to studies by researchers and appropriately trained practitioners, children who may not have had previous opportunities to be consulted within research can provide detail of their lived experiences, which include both the positive and negative aspects of their lives.

Section 6.4 presented the three themes generated by the completed Talking Mats®.

1. Mobility and transport,

2. Activities of daily living,

3. Choices and preferences.

Jack's and John's Talking Mats® themes bore similarities to the final themes elicited from the qualitative semi-structured interviews and the case studies from Lily and Amber detailed within Chapter 5. The innovative Talking Mats®

method demonstrated the importance of the inclusion of children of all abilities to participate in daily decisions concerning them. The impact on health, wellbeing, educational achievement, and social development is shown by Jack and John within their completed Talking Mats®. The choice and control over daily activities, leisure and mobility was evidenced within the Talking Mats® completed by Jack and John and the impact from others on the quality of life that they had experienced was demonstrated.

The findings from Jack's and John's Talking Mats® provided the boys' authentic voices and perceptions of their quality of life and can provide the additional benefit of being submitted as evidence of their progress, or of a regression in their health and wellbeing at their annual GIRFEC healthcare and educational reviews (Scottish Government, 2019).

Section 6.5 provided a reflexive account from the researcher which outlined the practicalities encountered that were mitigated against and the unintended consequences experienced when conducting this research study. The reflection on the process was valuable and will be key to implementing improvements for future studies.

Section 6.6 explained the participants' involvement and detailed how Jack and John were enabled to provide an authentic Talking Mats® picture of their views and experiences, along with a barometer of their daily lives which may be used constructively during the children's statutory annual GIRFEC reviews which monitor their progress.

Section 6.7 synthesises the Talking Mats® data with the findings of the semi-structured interviews and Lily's and Amber's case studies. This section is presented in relation to the relevant themes which are 6.7.1 Themes of TM1. Mobility and Transport synthesised with SSI 3. Living with my condition and SSI 4. Living with my child's condition, Themes of TM2. Activities of Daily Living synthesised with SSI 2. Relationships, and 5. Bringing it all together, 6.7.2 Themes of TM2. Activities of Daily Living synthesised with SSI 2. Relationships, and 5. Bringing it all together 6.7.3 Themes of TM3. Choices and preferences synthesised with SSI 1. Choices and control and Section

6.8 presented a reflective account of the synthesis, and the final summary of the chapter was provided in this section.

CHAPTER 7:

DISCUSSION

The contribution of this thesis will be examined in relation to the research question in this study, 'What are the views and experiences of children living with disabilities and complex health needs, and those of their families?'

7.1 Introduction and chapter overview

The purpose of this chapter is to critically appraise the key findings from Chapters 3, 4 and 5 detailing the literature review (LR), the qualitative semi-structured interviews, the case study and Talking Mats ® interviews.

The study findings will be explored against the research question and the stated aims and objectives of the study detailed in Chapter 1. The discussion will take account of how the research objectives were achieved, or partially achieved, and the challenges that were encountered during conducting the study. The outcomes from the study will be identified and the implications will be explored in relation to nursing practice, education and within nursing research.

Section 7.2 will discuss the relevance of the LR and Section 7.3 will discuss the value of the chosen qualitative approaches. 7.3.1 will explore the contribution to the study of the supplementary, personal material offered by two child participants, Lily and Amber. A discussion of the semi-structured interviews influenced by IPA will be presented in 7.3.2. The contribution to the study from the Effectiveness Framework of Functional Communication (EFFC) and Talking Mats® will be presented in Section 7.4 and a synthesis of the findings from the themes generated from the IPA and Talking Mats® methods will be provided. A discussion of the collective ideography and the supporting

evidence will be presented in Section 7.5. The relevance of the study findings linked to policy and legislation will be demonstrated in Section 7.6 and the contribution of the thesis to the knowledge of the impact of living with disabilities and complex health needs will be detailed in Section 7.7. The strengths and limitations of the research are presented in points 7.7.1 to 7.7.7. A conclusion is provided in Section 7.8 and a summary of the chapter will be detailed in Section 7.9. Concluding remarks are provided in Section 7.10.

7.2 Discussion of the Literature Review

The literature review found that children living with disabilities experience stigma, discrimination and exclusion during their daily lives, and that the children and their parents require support beyond that which is provided by the National Health Service (NHS, 2020). In addition, that the universal education services provided by local authorities were inadequate for the children's needs. The service deficits for children living with disabilities and additional or complex health needs are a perpetual unresolved issue. The issues were highlighted by the Children and Young People (Scotland) Act 2014, the Care Quality Commission (2015) and the two reviews of children's and families' experiences undertaken a decade apart by Bercow in 2008 and 2018.

The literature review (LR) identified that staff often do not possess the appropriate knowledge and skills to communicate with children who are diagnosed with Speech, Language and Communication Needs (SLCN) or the children who are living with disabilities (McNeilly et al., 2015). There are misconceptions among professionals regarding children's health literacy, which is the child's ability to understand their health condition or conditions, the treatment that is needed, and the healthcare services required to provide the relevant care (Velardo & Drummond, 2017). The professionals' misconceptions were also highlighted by Davys et al. (2017) who presented fathers' views who are an underrepresented population in research.

Singer (2012) refuted the view that young children, and children living with disabilities, do not have the ability to participate in consultations about health service provision. This view is supported by Mitchell et al. (2021) who successfully conducted research with children as young as five years who were living with life-limiting conditions. Healthcare providers are advised to address the issue of a person's understanding of their health through a formal assessment of the health literacy of children and their families (Public Health England, 2015). The responsibility of staff to explore health literacy to help children and families understand their health status and to teach children and families how to manage their health conditions, is advocated by The World Health Organisation (WHO, 2010). According to Tzeng et al. (2018) the awareness of health literacy is crucial to the effective management of the symptoms of diseases such as asthma and to the prevention of the exacerbation of disease. This view concurs with the findings of the LR undertaken in this study that health literacy is important to children's and families' understanding of living with and the management of health conditions. In addition, the provision of pro-active health education sessions with children and their families can impact positively on the quality of children's and families' lives and this may enable the most cost-effective delivery of health service provision (Tzeng et al., 2018).

Consultations with children and their families regarding their experiences of living with disabilities or with disease, and the management of their symptoms enables the adherence to the rights of the child as stated within the United Nations Convention on the Rights of the Child (UNCRC, 2009) and can reduce the risk of children's and families' participation becoming a token gesture. When children and their families actively contribute to the development of health policy and the planning of services through participation the aim is met of the Scottish Government's strategy of co-development and co-production to improve and co-deliver health and social care services (Vennik et al., 2015).

Each of the studies included within the LR recommend that further research should be undertaken with children and families who are living with the impact of disabilities and complex health needs. Cultural, spiritual, and religious issues were considered within the studies and were deemed significant when developing and providing health and education services. The public's negative perception of populations living with disabilities (NHS, 2020) was acknowledged within the included peer reviewed articles. The Royal College of Paediatrics and Child Health (RCPCH, 2018) advocate addressing the perceived and actual multi-cultural issues and barriers to child-focussed healthcare advising that this would be instrumental in enhancing the patient experience. In addition, this holistic approach may prevent or reduce the risks of sub-optimal health experiences which may result in Adverse Childhood Experiences (ACEs) whose negative impacts on children's psychological security and physical development are highlighted by Hardcastle et al. (2019).

The employment of suitable approaches for example, Talking Mats® (Murphy, 1998a) as a method and resource that aids and improves communication, is recommended by Rabiee et al. (2005) and McNeilly et al. (2015) to address the issues of intentional or non-intentional exclusion from research of the population of children living with disabilities. Coad et al. (2020) advocate the value of using novel approaches to widen children's participation and to facilitate the inclusion of children with disabilities and complex health needs in research. The author of this study was cognisant of the importance and value of novel approaches to enable the inclusion of the voices of children who are seldom heard in research.

The findings from the LR justify the qualitative approach taken in this study and the findings from this study highlight the importance of the exploration of the views of children with disabilities and complex health needs, and those of their families. The services provided for the participants are found to be not wholly suitable for their needs and by

conducting research using the most suitable approaches for the study population, the opportunities for services to be developed and produced in partnership can be achieved. The evidence from the cited research assists practitioners to meet the aim of co-development, co-production and co-delivery advocated by Brocklehurst et al. (2019) to achieve an authentic and collaborative approach to health and social care services and to the educational provision for children with additional needs as recognised under the Children and Young People (Scotland) Act 2014.

7.3 Discussion from the qualitative approaches

Chapter 3 outlined the decision-making process undertaken regarding the three qualitative approaches and methods which were systematic review, semi-structured interviews influenced by IPA and an adapted Talking Mats®. These were the most suitable approaches and methods to employ within the study population and to address the research question and to meet the study aim and objectives. The findings of the LR identified that the research studies conducted with children living with complex health needs and disabilities, their families and the teams involved in service delivery required careful consideration of the approaches used. The qualitative approaches used by Rabiee et al. (2008) and McNeilly et al. (2015) employed innovative techniques of communication, assisted technology and visual images as methods by which children as participants could provide their views on their lived experiences. The practical issues encountered by the researchers cited within the systematic review prompted the search for suitable approaches and methods to employ within this study which would consider and appreciate the range of cognitive abilities of the whole of the study population and that would address the SLCN of the children living with disabilities and complex health needs.

7.3.1 Discussion from the case study informed by the supplementary, personal material offered by two child participants, Lily and Amber

The additional contributions to the study from two of the children, Participant 1 Lily, and Participant 5 Amber provided insight into their unique view of living with their condition. The supplementary personal information provided had significance to their lived experiences and was offered unprompted by the researcher, demonstrating the emotional importance that Lily and Amber placed on the information. Lily was aged 15 years and was living with Cystic Fibrosis, repeated infections, and panic attacks. Lily's written personal story was a biography which highlighted her deep feelings about the impact of living with a respiratory disease that was similar to but not formally diagnosed as Cystic Fibrosis, a respiratory condition affecting the lungs which is life changing and life threatening if not carefully clinically managed (Chang & Bilton, 2008).

Amber aged eight years was living with heart disease, epilepsy and a cerebrovascular accident or stroke, and Amber reflected on the significant experiences that were important to her during the semi-structured interview. Amber expressed her emotions through a tactile demonstration, physically handling individual beads on a string of beads, whilst illuminating the personal story attached to each one.

Sheridan and Chamberlain (2011) outline the value of enabling participants to explore and demonstrate their feelings and experiences through personal tangible, material objects and describe the significance of including the information gained with the research interview to simultaneously depict an enhanced view of the lived experience from the encoded memories that the objects provide. The benefit of this first-person, phenomenological approach is supported by the participants' use of objects, drawings, photographs and written accounts or poems composed by the participants provide researchers with a powerful, visual ethnographical perspective of the participant and enriched data. The findings from Lily and Amber demonstrate the importance of seeking participants' views from a range of sources and that the adjuncts can provide richer and deeper information than an

interview alone. The value of facilitating the participants' views through the means of their personal objects and first-person, rich, deep written accounts is advocated by Boden et al. (2019) who observes that this exploratory, personal approach expands the concept of hermeneutic phenomenology. This view supports the fact that the inclusion of the supplementary material provided by Lily and Amber was an important benefit and enhancement to enrich the findings of this study.

Lily and Amber illustrated the impact of living with complex health, not only to themselves, but to the significant others in their lives. The children's interpretation of the positive, negative, and occasionally the ambivalent impact of their conditions concurred with those of their parents who described the complexity and intensity of daily routines which allowed minimal time for social occasions and fundamental needs, including for eating, bathing, and sleeping.

The issues raised by Lily and Amber were reflected in the findings from Teuma (2013) who highlighted that people who are living with complex health conditions feel a degree of anger, but this may be counterbalanced with positivity and a desire to achieve the maximum potential possible in life. A similar paradox was demonstrated within this study by Lily and Amber through their supplementary information from the tangible materials they offered with spontaneity during their interviews. Lily's eloquent use of metaphor to illustrate the impact of her experiences on her physical appearance and emotional state create a profound impact on those who read 'Just Breathe' or hear her first-person narrative, for example:

"I can remember having pneumonia, very vividly, my lips as
blue as sea water, struggling to breathe".

7.3.2 Discussion from the semi-structured interviews influenced by an Interpretative Phenomenological Analysis (IPA) approach

The results from the thirteen semi-structured qualitative interviews which were influenced by Interpretative Phenomenological Analysis

(IPA) were presented in Chapter 5 and demonstrated that children and parents were both weary and frustrated from the effort of living with disabling conditions. The lack of suitable provision from the statutory health and support services to meet the needs of the participants was highlighted as an issue that required urgently addressing for the children and their families. Bercow (2018) and the Royal College of Paediatrics and Child Health (RCPCH, 2017) raised similar issues nationally with government ministers regarding the variability and paucity of suitable services for children with additional, complex health needs and disabilities.

The study findings demonstrate that children and families search for information about their disability or health condition and how to follow treatment plans, defined as health literacy. The lack of explanations provided by health staff, especially regarding the impact of living with and managing symptoms which result from disability and complex health needs are highlighted. The findings within this study indicate that despite legislation (Scottish Government, 2014), statutory obligations and service reviews (RCPCH, 2017; Bercow, 2018) there are service deficits and a negative impact on children and their families. This may raise a debate with researchers due to the knowledge that children and their families should be made aware of and enabled to achieve health literacy (Public Health England, 2015). The effective implementation of health literacy may positively influence health care providers and children and their families to co-produce healthcare policy and to commission and co-develop healthcare services. Velardo and Drummond (2017) advocate that health literacy is crucial to the quality of health services and that the child must be at the centre of child health literacy if health care services are to be improved.

The negative experiences of parents and children within some healthcare and educational establishments indicates that a degree of emotional and physical harm was caused, known as 'toxic stress' (Hardcastle et al., 2019) but this issue was not recognised or mitigated

against in the experience of the participants of this study. The participants reported a lack of knowledge and skills from the healthcare providers, and the staff in the wider services of social care and education. This issue added to the frustration and dissatisfaction of the children and families with the services that had been provided for them. The children and their families provided both positive and negative examples of the quality of care that they had experienced, and it was evident from the study findings that services provided were variable, unreliable and of an inconsistent quality. The lack of staff knowledge, skills, and experience in caring for children with disabilities and complex health needs increased the risk of the accumulation of toxic stress in the children and the potential for the stress to manifest as an Adverse Childhood Experiences (Bellis et al., 2015). The difficulties of inexperienced staff in relation to providing effective communication when caring for children with disabilities and their families was highlighted by Shilling et al. (2012) and the findings of this study confirm through comparison with established, published research findings (Coad et al., 2019; McNeilly et al., 2021) that staff may benefit from undertaking both basic and enhanced training in communication techniques, which include effective listening skills.

The phenomenological approach employed within this study enabled intense listening to the participants' rich deep experiences relating to the impact of living with complex health and disabilities. The participants experienced frustration at not being heard and taken seriously when reporting the negative impact on their quality of life from their lived experiences. The lack of continuity of services due to opportunities within leisure and recreational activities being short-term and inadequately funded proved frustrating for children and families. The participants reported that services were not sustained and that the funding was non-recurring, in addition, the study found that inadequate justification for the lack of services was provided, leaving children and families feeling undervalued and disrespected. The participants reported that the benefits gained from the provision of dance and

sporting activities were eliminated by the disappointment of the services being withdrawn. Article 21 (UNCRC, 2009) states the right of children to have access to play, leisure, and recreation but this study found that this right is not being upheld for the participants.

The dismissive attitude of staff when children and parents reported subtle or significant changes in the clinical condition or deterioration of cognitive abilities was particularly frustrating and upsetting for children and families. RCPCH (2017) described the importance of healthcare providers listening to children and families and to the development of partnerships that will enable appropriate, quality services to be provided.

7.4 Discussion of the Effectiveness Framework of Functional Communication (EFFC) Assessment and the Talking Mats® interviews

Two children, Jack aged eight years, and John aged nine years, who were living with SLCN took part in this study using the Talking Mats® (Murphy, 1998a) method which had been adapted by the researcher to provide a bespoke method of communication. Jack and John had complex health diagnoses and disabilities, and their families had reported through their semi-structured interviews within this study that their children's views on the services they had received were seldom asked for. The parents interpreted the lack of inclusion by health and care providers as their children being marginalised and excluded.

Jack's and John's inclusion in this study and their ability to communicate effectively was facilitated by the Talking Mats® method. Jack and John were able to express their views on both the negative and positive aspects of their daily lives by choosing Talking Mats® symbols and thinking about the central Talking Mats® topics and domains.

Jack's and John's Talking Mats® interviews demonstrate the aspects of their lives they liked, enjoyed, were happy with and that were important

to them. Their first-person narrative was demonstrated through the pictures they had placed on their Talking Mats® and showed the prominence they gave to their body systems which were impacted by disability and disease, and which required daily routines and medications. The children's family members and the staff within the teams providing care for them were featured on both Talking Mats® showing the importance of their families and their dependency on wider relationships to help them remain healthy and within their communities. In addition, the Talking Mats® provided a snapshot of aspects of their lives that had not routinely been explored by their families or the health and education teams responsible for their health, wellbeing, and development.

The children's lives were negatively impacted by the complexity of their health conditions, their disabilities and by their speech, language, and communication needs. The Talking Mats® method enabled the findings detailed below.

7.4.1 Jack's Talking Mats® EFFC assessment and interview discussion

Jack was concerned about and objected to the way that the staff within his school steered the way he held his pen and how he wrote. These actions by the adults responsible for Jack's education had the potential to cause Jack stress and to restrict his creativity in relation to writing and drawing. This would contradict the aim of the national practice model 'Getting it right for every child' (Scottish Government, 2014) where every child must be encouraged to achieve their full academic potential and to enhance their wellbeing and life chances.

7.4.2 John's Talking Mats® EFFC assessment and interview discussion

John's Talking Mats® clearly demonstrated a preoccupation with his daily health routines and his body systems. John experienced a lack of choice when he was admitted to hospital and his preferences were not

met regarding the provision of suitable recreational activities, or the continuity of familiar staff to provide play and distraction. The medical and nursing knowledge of the health clinicians, along with their skills and experience, was very important to John. He was afraid that any lack of familiarity with his complex health condition, his treatment or his care routines could cause him harm and may delay his discharge home from hospital. The significance of John's relationships was evident from his Talking Mats® interview, and it would be beneficial for the health staff involved with John to understand his first-person account of his health experiences as depicted on his Talking Mats® to enable his care to be accurately person-centred.

The findings from the Talking Mats® interviews demonstrated that children of all abilities can provide a first-person, authentic account of their lived experiences from which to plan appropriate care.

7.5 Discussion of the collective idiography and supporting evidence

The phenomenological approach taken to explore the views and experiences of Jack's and John's lives enabled them to clearly demonstrate concrete ideas and concepts through pictures which showed what was important to them. The Talking Mats® method enables children of all abilities to take part and be included in the phenomenological studies available to their peers. Parents of children living with disabilities and complex health conditions can be confident that their children's views on their life experiences can be obtained when given the opportunity to do so and as advocated by the Children and Young People (Scotland) Act 2014.

In this study the views of the parents were similar to those of their children and indicated that the impact of living with complex health needs, SLCN and disabilities affects the quality of life of the whole family. The uncertainty and unpredictability of each day affects attendance at work, education, and their ability to socialise and to plan

family outings. The findings show that the fundamentals of life that families enjoy, and may take for granted, may be out of reach for the families within this study.

There was evidence of mutual protectionism from the children and parents with the children feeling guilty that their conditions were affecting every aspect of family life and finances, reducing the potential to achieve the optimum family life available. The children's parents, who were feeling exhausted and frustrated by the lack of professional help and expertise available on their child's condition, were careful to avoid their children being aware of the reality of the situation and the negative emotions being experienced.

The idiographic and collective discussion within this study outlined the similarities and differences between the children's and their parents' perceptions of living with a disability, complex health needs and SLCN, for example, it can be seen from the Lily's narrative account that living with Cystic Fibrosis, repeated infections and panic attacks had profoundly and adversely impacted on the quality of Lily's and her family's life.

> *"I know that the journey of battling this condition does not get any easier, only harder, Disappointment no longer comes as a shock. I will never use it as an excuse but a reason to take advantage of any opportunity.*

Lily's mother's account demonstrated similar feelings and impact on quality of life,

> *"I would love nothing more than to be able to go to bed at night, shut off my mind and be able to relax but I know that's never going to happen".*

These views are mirrored in the studies with children and families undertaken by McNeilly et al. (2015), Misuk and Emmett Gardner (2015) and Davys (2017). This study similarly facilitated the inclusion

and participation of children living with complex health and disabilities but with the difference being that a unique approach was taken by developing a bespoke Talking Mats® method. This enabled rich, deep information to be gained about the lived experiences of the participants. The application of suitable research approaches with children living with SLCN and disabilities is a point that was debated by researchers who were not prepared to explore the range of possibilities within research to conduct studies with this group of children (Clark et al., 2014). The findings from this study provide additional knowledge within this topic area to add to the existing body of knowledge on the inclusion and participation of children in research.

The views of the children who were interviewed using the qualitative approach influenced by Interpretative Phenomenological Analysis (IPA) and detailed within Chapter 5, mirrored the advice given and the findings of Teuma (2013), Coad et al. (2019) and McNeilly et al. (2021).

According to this study, the status of healthcare services provided for children living with disabilities did not meet their needs and was rated by the children and families as variable, services could range from good to lacking and sub-optimal. The participants of this study stated that they are often excluded from activities and social events both at home and at school and this impacts negatively on the quality of their life. Health and education providers are perceived by the participants as being out of touch with their needs and abilities, labelling the children as hard to reach, an issue identified by Stalker and Moscardini (2012). This study found that there are risks of harm to children when receiving healthcare and within education services, issues that were also identified by Bercow in 2008 and captured within a further review conducted in 2018.

The children and families within this study send an important message to service providers about upholding the right to be actively listened to and to act on their concerns, the feelings of marginalisation and discrimination were clearly felt and expressed within the interviews, an

issue that has been identified in other studies across several decades (Bercow, 2008, 2018; Davys et al., 2017; Coad, 2020). The children's and families' lives within this study are markedly impacted by the mandatory daily complex routines relating to nutrition, medication, transport, and education. The children and families were aware of the heavy responsibility attached to daily routines and that a lack of attention or deviation to the routines could culminate in hospital admissions and emergency, life threatening events which they felt guilty about and would take the blame for. The ethical issues and social justice culture of fairness and equity for children in Scotland living with disabilities, and their families is identified in UK research on social justice and participation (McNeilly et al., 2015). The impact of the inequities in care and the guilt, helplessness and blame families feel about this can be mitigated against through targeted support from health, social care, and education providers (Scottish Government, 2004, 2014, 2018).

7.6 Relevance of policy and legislation to the study

The impact of policy and legislation on the commissioning, development, co-production, co-delivery, and the quality of healthcare service provision is significant to the findings within this study. The results of the systematic review, the findings of the semi-structured interviews influenced by Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) and the novel Talking Mats® (Murphy, 1998a) demonstrate that disparity exists in the standards delivered across health, education, and care services, particularly in relation to disabled children. The children and parents identified significant variation in the quality of statutory services across all clinical and educational settings and the lack of tailored, individual support for their child's needs that had been formally identified through the national practice model for children and young people living in Scotland, 'Getting it right for every child' (GIRFEC) (Scottish Government, 2014). The Act mandates the statutory duty of the 'Named Person' and a Lead Professional, where

necessary, to coordinate and monitor multi-agency activity to address the child's additional health needs (Appendix 3). The GIRFEC assessment process is made known to the families as a statutory obligation by the named professionals involved with the child, known as 'the team around the child'. There is the general expectation that the Named Person and Lead Professional will exact their statutory duties for the children identified with an additional need, but the families within this study reported that this was not their experience, and it was often left to local and national charities to provide the children with services and activities that were expected to be provided through statutory means. The findings from this study highlight that a disconnect exists between the participants' lived experiences and the legislation detailed in the Children and Young People (Scotland) Act 2014, The Children Act (1989), the Health and Social Care (Reform) ACT (Northern Ireland) (2009), the Rights of Children and Young Persons (Wales) Measure (2011) and the Health and Social Care (Reform) ACT (2012). The policies and legislation cited provide the barometer from which to gauge service provision and from which to compare the study findings. and policy. This legislation mandates the duty of the UK government and its devolved entities to provide ethical, age-appropriate care and services which protect all children and young people, particularly those children that are defined as disabled.

Equity in health service delivery is fundamental to the Children Act (1989), the Children and Young People (Scotland) Act 2014 and the Public Interest Disclosure Act (1998) which inform health professionals about the importance of hearing and acting on patient feedback. The tenets of the Disability Discrimination Act 2005 and the 54 articles of UNCRC (2009) highlight the lack of respect of children's rights and of children's views to be heard, particularly in relation to healthcare services. This study reflects this point because the children and families reported that when feedback was provided to their service providers, they were informed that improvements could not be made due to a lack of staff, of training and uncertainty of continuous funding which led the

families to believe that their voices and those of their children are not heard and that they belong to a disadvantaged group within society. The Equality Act (2010) provides the incentive for researchers to investigate the duty of care from health, education, and social care providers to include disabled children. In addition, the UK government's legislation must demonstrate that the lack of implementation of children's rights has the potential to cause harm to children and their families (The Health and Social Care [Reform] ACT, 2012). The obligations to mitigate the risks of harm and to prevent Adverse Childhood Experiences (ACEs) must be met and the commitment to uphold Children's Rights (UNCRC, 2009) be honoured.

Approximately 1,100,000 UK children from birth to eighteen years of age require services beyond those universally provided due to their living with substantial and long-term physical or mental health impairment (Department for Work & Pensions, 2021). Disabilities and health impairments negatively affect the child's ability to undertake normal daily activities and to achieve their maximum potential, and this group of children are overrepresented in the use of health services (RCPCH, 2018). Families of disabled children often report to healthcare service providers that health services are either lacking or inadequate for disabled children and the importance of listening and acting upon patient feedback in improving person centred care and services was highlighted by Luxford et al. (2011). The parents' interviews highlighted the lack of appropriate facilities within health settings and the inexperience of health staff of how to care for children with complex health needs and disabilities. Where parents and their children had highlighted care deficits the issues were not addressed, and managers of services often cited that there was a need for specialist training that could not be provided without additional and sustainable funding being made available. Similar issues were raised in the public inquiries into the increased mortality and morbidity of patients within the Mid-Staffordshire NHS Foundation Trust (Francis, 2013) and within Shrewsbury and Telford Hospital NHS Trust (Ockenden, 2020). The

recommendations from the Francis report (2013) and the Ockenden report (2020) inform health professionals about the importance of leadership and of the leaders of services hearing and acting on patient feedback regarding the quality of healthcare. Gilljam et al. (2016) state that the participation of children and young people to influence healthcare providers is crucial to the quality of health services. Complaints are received by healthcare providers when care has not met the expected standards and staff within organisations also raise concerns about sub-optimal practice. People who raise concerns about sub-optimal practice and services are known as whistle-blowers and are described as acting in accordance with the Public Interest Disclosure Act (1998). The freedom to speak up about concerns is encouraged and supported by NHS Improvement and the National Guardian's Office (2019). Unsuitable, inappropriate services provided by those with inadequate training in children's needs and safeguards may increase the risks of ACEs for children (Bellis et el., 2015). The significance to health and wellbeing of being impacted adversely during sub-optimal healthcare events was presented in the results of the LR, the findings from the semi-structured interviews influenced by IPA, the case study and the novel Talking Mats® interviews.

This thesis identified the importance of the practitioners communicating effectively with populations of vulnerable children and young people. The necessity to develop health literacy with populations who are seldom heard and hard to access was indicated in the NHS Long Term Plan (NHS, 2019). Governments have pledged the co-production of healthcare policy and the commissioning, co- development, and co- delivery of healthcare services with vulnerable populations (Velardo & Drummond, 2017). The significance of policy and legislation in improving children's life chances was highlighted by Bercow (2018) and this view is supported by the Royal College of Paediatrics and Child Health (RCPCH, 2018), along with the findings of this research thesis.

7.7 Contribution of the thesis to the knowledge of the impact of living with disabilities and complex health needs

The completion of this research thesis has fulfilled the written requirement for the award of a Professional Doctorate in Healthcare, and in providing experience of the research process. The thesis demonstrates the value of phenomenology as an approach from which to gain the first-person rich, deep lived experiences of children who may not usually be given the opportunity to take part in research, an issue which was raised by Davys et al. (2017). The study contributes to the discussion about the value of using the Talking Mats® method with people living with communication difficulties. The development of the novel Talking Mats® method is worth the consideration of researchers who find that participants may be negatively impacted by cognitive overload. This study reduced this risk by the removal of ambivalence and forcing a dichotomous choice to provide either a positive or negative response to the Talking Mats® pictures. The Talking Mats® symbols represented concrete topics and the concepts of daily living was instrumental in reducing the risk of cognitive overload for Jack and John. This was important to safeguard their health and to prevent any adverse childhood experiences occurring for Jack and John whilst they participated in this research. It was also important to acknowledge the researcher's ethical duty of care towards the child participants. The findings will be published to provide information on the topic of the impact of living with complex health needs and disabilities to inform those involved in the commissioning and delivery of health, education, and social services, and including all teams involved with children and families.

This phenomenological study was informed by conducting a literature review (LR) and by using the semi-structured interview and case study method. The analysis of the children's and families' first-person accounts was undertaken using the six steps model within Interpretative Phenomenological Analysis (IPA) developed by Smith et al. (2009).

This presented practical issues for a novice researcher due to the amount of data generated and the time required to read and re-read the transcripts to enable the initial noting and the generation of the themes.

The novel Talking Mats® was adapted from Murphy's original Talking Mats® method (Murphy, 1998) and provided a dichotomous choice for children with cognitive impairments to reduce the risk of their cognitive overload and possible harm to health. The Talking Mats® method demonstrates that populations who are marginalised and seldom heard, for example, children living with disabilities and SLCN can participate in research when suitably tailored phenomenological approaches are provided.

The account of the research process is provided within Chapter 3 and the findings detailed in Chapters 5 and 6, semi-structured qualitative interviews, case study and Talking Mats® interviews respectively. This thesis reflects an analysis of policy context in relation to the application of Articles 2, 12, 19, 24 and 41 of the UNCRC (2009), in addition to the legislation within the Children and Young People (Scotland) Act 2014 and the responsibilities to children found in the policies of the devolved governments of the UK.

In this thesis, children and parents' views were presented regarding the variance the quality of the health, care and education services experienced. The quality of services ranged from sub-optimal to high quality, safe and effective care that fully met the children's and families' needs. This study's findings mirror the results presented from the LR and raises the issue of a dearth of relevant information that children and families require to understand their rights in relation to healthcare and specialist education services. It was evident from the study findings that little attention was paid by healthcare providers to children's and families' health literacy and the commitment to patient and public engagement as advocated by the model of Information Feedback Engagement Co-design and Partnership (NHS Institute, 2013). The positive findings within this thesis demonstrate that several practitioners

and multi-professional teams within the NHS deliver positive care experiences to children and families which builds trust and confidence between patients and clinicians. The negative findings from the study are that the children and their families highlighted there is a prevalence of sub-optimal care which creates negative experiences, and which reduces trust and confidence in services. The risk of potential harm to children's health and wellbeing from traumatic health experiences was raised by Bellis et al. (2015) and confirmed within a national review of healthcare provision by RCPCH (2018). Emphasis was placed in this study on the provision of optimal quality of care as 'always events' and sub-optimal, unsafe care as 'never events' within healthcare. This discussion links to the concerns raised within this study by the children and families relating to the receipt of safe, appropriate, and flexible services which fully meet their health and educational needs.

7.7.1 Review of study objectives and thesis contributions

The aim of this research was to gain a greater understanding of the daily experiences of children who are living with disabilities, with complex health needs and with SLCN and the impact on their families. The study applied the lens of children's rights through the 54 articles of the United Nations Convention on the Rights of the Child (UNCRC, 2009) as a barometer of the quality and suitability of healthcare provision for the children who participated in the study. The theory and evidence presented throughout this thesis support the policy context in relation to the application of Articles 2, 12, 19, 24 and 41 of the UNCRC (2009) whose premise is the safeguarding, inclusion and participation of children and their right to influence policy and services (Appendix 1). The responsibilities of the UK government to children and young people's health and health services are found within the Children Act (1989), the Health and Social Care (Reform) Act (Northern Ireland) (2009), the Rights of Children and Young Persons (Wales) Measure (2011), the Health and Social Care (Reform) ACT (2012) and the Children and Young People (Scotland) Act 2014. The findings of this

study are relevant to the cited legislation and policy context due to integrated Health and Social Care in Scotland being delivered through integration partnerships (Appendix 2) which have a legal responsibility to deliver the national practice model 'Getting it right for every child' (GIRFEC) for all children and young people living in Scotland (Scottish Government, 2014). The integration partnerships state that healthcare services must employ a co-produced approach commissioned through legislation to ensure the participation and incorporate the views of the populations who will use the services (Vennik et al., 2015). This study found a similar result to the existing evidence produced by the VIPER project (NIHR, 2012) which indicated that the population of children who are not being listened to are children living SLCN and as a result, their right under Article 12 to have their views heard is not upheld. The objectives for this research study were to gain perspectives on children and families' lived experiences of healthcare and services to acquire a deeper understanding of the topic of children's healthcare provision. Central to this premise was the child's right to receive equitable services to those provided for the adult population and to meet the recommendations for healthcare from RCPCH (2018).

7.7.2 Strengths and limitations of the research

It is important for researchers to identify the strengths and limitations of their research to inform those who may wish to replicate the study of any elements of the research that may require consideration of amendments to the methodology or methods used.

7.7.2.1 Strengths of the research:

A strength of this study is that it was developed from a base of the existing evidence on the topic of the lived experiences of children and families gained from the literature review. The results helped inform which methodology and methods would be most suitable to answer the research question posed. A benefit of this study was the application of a phenomenological approach and three qualitative research methods.

Rich, first-person data was gained from thirteen semi-structured interviews and two case studies from children's personal accounts and possessions. Two children provided their lived experiences through Talking Mats® (Murphy, 1998a) adapted as a method to meet the needs of children living with speech language and communication needs (SLCN) who previously had not had an opportunity to take part in research. Two boys, Jack aged eight and John aged nine, were enabled demonstrate their experiences through the dichotomous response symbols of Talking Mats® to produce a unique and rich picture of their daily lives. The Talking Mats® method enabled Jack and John who were living with SLCN the opportunity to recount their lived experiences and these findings may encourage researchers to invite children living with SLCN to participate in research. Bercow (2018) found that children with disabilities are often marginalised in society and are seldom included in research studies. For this study, the child's right to participate and to speak was upheld, the children's rights were respected, and the ethical requirements for safeguards were met by the prevention of harm or Adverse Childhood Experiences during the research process (BERA, 2011). A supplementary strength of the study which resulted from the children's interviews and Talking Mats® was the provision of a contemporary record which the children were able to present at their clinical and educational reviews. The record of a child's views is an important part of the GIRFEC assessment and monitoring process (Scottish Government, 2014), which is a crucial element of planning children's service provision.

An additional strength of this study is the evidence gained from the supplementary information provided within Lily's unique written account 'Just Breathe' and Amber's story of the significance of the bead necklace and beads given to her by hospital staff. This information which was spontaneously offered during their semi-structured interviews enhanced the rich description of the children's daily lives. The participants' use of objects, drawings, photographs and written accounts or poems composed by the participants provide researchers

with a powerful, visual ethnographical perspective of the participant and enriched data. Boden et al. (2019) advocate that personal objects and first-person, rich, deep written accounts provide an exploratory, personal approach which expands the concept of hermeneutic phenomenology. Lily's eloquent use of metaphor illustrated the impact of her experiences on her physical appearance and emotional state and created a profound impact on those who heard or read her first-person narrative.

A strong point of this study is the robust analysis process using the six steps analysis model within Interpretative Phenomenological Analysis (IPA) developed by Smith et al. (2009). The analysis of the qualitative data was conducted with rigour through the checks and balances provided by the researcher and the research supervisors to ensure that accurate findings were produced which reflected the authentic voices of the children who participated, and whose views are seldom heard within research studies. The greatest strength of the study is the evidence provided that children of all abilities have been listened to and have had their views heard. The strengths of the study are additionally demonstrated through the reflexive accounts provide by the researcher regarding the research journey and process and through the achievement of the four stated objectives detailed below.

Objective 1: This objective was concerned with qualitative methodologies and novel methods to enable the participation of children living with disabilities, including those who are seldom heard and often excluded. It became evident that children with disabilities remain out of reach due to the reluctance of healthcare and education providers, the gatekeepers, to promote the value of participation of children living with disabilities in research. This approach does not meet the obligations of UNCRC (2009). The findings within the LR acknowledged the lack of inclusion of this cohort of children in research and that this is a limitation of research. The LR highlighted the need to identify the children not routinely invited to participate in research and to promote their inclusion

to enable all the authentic voices of children to be heard regarding their lived experiences.

Objective 2: The second objective was to effectively gain and hear the authentic, seldom heard voices of the child and adult study participants and to examine the information received. This objective was accomplished using a phenomenological approach and the qualitative methods of semi-structured interviews (Smith et al., 2009), case study (Boden et al., 2019) and the adapted Talking Mats® (Murphy, 1998a) which enabled the authentic voices of children living with complex health needs, SLCN and disabilities to be heard.

Objective 3: The third objective was to establish themes from the data to help researchers to understand the first-person lived experiences of the participants through the dissemination of findings to practitioners, health and education providers and students within clinical practice and in educational settings. This objective was demonstrated through the results of the LR, and the themes generated from the analysis of the semi-structured interviews which were 1. Relationships 2. Choices and control, 3. Living with my condition, 4. Living with my child's condition and 5. Bringing it all together. The themes from the Talking Mats® were Mobility and transport 2. Activities of daily living and 3. Choices and preferences.

Objective 4: The fourth objective was to promote interest in conducting further studies within this topic area which will add to the existing body of knowledge on the healthcare services provided for children living with disabilities and complex health needs, and those of their families. This objective was achieved because additional and important knowledge was gained on the topic of children's rights and safeguards from harm when receiving healthcare and whilst in educational settings, issues that had been raised by Hardcastle et al. (2019). The evidence within this thesis will help inform health practitioners of the importance of providing safe services and of their responsibilities under the Children and Young People (Scotland) Act 2014.

An additional strength of the study is the application of reflexivity demonstrated in the reflexive accounts of the researcher which provide critical insight into the researcher's journey, situational awareness and self-development. The strength of the thesis is that it will bring to healthcare practice, social services, and childhood education the recognition that children with disabilities, complex health needs and SLCN are overlooked for participation and inclusion and that there is a risk of the children's fundamental needs and rights within UNCRC (2009) not being met due to their views not being sought and therefore not considered.

7.7.2.2 Limitations of the study

The children and families recruited for this study were interviewed in southwest Scotland due to this being the local geographical area served by the health and social care integrated board accessible by the researcher (Appendix 2). The recruitment of the participants required negotiation over several weeks, and through governance processes which took up to eight weeks, with gatekeepers from both health and education services and this impacted on the implementation of the original study timeline (Appendices 6 & 7). This thesis may inform researchers of the practicalities, challenges and limitations that arise when planning and conducting a study, prior knowledge of the stages and processes involved will assist in creating realistic timelines for each step required of a research study. This may include the issue of the withdrawal of participants, for this study, one child withdrew prior to the arranged date of interview due to a deterioration in the child's clinical condition. The situation prevented the child and their parents from being able to be participants, despite showing positive interest in the study. The recruitment numbers were not affected due to additional children and families being available to participate, and the limitation of participant withdrawal resulted in a study strength because of an over-recruitment.

Researchers who conduct studies whilst working full or part-time in clinical or other settings may have to amend the study timeline in response an increase in the workload and this may impact on the final quality of the study. For this study, and in relation to this researcher, there were delays to the research timeline due to the time required to gain ethical approval and to address the practical and professional educational requirements to employ the novel Talking Mats® method. A change of employment necessitated that the PhD candidate relocated from Scotland to Wales, and this required a change of Higher Education Institution and research supervisors. This subsequently led to a delay in the writing up process which impacted on the date for submission and the quality of the thesis.

There was a limitation in relation to the sample size of only two children available for participation through Talking Mats®. The lack of fathers' perspectives was an additional limitation, of the eight adult participants, seven were mothers and one was a father. Hampson (2016) raised the issue of the importance of hearing the voices of fathers to enable a non-stereotypical patriarchal but balanced view to be achieved. Fathers provide a whole family perspective and help researchers to recognise the impact of fathers on the whole family dynamic.

The limitations identified of using the three identified methods were in relation to the paucity of research with the population of children with disabilities and of those who use Augmentative Alternative Communication (AAC) and other methods of non-verbal communication (Rabiee et al., 2005; McNeilly et al., 2015). The evidence which informed the study from the LR highlighted the lack of inclusion of this cohort of children within research and that this issue is noted as a limitation of research (Clark et al., 2014).

7.7.3 Possible policy implications

It is clear from the findings of this study that children with disabilities, complex health needs and SLCN are able to take part in research

provided that they are asked and supported to do so using appropriate methodologies and methods. Policy makers and supporters of children's rights may consider the following points and may lobby the UK legislators to embed the participation and inclusion of this group of children into all policies impacting on children.

1. To examine multicultural issues, stigma and discrimination experienced by children living with disabilities and their families by the application of values-based inquiry and measuring against the review of Articles 2, 12, 19, 24 and 41 of UNCRC (2009).

2. Conduct research exploring children and their families' experiences within a range of services and settings and by various populations. Develop innovative strategies to facilitate the co-production of research studies with the teams and services around and involved with children. The relevant policymakers are practitioners and managers within social care, education, and local authorities, especially where their role is as corporate parents for children within the care system and who are often excluded or marginalised within society (Bercow, 2018).

3. Research to examine the lack of understanding of children's needs and inadequate service provision that is not sustained and to investigate why this is important. Investigate the models of compassionate and intelligent leadership to determine how the recommendations of the NHS Long Term Plan can be met in relation to children with complex health needs and disabilities (NHS, 2020).

4. Future research to examine the training and education of staff induction programmes or within continuous professional development to identify staff needs in meeting the needs of children and families living with complex needs and disabilities. Map the educational needs with current provision to assess whether this leads to the development of more training to address this gap (Care Quality Commission, 2015). It is important to add in the cost of training to

studentship budgets for resources such as Talking Mats® to enable the method to be used by researchers when investigating the needs and preferences of children and young people living with disabilities, complex health needs and SLCN.

5. Policymakers may examine whether practitioners and researchers are taking a collaborative approach which includes children with disabilities, complex health needs and SLCN and their families in PPI (Public and Patient Involvement). Investigation of collaboration in research should establish whether research is 'with' children is not just a token inclusion within the research process (BERA, 2011).

7.7.4 Future research

- Future research could utilise qualitative methods and Talking Mats® methods to investigate the lived experience of different ethnic groups with complex healthcare needs in the UK.
- Future research could utilise a co-production approach to develop a research study on an aspect of care decided upon by children and young people and their families.
- Future research could investigate how young people with complex needs feel about transferring to adult services. Further studies could present a longitudinal view of health journey of the young person and the impact of the services provided on the physical and emotional health and wellbeing.

7.7.5 Review of methodology

For this study the central premise was to hear the views of children and their families of living with disabilities, complex health needs and SLCN and to understand their experiences of the services provided for them. From the results of the LR, it was clear that the qualitative approach of phenomenology was the most suitable for this study. Phenomenology provides and enables researchers with the ability to gain the rich detail, first- person accounts of the lived experiences of the participants who

for this study were children and their families. An important consideration within qualitative methodology is the ethical process which ensures the protection and safeguarding of the participants. The strategies required within qualitative research methodologies must demonstrate that participant protection is inherent in the study protocol before ethics permission is granted. Ethics committees recommend that any research studies conducted by novice researchers must be supervised by experienced research supervisors (The British Education and Research Association [BERA], 2011). The allocated research supervisors to approved studies are expected to have expertise within the chosen methodology and to have credible, contemporary subject knowledge. This factor was important in relation to this study and was applied to the selection of the members of the academic supervisory team. The allocated supervisors monitored and supported the rigour of the research process to meet the requirements of the Health Board, the University and the Regional ethics committees granting permission for this study. The supervisors were experienced in conducting qualitative studies and they raised the supervisee's awareness of the limitations within research that are often encountered, in addition to how study limitations may be mitigated or managed. Limitations were identified for this study by taking into consideration the inexperience of researcher. Supervision was required regarding how to conduct a qualitative study and to use a LR (Aveyard, 2018) and the three identified methods of semi-structured interviews (Smith et al., 2009), case study and Talking Mats® (Murphy, 1998a).

The Regional Ethics Committee (REC) highlighted two possible limitations, the first in relation to the study population and sample numbers and the second regarding the perceived ability of children with speech, language, and communication needs (SLCN) to provide their views and these possible limitations are now discussed.

The optimum participant numbers for semi-structured interviews are between 20 and 30 (Baker & Edwards, 2012) and the numbers of

participants in this study were agreed as fifteen participants, seven children and eight adults by the REC.

The adult participants were over-represented by mothers with only one father participating, this was considered a limitation and presented an inequity within the sample. The age ranges of the children advised by the REC was no younger than eight years or older than fifteen years and this was seen as a limitation due to evidence that children younger than eight years can contribute effectively to qualitative research studies provided suitable, age-appropriate methods of communication are used (Clark et al., 2014; Coad et al., 2020). The REC expressed concern and one REC member, a Speech and Language therapist, indicated that children living with SLCN may not be able to effectively participate and that this was a limitation of the study proposal before ethics permission was granted. The limitations were addressed by providing all information for children living with SLCN in accessible formats and by using the Talking Mats® method (Murphy, 1998a) for interviews, once the accredited training had been successfully undertaken, with the children who used the intervention as their established method of communication.

Following the consideration of the limitations of methods, and study sample in relation to the research question being asked, attention was focussed on the selection and appropriateness of the methods to address the research question, ensuring that validity, rigour and elimination of researcher bias had been fully considered. The study objectives were reviewed against the findings to allow reflection and suggestions for further research and for the achievements and the limitations of the study were identified.

7.7.6 Comparison of results with theory

The theory and evidence presented throughout this thesis support the policy context in relation to the application of Articles 2,12, 19, 24 and 41 of the UNCRC (2009) whose premise is the safeguarding, inclusion

and participation of children and their right to influence policy and services. The responsibilities of the UK government to children and young people are found within the Children Act (1989), the Health and Social Care (Reform) ACT (Northern Ireland) (2009), the Rights of Children and Young Persons (Wales) Measure (2011), the Health and Social Care (Reform) ACT (2012) Children and Young People (Scotland) Act 2014 and commit to patient and public engagement, using the model of Information Feedback Engagement Co-design and Partnership of the NHS Institute (2013) and the Department of Health & Social Care (2021).

Failures in leadership within healthcare as identified by Francis (2013) and Ockenden (2020) have led to increased morbidity and mortality and promoted the requirement for the implementation of health improvement programmes (NHS, 2020). The results of the literature review (LR) and the findings the semi-structured interviews and the Talking Mats® supported the existing knowledge within the research topic. This related to sub-optimal healthcare provision leading to the adverse experiences of healthcare in childhood (Bellis et al., 2014). The evidence suggests that negative consequences for children may result from service not listening to children and their families about the quality and suitability of the services provided. The results of the LR clearly demonstrated the multicultural issues, stigma and discrimination experienced by children living with disabilities and their families within a range of services and settings and by various populations. In addition, the LR highlighted lack of understanding of children's needs and inadequate service provision due to training and education not being provided, either within staff induction programmes or within continuous professional development fails to meet education and health policy (Bercow, 2018).

7.7.7 Recommendations for future research

The findings of the research presented in this thesis will be disseminated to relevant interested communities of practice who are members of the nursing, medical, education and social care professions

and the students within those professions, along with the teams involved with children and families, charities, third sector providers and the children and families themselves. This will be achieved by writing publications for peer reviewed academic journals, developing formal and informal presentations using traditional and novel methods. Consideration may be given for example, to applying for research funding to develop educational and social media platforms, including information applications (apps) which could be available on mobile devices using Smart technology, iPhones and iPads. In addition, multiagency and multidisciplinary seminars will be arranged with a strong focus on public co-production and inclusion by inviting children and their families to attend, to contribute to the content and to participate in the presentations and workshops to any degree that they feel is appropriate and that they are comfortable with. Accessibility would be promoted by providing the information and delivering the content of all aspects of this study in formats relevant to any persons reading, using technology or participating in the seminars, for example, British Sign Language, Hearing Loops, easy read documents with explanatory picture content and other assisted communication applications. The expectation from the workshop seminars is that recommendations for improvement of care and services will be co-produced and presented to all relevant service providers for further consideration.

7.8 Conclusion

The research question for this study was, 'What are the views and experiences of children living with disabilities and complex health needs and those of their families?'. The motivation and enthusiasm to conduct this research was based on professional, academic and personal curiosity to discover the experiences of children's and their families' lives, in addition to the desire to provide a valid contribution to service improvements and patient care through research. The importance of research to the art and science of nursing is recognised and highlighted

in the standards of the Nursing & Midwifery Council (NMC, 2018). This research was conducted with the aim of hearing the authentic voices and first-person experiences of children, and those of their families, who were living with the impact of disabilities, complex health needs and speech language and communication needs (SLCN). This study provided opportunity for the children and their families to tell their life stories and to paint a rich picture of their experiences through the application of a qualitative, phenomenological approach, influenced by Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) and the qualitative semi-structured interview and case study methods. Children who were living with SLCN and who previously had not had an opportunity to take part in research, were enabled to demonstrate their experiences through the visual symbols of Talking Mats®. The original Talking Mats® method (Murphy, 1998a) was adapted by the removal of the neutral response option to provide a dichotomous positive or negative choice and to potentially reduce the cognitive overload for the children. The adapted Talking Mats® provided a novel approach to listening to children and enabled two children, Jack and John, who were living with SLCN, to successfully demonstrate their daily experiences through a rich picture using Talking Mats®. Gillam et al. (2016) found that the voices and opinions of children with disabilities, and those of their families, are not always sought or heard due to the lack of an invitation from researchers to participate in the studies that are relevant to child and family topics. For this study the issue of disparity and inequity within research was addressed by the employment of an adaptation to the research process and to the Talking Mats® method. The chosen adjustments strengthened the suitability of the Talking Mats® for this research population and helped to ensure that the child's right to inclusion and participation, as recommended within the articles of the United Nations Convention on the Rights of the Child (UNCRC, 2009), was implemented. As a consequence of employing this unique and tailored Talking Mats® method the resultant themes were 1. Mobility and transport 2. Activities of daily living and 3. Choices and preferences.

Whilst the lived experiences of the participants were unique, there were similarities in the findings and the themes identified by the children and their parents. The findings highlighted both the positive and negative aspects of living with disabilities, complex health needs and SLCN. An interesting finding was that the children and their parents had developed both strength and resilience from the adversity of living with health uncertainty along with complicated medication and feeding regimens and were proud to have acquired coping strategies and the status of being deemed an 'expert by lived experience'. The perverse of this positivity was that the children and families' perceived expertise often led to their continually having to explain their situations and health conditions to service teams. The parents stated that the onus was regularly placed on them to provide training for staff involved in their children's care which was perceived as an unfair and unrealistic expectation. In addition, parents believed that this situation constituted a denial of their right be recognised in the primary role of a mother or a father and not as a member of staff or as an unpaid carer.

The premise held that children's rights are enshrined in legislation and protected provided a major driver for the research. These rights are assessed by the Children's Rights Alliance England (Williams, 2021) against the 54 articles of the United Nations Convention on the Rights of the Child (UNCRC, 2009).

This study has demonstrated the value of qualitative research within children's nursing and detailed the positive influence of employing effective research methods to reach children of all abilities, including children living with disabilities, complex health needs and SLCN. The conclusions drawn from the discussion of the study findings provide recommendations for future research. This thesis may encourage researchers to apply novel research methods to engage children and families in research. There is potential within this study to seek the solutions for improving children's participation and inclusion in research which would uphold children's rights as recommended within the

articles of the United Nations Convention on the Rights of the Child (UNCRC, 2009). The thesis demonstrates the importance of ensuring the safeguarding of children within research (The British Education and Research Association [BERA], 2011) and within healthcare (Royal College of Paediatrics and Child Health [RCPCH], 2018). The chosen phenomenological approach and qualitative methods provide the evidence that children of all abilities can participate in research when supported by suitable methods that are tailored to their specific needs. This chapter detailed the study findings, the strengths and the limitations of this study and provided a discussion of the research experience and the implications for future practice.

7.9 Chapter summary

The discussion of findings within this chapter links the LR with the three approaches applied within this research thesis: semi-structured interviews influenced by Interpretative Phenomenological Analysis (IPA), case study and the application of a novel Talking Mats® method.

The exclusion from research of the groups of children who require additional time and help to provide their views was an issue of concern that was raised by Davys et al. (2017). This study enabled the inclusion and participation of children who are often marginalised and seldom heard within health care systems and demonstrates that the children's views and experiences were captured through careful consideration, selection and adaptation of suitable approaches which were matched appropriately to the children's cognitive abilities.

This chapter discussed the key findings from the children's and their families' interviews and demonstrates that the findings within this study along with the qualitative studies examined in the LR identified recurring themes for children and families living with complex health needs, speech, language, and communication needs (SLCN) and disabilities. There was a predominance of negative experiences within healthcare for children with disabilities and their families and a recognition of the

detrimental impact on quality of life from Adverse Childhood Experiences (ACEs) (Bellis et el., 2015). This study presented the children's and families' views of the impact and demands on their physical health, mental wellbeing, and their emotions throughout their life course of living with complex health needs and disabilities, including SLCN.

The findings from this thesis provide evidence that not all health and education care providers have adequate awareness of the rights of children and families to be consulted about, and to be involved in health policy making. These issues were raised by RCPCH (2018) who expressed concern regarding the lack of the recognition of children's rights and safeguards across health settings.

Applying the currently underutilised Taking Mats® and adapting it as a novel research method with a dichotomous choice option, provided the opportunity for the children in this study living with complex health needs, SLCN and those living with disabilities to have their voices heard. The children within this study comprise a seldom heard population, listening to their lived experiences could provide them and other children with improved health benefits and prevent harm from Adverse Childhood Experiences (Bercow, 2018) due to sub-optimal service provision. This study demonstrates that prejudice, stigma, and a lack of knowledge and understanding of the needs of disabled children affect the quality of healthcare delivery and impact on the quality of the patient experience. Children and parents reported that they were often ignored by staff within hospitals and educational establishments who avoided engaging with children because of a lack of appropriate communication skills. This issue was especially evident where alternative forms of communication such as sign language, symbol techniques and augmentative and assisted communication were required.

7.10 Concluding remarks

The findings from this study demonstrate that when suitable research methodologies and approaches are used, deep rich insight can be gained into the lived experiences of children and families living with disabilities, SLCN and complex health needs. The chosen methods of semi-structured interviews, case study and novel Talking Mats ® enabled the authentic voices of vulnerable groups, as defined within the Disability Discrimination Act 2005 to be heard. The findings from the children's Talking Mats ® interviews demonstrated that when children are provided with the appropriate communication method, along with the opportunity for inclusion, they are enabled to express their views and can relate their lived experiences. This study has provided results, findings and supporting evidence which link to policy, legislation, children's rights, safeguards, inclusion, and participation.

The participants' experiences of healthcare presented in this study enrich the body of existing knowledge on the research topic of children's and families' experiences of living with complex health needs and disabilities, including speech, language, and communication needs. The evidence gained from this research, and the reflexive accounts provided by the researcher, who is a nurse lecturer and an experienced children's nurse with a background in clinical service management and health and social care integrated working in Scotland, demonstrates the significance of the roles that can be undertaken by health and education care providers. The findings of this study highlight the necessity to include children and families in the commissioning, co-development, co=production and co-delivery of health care services.

This conclusion has identified the value of taking a qualitative research approach and of developing novel research methods or adapting current research methods to meet the needs of the participants. This study has gained the authentic views and experiences of the children and families who are often not invited to take part in research studies and as a consequence of this, are underrepresented in research.

REFERENCES

Abbott, D., Townsley, R., & Watson, D. (2005). Multi-agency working in services for disabled children: what impact does it have on professionals? *Health and Social Care in the Community, 13(2),*155–163.

Aruma, E. O., & Hanachor, M. E. (2017). Abraham Maslow's Hierarchy of Needs and Assessment of Needs in Community Development. *International Journal of Development and Economic Sustainability,* 5(7), 15-27. https://www.eajournals.org/wp-content/uploads/Abraham-Maslow%E2%80%99s-Hierarchy-of-Needs-and-Assessment-of-Needs-in-Community-Development.pdf

ATLAS.ti (2002) *All in one research software. Code Bar Charts & Clouds in ATLAS.ti* ATLAS.ti: The Qualitative Data Analysis & Research Software (atlasti.com)

Aveyard, H. (2018). *Doing a Literature Review in Health and Social Care: A Practical Guide.* Oxford University Press.

Backman, E., & Karlsson, A. (2021). Children's Perspectives on Mealtimes When Living with a Gastrostomy Tube: A Qualitative Study. *Journal of Pediatric Nursing,* 58, 53-59. https://doi.org/10.1016/j.pedn.2020.11.018

Bailey, J. (2008). First steps in qualitative data analysis: transcribing. F*amily Practice,* 25(2), 127–131.

Baillie, J., Gill, P., & Courtenay, M. (2021). Seeking help for peritoneal dialysis-associated peritonitis: Patients' and families' intentions and actions. A mixed method study. *Journal of Advanced Nursing,* 1–15. https://doi.org/10.1093/fampra/cmn003

Baker, S. E., & Edwards, R. (2012). How many qualitative interviews is enough？ *National Centre for Research Methods Review Paper*, 1–42. https://doi.org/10.1177/1525822X05279903

Bardach, L., Oczlon, S., Pietschnig, J., & Lüftenegger, M. (2020). Has achievement goal theory been right? A meta-analysis of the relation between goal structures and personal achievement goals. *Journal of Educational Psychology, 112*(6), 1197-1220. http://dx.doi.org.ezproxy.bangor.ac.uk/10.1037/edu0000419

Barreto, M., Garcia-Vivar, C., da Silva, T., Girardon-Perlini, N. M., & Marcon, S. (2021). A Corbin and Strauss Grounded Theory on the Experiences of Patients, Relatives, and Health Professionals About the Family Presence During Emergency Care. *Advances in Nursing Science, Publish Ahead of Print* , doi: 10.1097/ANS.0000000000000390.

Batalden, P. (2018). Getting more health from healthcare: quality improvement must acknowledge patient coproduction. *British Medical Journal,* 362, k3617. https://doi.org/10.1136/bmj.k3617

Beecroft, C., Booth, A., & Rees, A. (2015) Finding the Evidence In K. Gerrish, & J. Lathlean, (Eds.) *The Research Process in Nursing* (7th ed., pp.89-104). Wiley Blackwell.

Bellis, M.A., Hughes K., Leckenby, N., Hardcastle, K.A., Perkins, C., & Lowey, H. (2015). Measuring mortality and the burden of adult disease associated with adverse childhood experiences in England: a national survey. *Journal of Public Health*, 37(3), 445–454.

Bellis, M., A., Hughes, K., Ford, K., Hardcastle, K.A., Sharp, C. A., Wood, S., Homolova, L., & Davies, A. (2018). Adverse childhood experiences and sources of childhood resilience: a retrospective study of their combined relationships with child health and educational attendance. *BMC Public Health (2018)*, 18, 792.

Bentley, H., Fellowes, A., Glenister, S., Mussen, N., Ruschen, H., Slater, B., Turnbull, M., Vine, T., Wilson, P., & Witcombe, S. (2020). *How safe are our children? an overview of data on adolescent abuse.* National Society for the Prevention of Cruelty to Children. Statistics briefing: child deaths due to abuse or neglect (nspcc.org.uk)

Bercow, J. (2008). *A Review of Services for Children and Young People (0–19) with Speech, Language and Communication Needs.* Department for Children, Schools and Families (DCSF). http://www.dcsf.gov.uk/bercowreview

Bercow, J. (2018). *An independent review of provision for children and young people with speech, language and communication needs in England.* I CAN, the children's communication charity, Royal College of Speech and Language Therapists (RCSLT). 337644-ICAN-Bercow-Report-WEB.pdf (bercow10yearson.com)

Bergström, A., Ehrenberg, A., Eldh, A.C., Graham, I.D., Gustafsson, K., Harvey, G., Kitson, A., Rycroft-Malone, J., & Wallin, L. (2020). The use of the PARIHS framework in implementation research and practice—a citation analysis of the literature. *Implementation Science,* 15, 68. https://doi.org/10.1186/s13012-020-01003-3

Bishop, C.F. (2017). *Investigating prevalence and healthcare use of children with complex healthcare needs using data linkage: a study using multi-ethnic data from an ongoing prospective cohort, the Born in Bradford project.* https://ethos.bl.uk/OrderDetails.do?did=2&uin=uk.bl.ethos.801477

Bordogna, C. M. (2021). Transnational Teaching: Evaluating the Application of Heideggerian Phenomenology and IPA in a Study of Lived Experiences. *International Journal of Qualitative Methods,* 20, 1-10.

British Educational Research Association. (2018). *Ethical Guidelines for Educational Research.* BERA.

Brocklehurst, P., Langley, J., Baker, S., McKenna, G., Smith, C., & Wassall, R. (2019). Promoting co-production in the generation and use of research evidence to improve   service provision in special care dentistry. *British Dental Journal*, 227(1), 15-18. https://doi.org/10.1038/s41415-019-0458-5

Brown, C., Spiro, J., & Quinton, S. (2020). The role of research ethics committees: Friend or foe in educational research? An exploratory study. *British Educational Research Journal, 46*, 747-769.

Caldicott, F. (1997). *Caldicott Principles*. http\\:igt.hscic.gov.uk

Care Quality Commission. (2013). *Our action on Winterbourne.* http://www.cqc.org.uk/public/our-action-winterbourne-view/review-learning-disability-services

Care Quality Commission. (2015). *Children and young people's inpatient and day case survey 2014 Key Findings Newcastle on Tyne.* Care Quality Commission. http\\:www.cqc.org.uk

Cavet, J. & Sloper, P. (2004) Participation of Disabled Children in Individual Decisions About Their Lives and in Public Decisions about Service Development. *Children & Society,* 18, 278-290.

Chambers, L. (2018) *A Guide to Children's Palliative Care. Supporting babies, children and young people with life-limiting and life-threating conditions and their families.* (4th ed.). Together for Short Lives. http://www.togetherforshortlives.org.uk/

Chang, A., & Bilton, D. (2008). Exacerbations in cystic fibrosis: 4 Non-cystic fibrosis bronchiectasis. *Thorax,* 63(3), 269-276.

Children Act 1989 (c. 41). London: The Stationery Office. https://www.legislation.gov.uk/ukpga/1989/41/contents/data.pdf

Children and Young People Act (Scotland) 2014. Scottish Government Children's Commissioner: Scottish Government. http://www.cypcs.org.uk/education/rights-in-pictures/children

Clark, M., McConachie, H., Price, K., & Wood, P. (2001). Views of young people using augmentative and alternative communication systems. *International Journal of Language and Communication Disorders,* 36, 107-115.

Clark, A., Flewitt, R., Hammersley, M., & Robb, M. (2014). *Understanding Research with Children and Young People.* Sage.

Cleary, S. R., & Doyle, K. E. (2016). Whistleblowing Need not Occur if Internal Voices Are Heard: From Deaf Effect to Hearer Courage. *International Journal of Health Policy Management,* 5(1), 59–61.

Coad, J., Harding, S., Hambly, H., Parker, N., Morgan, L., Marshall, J., & Roulstone, S. (2020). Perspectives of preschool children in England with speech and language needs in the development of evidence-based activities. *Child: Care, Health & Development,* 46(3), 283–293. https://doi.org/10.1111/cch.12746

Coad, J. E., Manning, J. C., Mills, E., Semple, C., Johnston, B., & McMahon, A. (2019). Capturing the real impact of clinical academics in practice. *International Journal of Practice-Based Learning in Health and Social Care,* 7(2), 47–56. https://doi.org/10.18552/

Cohen, L., Manion, L., & Morrison, K. (2011). *Research Methods in Education,* (7th ed.). Routledge.

Collins, C. S., & Cooper, J. E. (2014). Emotional Intelligence and the Qualitative Researcher. *International Journal of Qualitative Methods,* 13, 88-103. Emotional Intelligence and the Qualitative Researcher (sagepub.com)

Communication Access Literacy and Learning (CALL) Scotland. (2020a). *Perspectives on AAC with Adults - Collected Papers 1998.* https://www.callscotland.org.uk/home/

Communication, Access, Literacy & Learning (CALL) Scotland. (2020b). *iPad Apps for Complex Communication Support Needs: Augmentative and Alternative Communication (AAC).* University of Edinburgh. iPad-Apps-for-Complex-Communication-Support-Needs.pdf (aacscotland.org.uk)

Data Protection Act 2018 (c12) Data Protection Act 2018 (legislation.gov.uk)

Davys, D., Mitchell, D., & Martin, R. (2017). Fathers of adults who have a learning disability: Roles, needs and concerns. *Journal of Learning Disabilities,* 45, 266–273

DeMarree, K. G., Christian Wheeler, S., Briñol, P., & Petty, R. E. (2014). Wanting other attitudes: Actual–desired attitude discrepancies predict feelings of ambivalence and ambivalence consequences. *Journal of Experimental Social Psychology,* 53, 5–18. https://doi.org/10.1016/j.jesp.2014.02.001

Department of Health. (2012). *Department of Health Review: Winterbourne View Hospital.* https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/141591/Department-of-Health-Review-Winterbourne-View- Hospital-Interim-Report1.pdf

Department of Health. (2014). *Children with special educational and complex needs Guidance for Health and Wellbeing Boards.* http://www.gov.uk/dh

Department of Health. (2015). *Government response to No voice unheard, no right ignored- a consultation for people with learning disabilities, autism and mental health conditions.* Government response

to No voice unheard, no right ignored - a consultation for people with learning disabilities, autism and mental health conditions (publishing.service.gov.uk)

Department of Health & Social Care. (2021). *Give feedback or make a complaint.* https://www.gov.uk/government/publications/the-nhs-constitution-for-england/how-do-i-give-feedback-or-make-a-complaint-about-an-nhs-service

Department for Work & Pensions. (2021). *Family Resources Survey 2019/2020. https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2019-to-2020*

Dewar, B., Stulz, V., Buliak, A., Connolly, L., McLaughlin, D. K., Newport, K., Rebolledo, S., Stephenson, L., MacBride, T., Lennon, K., & Drayton, N. (2020). Exploring and developing student midwives' experiences (ESME)—An appreciative inquiry study. *Midwifery,* 91, 102844–102844. https://doi.org/10.1016/j.midw.2020.102844

Diffin, J., Byrne, B., Kerr, H., Price, J., Abbott, A., McLaughlin, D., & O'Halloran, P. (2019). The usefulness and acceptability of a personal health record to children and young people living with a complex health condition: A realist review of the literature. *Child: Care, Health & Development,* 45(3), 313-332.

Disability Discrimination Act 1995 (c.51) London: The Stationery Office. Disability Discrimination Act 1995 (legislation.gov.uk)

Donaldson, S.I., Christie, C.A., & Mark, M.A. (2009). *What Counts as Credible Evidence in Applied Research and Evaluation Practice?* Sage.

EBSCO. (2020). *CINAHL the world's largest source of full-text nursing and allied health journals, is one of the most widely used research tools for nurses, students, and other health professionals.* https://www.ebsco.com/products/research-databases/cinahl-complete

Edwards, M. L. and Smith, B. C. (2014) *The Effects of the Neutral Response Option on the Extremeness of Participant Responses.* https://blogs.longwood.edu/incite/2014/05/07/the-effects-of-the-neutral-response-option-on-the-extremeness-of-participant-responses/

Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., Koss, M. P., & Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: the Adverse Childhood Experiences (ACE) Study. *American Journal of Preventative Medicine,* 14, 245–58. https://doi.org/10.1016/s0749-3797(98)00017-8

Flewitt, R. S. (2006). Using video to investigate preschool classroom interaction: Education research assumptions and methodological practices. *Visual Communication,* 5(1) 25-30.

Francis, R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Enquiry.* London: The Stationery Office.

Franklin, A., & Sloper, P. (2009). Supporting the Participation of Disabled Children and Young People in Decision- making. *Children & Society*, 23, 3-15.

Freeman, M. (2010). Reflective Logs: An Aid to Clinical Teaching and Learning. *International Journal of Language & Communication Disorders,* 36(1), 1411-417.

Gerrish, K. & Lathlean, J. (Eds.). (2015). *The Research Process in Nursing* (7th ed.). Wiley Blackwell.

Gill, P. (2020). Imposter syndrome; why is it so common amongst nurse researchers and is it really a problem? *Nurse Researcher,* 28(3), 10.

Gilljam, B., Arvidsson, S., & Svedberg, P. (2016). Promoting participation in healthcare situations for children with JIA: a grounded theory study. *International Journal of Qualitative Studies on Health and Well-being,* 11(1), 1-10 https://doi.org/10.3402/qhw.v11.30518

Glasper, A., & Rees, C. (2012). *Posing and evidence-based practice question using the PICO and SPICE models* In: Glasper, A. & Rees, C. (eds) *How to write your research dissertation.* Wiley Blackwell, 86-92.

Goldstein, S. E. (2017) Reflexivity in narrative research: accessing meaning through the participant-researcher relationship. *Qualitative Psychology,* 4, 149–64.

Goodenough, T., & Williamson, E. (2002). 'What Did You Think About That?' Researching Children's Perceptions of Participation in a Longitudinal Genetic Epidemiological Study. *Children & Society,* 17, 113-115.

Graham, J, (2012). *Children with disabilities and their families: team working and the role of the key worker.* University of Brighton for the degree of Professional Doctorate in Physiotherapy ETHoS ID. 590047.

Gray, B., Bright. D., Bolton, S., & Davies, A. (2020). *Towards a healthy and sustainable workforce for the future. The current health and wellbeing of the nursing and midwifery workforce in Wales.* Public Health Wales NHS Trust. https://phw.nhs.wales/publications/publications1/towards-a-healthy-and-sustainable-workforce-for-the-future1/

Green, J., & Thorogood, N. (2018). *Qualitative methods for health research*. Sage.

Griffiths, F. (2009). *Research Methods for Health Care Practice.* Sage.

Hammersley, M. (2011). *Methodology: Who Needs It?* Sage.

Hammersley, M. (2013). *What is qualitative research?* Bloomsbury.

Hardcastle, K., Bellis, M.A., Sharp, C.A., & Hughes, K. (2019). Exploring the health and service utilisation of general practice patients with a history of adverse childhood experiences (ACEs): an observational study using electronic health records. *British Medical*

Journal Open, 10(9), 1-9.
https://bmjopen.bmj.com/content/bmjopen/10/9/e036239.full.pdf

Health Improvement Scotland. (2019). *'What matters to you?'*
Supporting more meaningful conversations in day-to-day practice.
http://www.healthcareimprovementscotland.org/

Hemsley, B., Sigafoos, J., Balandin, S., Forbes, R., Taylor, C., Green,
V., & Parmenter, T. (2001). Nursing the patient with severe
communication impairment. *Journal of Advanced Nursing,* 35, 827–835.

Hemsley, B., Kuek, M., Bastock, K., Scarinci, N., & Davidson, B. (2013).
Parents and Children with Cerebral Palsy Discuss Communication
Needs in Hospital. *Developmental Neurorehabilitation,* 16(6), 363-74.

Higgins, J.P.T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page,
M.J., & Welch, V. A. (Eds). (2019). *Cochrane Handbook for Systematic
Reviews of Interventions.* (2nd ed). John Wiley & Sons.

Holland, K., & Rees, C. (2010) *Nursing Evidence-Based Practice Skills.*
Oxford University Press

Howlett, B., Rogo, E., & Gabiola-Shelton, T. (2020). *Evidence-based
Practice for Health Professionals: An Interprofessional Approach.*
(2nd ed.). Jones & Bartlett Learning.

Hughes, K., Ford, K., & Bellis, M. A. (2018). Sources of childhood and
adult resilience and their impact on harms associated with adverse
childhood experiences. *Injury Prevention,* 24(2), 110,
https://doi.org/10.11.36/injuryprevention-2018-safety.304

Ilkhani, M. (2013). *The inpatient hospital care delivery to disabled
children and young people and those with complex health needs
Doctoral thesis.*
https://ethos.bl.uk/Home.do;jsessionid=6B9AF817F9EF2B7775771D58
91F73EE2

Information Commissioners Office (2018). *General Data Protection Regulations (2018).* Information Commissioners Office.

Janse, A. J., Uiterwaal, C.S., Gemke, R. J., Kimpen, J. L., Sinnema, G. (2005). A difference in perception of quality of life in chronically ill children was found between parents and pediatricians. *Journal of Clinical Epidemiology*, 58 (5), 495-   502.

Kay, E., & Tisdall, M. (2017). Conceptualising children and young people's participation: examining vulnerability, social accountability and co-production. *The International Journal of Human Rights,* 21(1), 59-75. https://doi.org/10.1080/13642987.2016.1248125

Kenny, O. (2016). *How do Young People Diagnosed with ADHD Perceive their Condition? An Interpretive Phenomenological Analysis.* (DEdPsy). University of East London.

Khan, N., & Qureshi, M.I. (2020). A Systematic Literature Review on Online Medical Services in Malaysia. *International Journal of Online and Biomedical Engineering,* 16 (6), 107-118.

King, N., & Horrocks, C. (2010). *Interviews in Qualitative Research*. Sage.

Laming, W. H. (2003). *The Victoria Climbie inquiry: Report of an inquiry by Lord Laming* (Cm. 5730). The Stationery Office. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attach   mentdata/file/273183/5730.pdf

Larkin, M., Thompson, A, R., & Smith, J.A. (2010). *Evaluating the contribution of Interpretative Phenomenological Analysis Health Psychology Review.* London: Taylor and Francis.

Lega, F., Prenestini, A., & Rosso, M. (2017). Leadership research in healthcare: a realist review. *Health Services Management Research*, 30(2), 94–104.

Light, J. (2000). Communication is the essence of human life: reflections on communicative competence, *Augmentative and Alternative Communication,* 13, 61-70.

Light, J., & McNaughton, D. (2014). Communicative Competence for Individuals who require Augmentative and Alternative Communication: A New Definition for a New Era of Communication? *Augmentative and Alternative Communication,* 30(1), 1-18, https://doi.org/10.3109/07434618.2014.885080

Long, H.A., French, D.P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences,* 1(1), 31–42.

Luxford, K., Safran, D. G., & Delbanco, T. (2011). Promoting patient-centred care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *International Journal for Quality in Health Care*, 23(5), 510–515.

Mackenzie, N., & Knipe, S. (2006). Research dilemmas: Paradigms, methods and methodology. *Issues in Educational Research*, 16(2), 193-205. http://www.iier.org.au/iier16/mackenzie.html

Maddox, C., & Pontin, D, (2013). Paid carers' experiences of caring for mechanically ventilated children at home: implications for services and training. *Journal of Child Health Care,* 17(2), 153-63. https://doi.org/10.1177/1367493512456113

Macnaghten, P., & Myers, P. (2004). Chapter 4 p.72 In Seale, C., Gobo, G., Gubrium, J.F. & Silverman, D. (2007). *Qualitative Research Practice*. Sage.

Manning, J., Latour, J. M., Curley, M. A. Q., Draper, E. S., Jilani, T., Quinlan, P. R., Watson, R. S., Rennick, J. E., Colville, G., Pinto, N., Latif, A., Popejoy, E., & Coad, J. (2020). Study protocol for a multicentre

longitudinal mixed methods study to explore the Outcomes of Children and Families in the first year after paediatric Intensive Care: the OCEANIC study. *British Medical BMJ Open,* 10(5), e038974–e038974. https://doi.org/10

Markham, C. (2007). Exploring children's quality of life: experiences of a clinical researcher. *Bulletin. The Official Magazine of the Royal College of Speech and Language Therapists,* 667, 12-13.

Markham, C. (2008). *The development and validation of a quality of life measure for children with speech language and communication needs.* Thesis is submitted in partial fulfilment of the requirements for the award of the degree of Doctor of Philosophy of the University of Portsmouth. EThoS ID., 500342.

Markham, C., van Laar, D., Gibbard, D., & Taraneh, D. (2009). Children with speech language and communication needs: their perceptions of their quality of life. *International Journal of language and Communication Disorders,* 44(5), 748-768.

McCormack, B., & McCance, T. (2017). *Person-centred Practice in Nursing and Health Care: Theory and Practice.* (2nd ed.). Wiley Blackwell.

McCormack, B., & Dewing, J. (2019). International Community of Practice for Person centred Practice: position statement on person-centredness in health and social care. *International Practice Development Journal,* 9(1), 1-7.https://doi.org/10.19043/ipdj.91.003

McDonald, M., McCormack, D., Avdagic, E., Hayes, L., Phan, T., & Dakin, P. (2019). *Children and youth services review*, 99, 270-278. Understanding resilience Similarities and differences in the perceptions of children, parents and practitioners (sciencedirectassets.com)

McFadyen, J. & Rankin, J. (2016). The Role of Gatekeepers in Research: Learning from Reflexivity and Reflection. *Journal of Nursing and Health,* 4(1), 82-88.

McNeilly, P., Macdonald G., & Kelly, B. (2015). The Participation of Disabled Children   and Young People: A Social Justice Perspective. *Child Care in Practice,* 21(3), 266–286. http://dx.doi.org/10.1080/13575279.2015.1014468

Merrick, R., & Roulstone, S. (2011). Children's views of communication and speech-language pathology. *International Journal of Speech-Language Pathology,* 13(4), 281-290.

Misuk, L., & Emmett Gardner, J. (2015). A Qualitative Inquiry of Korean Mothers' Perceptions of Grandparents' Roles and Support for Families of Children with Severe Disabilities, *International Journal of Developmental Disabilities*, 61(4), 206-221. https://doi.org/10.1179/2047387714Y.0000000053

Mitchell, S., Slowther, A.-M., Coad, J., Bertaud, S., & Dale, J. (2022). Facilitators and barriers to the delivery of palliative care to children with life-limiting and life-threatening conditions: a qualitative study of the experiences and perceptions of healthcare professionals. *Archives of Disease in Childhood,* 107(1), 59–64. https://doi.org/10.1136/archdischild-2021-321808

Mitchell, S., Slowther, A.-M., Coad, J., & Dale, J. (2021). Experiences of healthcare, including palliative care, of children with life-limiting and life-threatening conditions and their families: a longitudinal qualitative investigation. Archives of Disease in Childhood, 106(6), 570–576. https://doi.org/10.1136/archdischild-2020-320189

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G., The PRISMA Group. (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement.* http://www.prismastatement.org/PRISMAStatement/FlowDiagram.aspx

Mundt, I. (2020). *Theories that underpin the principles and strategies of the Talking Mats tool.* https://www.talkingmats.com/wp-content/uploads/2014/11

Mueller, T.G., & Buckely, P.C. (2014). Fathers' experiences with the special education system: The overlooked voice. *Research and Practice for Persons with Severe Disabilities,* 39(2), 119–135.

Murphy, J. (1998a). Talking Mats® Speech and language research in practice. *Speech and Language Therapy in Practice,* Autumn,11-14.

Murphy, J. (1998b). Helping people with severe communication difficulties to express their views: a low tech tool. *Communication Matters Journal,* 12(2), 9-11.

Murphy, J., & Cameron, L. (2008). The effectiveness of Talking Mats® with people with intellectual disability. *British Journal of Learning Disabilities*, 36(4), 232-41.

Murphy, J., & Boa, S. (2012). Using the WHO-ICF with Talking Mats to Enable Adults with Long-term Communication Difficulties to Participate in Goal Setting. *Augmentative and Alternative Communication,* 28(1), 52-60. https://doi.org/10.3109/07434618.2011.653828

National Institute for Health and Care Excellence (2022) Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education https://www.nice.org.uk/guidance/ng213/resources/disabled-children-and-young-people-up-to-25-with-severe-complex-needs-integrated-service-delivery-and-organisation-across-health-social-care-and-education-pdf-66143773521349

National Society of the Prevention of Cruelty to Children. (2018a). *Child Protection: Conducting safe and ethical research.* NSPCC.

https://www.nspcc.org.uk/services-and-resources/impact-evidence-evaluation-child-protection/conducting-safe-and-ethical-research/

National Society for the Prevention of Cruelty to Children. (2018b). *Services and resources, impact evidence evaluation.* NSPCC. https://www.nspcc.org.uk/services-and-resources/impact-evidence-evaluation-child-protection/conducting-safe-and-ethical-research/

NHS Education for Scotland. (2015). *Promoting Inclusion and Participation Talking Mats.* NHS Education for Scotland. Promoting Inclusion and Participation - Children and Young People's Services MKN (scot.nhs.uk)

NHS Improvement NHS England. (2016). *Freedom to speak up: raising concerns (whistleblowing) policy for the NHS.* NHS Improvement. freedom-to-speak-up-raising-concerns-policy-for-the-nhs-april-19.pdf (england.nhs.uk)

National Institute for Health Research. (2019). *Improving care by using patient feedback.* NIHR Dissemination Centre. Patient-Feedback-WEB.pdf (nihr.ac.uk)

NHS Institute for Innovation and Improvement. (2007). *Improvement Leaders' Guide Sustainability.* Institute for Public Policy Research. http//: www.patients in research.org/nhs-change-model/spread-of-innovation/partnership

NHS Institute for Innovation and Improvement. (2013). *The Patient Experience Book* Institute for Public Policy Research (IPPR). https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11Patient-Experience-Guidance-and-Support.pdf

NHS Improvement and the National Guardian's Office. (2019). *Guidance for boards on Freedom to Speak Up in NHS trusts and NHS foundation trusts* NHS Improvement. Report template - NHSI website

(england.nhs.uk) http://www.england.nhs.uk/wp-content/uploads/2021/05/ftsu-guidance.pdf

NHS. (2019)*. Long Term Plan.* NHS England. http://longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs- long-term-plan-version-1.2.pdf

NHS. (2020). *We are the NHS: Action for us all. People Plan 2020/21*. NHS England. http://www.england.nhs.uk/ournhspeople

NHS Wales GIG Cymru. (2020). *NHS Wales Planning Framework, 2020-2023.* Llywodraeth Cymru The Welsh Government. nhs-wales-planning-framework-2020-to-2023.pdf (gov.wales)

Norris, E., & Shepheard, M. (2017) *How public inquiries can lead to change.* Institute for Government. How public inquiries can lead to change (instituteforgovernment.org.uk)

Nursing & Midwifery Council. (2018). *The code: Professional standards of practice and behaviour for nurses, midwives and nursing associates.* NMC. https://www.nmc.org.uk/standards/code/record-keeping

O'Connor, P. J., Hill, A., Kaya, M., & Martin, B. (2019). The Measurement of Emotional Intelligence: A Critical Review of the Literature and Recommendations for Researchers and Practitioners. *Frontiers in Psychology*, 10, 1116–1116. https://doi.org/10.3389/fpsyg.2019.01116

Ockenden, D. (2020) *Emerging findings and recommendations from the independent review of maternity services at the Shrewsbury and Telford Hospital NHS Trust.* The Stationery Office. Ockenden review of maternity services at Shrewsbury and Telford Hospital NHS Trust - GOV.UK (www.gov.uk)

Offit, P. A. (2020). Flawed research and its enduring repercussions The Doctor Who Fooled the World Brian Deer Johns Hopkins University Press, 2020. 408 pp. *Science (American Association for the*

Advancement of Science), 370(6512), 43–43.
https://doi.org/10.1126/science.abb3587

Oflazoglu, S. (2017). *Qualitative versus Quantitative Research.*
IntechOpen. https://doi.org/10.5772/65619

O.Nyumba, T., Wilson, K., Derrick, C.J., & Mukherjee, N. (2018). The
use of focus group discussion methodology: Insights from two decades
of application in conservation. *Methods in Ecology Evolution,* 9, 20–32.
https://besjournals.onlinelibrary.wiley.com/doi/epdf/10.1111/2041-
210X.12860

Parahoo, K. (2014). *Nursing Research Principles, Process and Issues.*
(3rd ed.). Palgrave Macmillan.

Pietkiewicz, I. & Smith, J.A. (2012) A practical guide to using
Interpretative Phenomenological Analysis in qualitative research.
Czasopismo Psychologiczne, (Psychological Journal), 18(2), 361-369.

Pontin, D., & Jordan, N. (2011). Issues in prognostication for hospital
specialist palliative care doctors and nurses: A qualitative inquiry.
Palliative Medicine, 27(2), 165-171. Issues in prognostication for
hospital specialist palliative care doctors and nurses: a qualitative
inquiry - PubMed (nih.gov)

Preece, D., & Jordan, R. (2010). Obtaining the Views of Children and
Young People with Autism Spectrum Disorders about Their Experience
of Daily Life and Social Care Support. *British Journal of Learning
Disabilities.* 38(1), 10-20.

Public Interest Disclosure Act 1998. (c23) London: The Stationery
Office. https://www.legislation.gov.uk/ukpga/1998/23/contents

Punch. (2014). *Introduction to social research: quantitative & qualitative
approaches* (Third edition.). SAGE Publications Ltd.

Rabiee, P., Sloper, P., & Beresford, B. (2005). Doing Research with Children and Young People Who Do Not Use Speech for Communication. *Children & Society.*19, 385-396.

Reitz, C., & Dalemans, R. (2019). The Use of 'Talking Mats' by Persons with Alzheimer in the Netherlands: Increasing Shared Decision-Making by Using a Low- Tech Communication Aid. *Journal of Social Inclusion.*7(2), 35. https://josi.org.au.articles/abstract/10.36251/josi.110/

Riley, T. (2017). *Charter for British Sign Language.* British Deaf Association. BDA-BSL-Charter-2017.pdf

Robles, V. D. (2018) Visualizing Certainty: What the Cultural History of the Gantt Chart Teaches Technical and Professional Communicators about Management, *Technical Communication Quarterly,* 27(4), 300-321.

Robson, C. (2002). *Real World Research: A Resource for Social Scientists and Practitioner-Researchers.* (2nd ed). Blackwell.

Royal College of Nursing. (2013). *Response of the Royal College of Nursing to Mid Staffordshire NHS Foundation Trust Public Inquiry Report.* RCN.

Royal College of Nursing. (2017). *Safe and effective staffing: nursing against the odds.* RCN. www.rcn.org.uk/professional-development/publications/pub-006415

Royal College of Nursing. (2021). *Healthy Workplace Toolkit.* RCN. https://www.rcn.org.uk/healthy-workplace/healthy-workplaces

Royal College of Paediatrics and Child Health & US. (2015). *Being Me.* Being me - supporting children and young people | RCPCH

Royal College of Paediatrics and Child Health. (2017). *State of Child Health Report 2017.* RCPCH.

Royal College of Paediatrics and Child Health. (2018). *Evidence-based early years intervention inquiry.* Science and Technology Committee (Commons) HC 506. Adverse childhood experiences – consultation response | RCPCH

Rycroft-Malone, J. (2008). Evidence-informed practice: from individual to context. *Journal of Nursing Management,* 16, 404-408.

Schünemann, H.J., Wiercioch, W., Etxeandia, I., Falavigna, M., Santesso, N., Mustafa, R., Ventresca, M., Brignardello-Petersen, R., Laisaar, K.T., Kowalski, S., Baldeh, T., Zhang, Y., Raid, U., Neumann, I., Norris, S.L., Thornton, J., Harbour, R., Treweek, S., Guyatt, G., Alonso-Coello, P., Reinap, M., Brozek, J., Oxman, A., & Akl, E.A. (2014). Guidelines 2.0: systematic development of a comprehensive checklist for a successful guideline enterprise. *Canadian Medical Association Journal*, 186(3), 123-142. https://www.cmaj.ca/contact/186/3/E123

Scottish Government. (2012). *A Right to Speak: Supporting Individuals who use Augmentative and Alternative Communication.* Scottish Government.

Scottish Government. (2017). *Nursing 2030 Vision Promoting Confident, Competent and Collaborative Nursing for Scotland's Future. The Chief Nursing Officer's long term strategy to shape the future of the nursing workforce.* Scottish Government. Nursing 2030 vision - gov.scot (www.gov.scot)

Scottish Government (2012) *A Right to Speak: Supporting Individuals who use Augmentative and Alternative Communication* Edinburgh: Scottish Government.

Seale, C., Gobo, G., Gubrium, J.F., & Silverman, D. (2007). *Qualitative Research Practice.* (Concise Paperback Edition). Sage.

Sellars, B. B., Sherrod, D. R., & Chappel-Aitken, L. (2018). Using word clouds to analyze qualitative data in clinical settings. *Journal of Nursing Management,* 49(10), 51-53. [Using word clouds to analyze qualitative data in clinical settings: Nursing Management (lww.com)](#)

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education Inform*, 22(2), 63–75. [ERIC - EJ792970 - Strategies for Ensuring Trustworthiness in Qualitative Research Projects, Education for Information, 2004](#)

Shilling, V., Edwards, V., Rogers, M., & Morris, C. (2012). The experience of disabled children as inpatients: a structured review and synthesis of qualitative studies reporting the views of children, parents and professionals. *Child: Care, Health & Development,* 38(6), 778-788.

Shipperlee, H., Taylor, J., & Wishart, J. (2009). Nursing and allied health bibliographic databases: a comparison. *Health Inform,* 18(2), 13-21.

Singer, B. (2013). Perceptions of School Nurses in the Care of Students with Disabilities. *Journal of School Nursing,* 29(5), 329–336.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis Theory Method and Research.* Sage.

Smith, J., & Noble, H. (2015). Literature Review. *Evidenced Based Nursing,* 19(1), 1-3.https://ebn.bmj.com/content/ebnurs/19/1/2.full.pdf

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis Theory Method and Research.* Sage.

Smyth, J. D., Dillman, D. A., Christian, L. M., & Stern, M. J. (2006). Comparing Check-All and Forced-Choice Question Formats in Web Surveys. *Public Opinion Quarterly,* 70(1), 66–77. https://doi.org/10.1093/poq/nfj007

Snyder, H. (2019). Literature review as a research methodology: An overview and guidelines. *Journal of Business Research,* 104, 333–339. https://doi.org/10.1016/j.jbusres.2019.07.039

Sohrabi, C., Alsafi, Z., O'Neill, N., Khan, M., Kerwan, A., Al-Jabir, A., Owhonda, G., Nwadiuto, E., Maduka,O., Alasia, D., Tobin-West, C., Ekanem, N., Okafor, C., Azi, E., Agala, V., Ojimah, C., Paul, J. M., Nria, D., Olofinuka, A-M., Ndekwu, I., Opara, C., & Newsom, C. (2020). World Health Organization Declares Global Emergency: A Review of the 2019 Novel Coronavirus (COVID-19). *International Journal of Surgery*, 76, 71-76. https://doi.org/10.1016/j.ijsu.2020.02.034

Stalker, K., & Moscardini, L. (2012). *A critical review and analysis of current research and policy relating to disabled children and young people in Scotland: A report to Scotland's Commissioner for Children and Young People.* University of Strathclyde.

Stern, C., Lizarondo., L., Carrier, J., Godfrey, C., Rieger, K., Salmond, S., Apostolo, J., Kirkpatrick, P., & Loveday, H. (2021). Methodological guidance for the conduct of mixed methods systematic reviews. *Joanna Briggs Institute (JBI) Evidence Implementation, 19* (2), 120-129.

Stewart, K., Bradshaw, J., & Beadle-Brown, J. (2018). Evaluating service users' experiences using Talking Mats®. *Tizard Learning Disability Review,* 23(2), 78-86.

Stewart, & Shamdasani, P. (2017). Online Focus Groups. Journal of Advertising, 46(1), 48–60. https://doi.org/10.1080/00913367.2016.1252288

Swift, K.D., Sayal, K., & Hollis, C. (2014). ADHD and transitions to adult mental health services: a scoping review. *Child: Care, Health & Development,* 40(6), 775–786.

Talbot, J. (2010). *Seen and Heard, supporting vulnerable children in the youth justice system.* Prison Reform Trust. YOT cover (prisonreformtrust.org.uk)

Taylor, M.J., McNicholas, C., Nicolay, C., Darzi, A., Bell, D., & Reed, J.E. (2014). Systematic review of the application of the plan–do–study–act method to improve quality in healthcare. *British Medical Journal Quality and Safety*, 23, 290–298. https://qualitysafety.bmj.com/content/qhc/23/4/290.full.pdf

Teuma, A. (2013). *Children's experiences of having a younger sibling with severe and complex special educational needs: An interpretative phenomenological analysis.* Professional Doctor of Applied Educational and Child Psychology. University of East London.

The Communications Trust. (2014a). *Involving children and young people with SLCN- A toolkit for education settings.* http://www.thecommunicationtrust.org.uk

The Communications Trust. (2014b). *Support for involving children, young people and their families.* http://www.thecommunicationtrust.org.uk

The Disability Discrimination Act. (2005). Statutory Instrument 2007 No. 1555 (C.63) Article 3. London: The Stationery Office.

Tolsgaard, M. G., Ellaway, R., Woods, N., & Norman, G. (2019) Salami-slicing and plagiarism: How should we respond? *Advances in Health Sciences Education* 24, 3–14 https://doi.org/10.1007/s10459-019-09876-7

Tuffour, I. (2017). A Critical Overview of Interpretative Phenomenological Analysis: A Contemporary Qualitative Research Approach. *Journal of Healthcare Communication,* 2(4) 52. A Critical Overview of Interpretative Phenomenological Analysis: A Contemporary Qualitative Research Approach (imedpub.com)

Tzeng, Y-F., Chiang, B.-L., Chen, Y.-H., & Gau, B.-S. (2018). Health literacy in children with asthma: A systematic review. Pediatrics and Neonatology, 59(5), 429–438. https://doi.org/10.1016/j.pedneo.2017.12.001

United Nations Convention on the Rights of the Child, Goodman, H. W., & Nurnberg, A. F. (1995). *Convention on the rights of the child: Know your rights: Translation by and for young people - children's rights in the UK.* UNICEF.

United Nations Convention on the Rights of the Child. (2009). *United Nations Convention on the Rights of the Child (Articles 2, 12 and 24).* UNICEF. http://www.unicef.org/crc/files/Right-to-Participation.pdf

Üstün T. B., Chatterji, S., Bickenbach, J., Kostanjsek, N., & Schneider, M. (2003). The International Classification of Functioning, Disability and Health (ICF): A new tool for understanding disability and health. *Disability Rehabilitation,* 25(11), 565 – 571.

Velardo, S., & Drummond, M. (2017). Emphasizing the child in child health literacy research. *Journal of Child Health Care,* 21(1), 5-13.

Vennik, F. D., van de Bovenkamp, H. M., Putters, K., & Grit, K. J. (2015). Co-production in healthcare: rhetoric and practice *Administrative Sciences,* 82(1), 150–168. https://doi.org/10.1177%2F0020852315570553

Voice, Inclusion, Participation, Empowerment Research VIPER. (2012). *What we found.* http://www.Viper.councilfordisabledchildren.org.uk

Voutilainen, L., Peräkylä, A., & Ruusuvuori, J. (2011). Therapeutic change in interaction: Conversation analysis of a transforming sequence. *Psychotherapy Research,* 21(3), 348-365. http://dx.doi.org/10.1080/10503307.2011.573509

West, M., Bailey, S., & Williams, E. (2020). *The courage of compassion: Supporting nurses and midwives to deliver high quality care.* The King's Fund. https://www.kingsfund.org.uk/topics/organisational-culture/

West, M., Collins., Eckert, R., & Chowla, R. (2017). *Caring to change: how compassionate leadership can stimulate innovation in health care.* The King's Fund. www.kingsfund.org.uk/publications/caringchange

Williams, N. (2021)*. Children's Rights Alliance England: UN Committee on the Rights of the Child List of issues prior to submission of the combined sixth and seventh reports of the United Kingdom of Great Britain and Northern Ireland.* https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbol   no=CRC%2fC%2fGBR%2fQPR%2f6-7&Lang=e

Wilson, J. M. (2003). Gantt charts: A centenary appreciation. *European Journal of Operational Research,* 149(2), 430-437.

Wilson, S.A. & Peterson, C.C. (2018). Medical care experiences of children with autism and their parents: A scoping review. *Child: Care, Health & Development,* 44(6), 807–817.

Wood, D.L. (2009). A multi-method assessment of satisfaction with services in the medical home by parents of children and youth with special health care needs (CYSHCN). *Maternal & Child Health Journal,* 13(1), 5–17.

World Health Organization. (2001)**.** *International classification of functioning, disability and health ICF EFFC.* World Health Organization. https://apps.who.int/iris/bitstream/10665/42407/1/9241545429.pdf

World Health Organization. (2005). *Young Voices Count for the World we Want in 2030.* World Health Organization. https://www.who.int/life-course/partners/global-strategy/youngvoicescount/en/

World Health Organization. (2010a). *International Classification of Disability coding system.* World Health Organization. International

Classification of Functioning, Disability and Health: Children & Youth Version, ICF-CY (who.int)

World Health Organization. (2010b). *Framework for Action on Interprofessional Education and Collaborative Practice* (No. WHO/HRH/HPN/10.3). World Health Organization. https://www.who.int/iris/handle/10665/70185

World Health Organization. (2016). *Strategizing national health in the 21st century: a handbook.* World Health Organization. https://apps.who.int/iris/handle/10665/250221

APPENDICES

A SUMMARY OF THE UN CONVENTION ON THE RIGHTS OF THE CHILD

unicef
UNITED KINGDOM

ARTICLE 1 (definition of the child)
Everyone under the age of 18 has all the rights in the Convention.

ARTICLE 2 (non-discrimination)
The Convention applies to every child without discrimination, whatever their ethnicity, gender, religion, language, abilities or any other status, whatever they think or say, whatever their family background.

ARTICLE 3 (best interests of the child)
The best interests of the child must be a top priority in all decisions and actions that affect children.

ARTICLE 4 (implementation of the Convention)
Governments must do all they can to make sure every child can enjoy their rights by creating systems and passing laws that promote and protect children's rights.

ARTICLE 5 (parental guidance and a child's evolving capacities)
Governments must respect the rights and responsibilities of parents and carers to provide guidance and direction to their child as they grow up, so that they fully enjoy their rights. This must be done in a way that recognises the child's increasing capacity to make their own choices.

ARTICLE 6 (life, survival and development)
Every child has the right to life. Governments must do all they can to ensure that children survive and develop to their full potential.

ARTICLE 7 (birth registration, name, nationality, care)
Every child has the right to be registered at birth, to have a name and nationality, and, as far as possible, to know and be cared for by their parents.

ARTICLE 8 (protection and preservation of identity)
Every child has the right to an identity. Governments must respect and protect that right, and prevent the child's name, nationality or family relationships from being changed unlawfully.

ARTICLE 9 (separation from parents)
Children must not be separated from their parents against their will unless it is in their best interests (for example, if a parent is hurting or neglecting a child). Children whose parents have separated have the right to stay in contact with both parents, unless this could cause them harm.

ARTICLE 10 (family reunification)
Governments must respond quickly and sympathetically if a child or their parents apply to live together in the same country. If a child's parents live apart in different countries, the child has the right to visit and keep in contact with both of them.

ARTICLE 11 (abduction and non-return of children)
Governments must do everything they can to stop children being taken out of their own country illegally by their parents or other relatives, or being prevented from returning home.

ARTICLE 12 (respect for the views of the child)
Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right applies at all times, for example during immigration proceedings, housing decisions or the child's day-to-day home life.

ARTICLE 13 (freedom of expression)
Every child must be free to express their thoughts and opinions and to access all kinds of information, as long as it is within the law.

ARTICLE 14 (freedom of thought, belief and religion)
Every child has the right to think and believe what they choose and also to practise their religion, as long as they are not stopping other people from enjoying their rights. Governments must respect the rights and responsibilities of parents to guide their child as they grow up.

ARTICLE 15 (freedom of association)
Every child has the right to meet with other children and to join groups and organisations, as long as this does not stop other people from enjoying their rights.

ARTICLE 16 (right to privacy)
Every child has the right to privacy. The law should protect the child's private, family and home life, including protecting children from unlawful attacks that harm their reputation.

ARTICLE 17 (access to information from the media)
Every child has the right to reliable information from a variety of sources, and governments should encourage the media to provide information that children can understand. Governments must help protect children from materials that could harm them.

ARTICLE 18 (parental responsibilities and state assistance)
Both parents share responsibility for bringing up their child and should always consider what is best for the child. Governments must support parents by creating support services for children and giving parents the help they need to raise their children.

ARTICLE 19 (protection from violence, abuse and neglect)
Governments must do all they can to ensure that children are protected from all forms of violence, abuse, neglect and bad treatment by their parents or anyone else who looks after them.

ARTICLE 20 (children unable to live with their family)
If a child cannot be looked after by their immediate family, the government must give them special protection and assistance. This includes making sure the child is provided with alternative care that is continuous and respects the child's culture, language and religion.

ARTICLE 21 (adoption)
Governments must oversee the process of adoption to make sure it is safe, lawful and that it prioritises children's best interests. Children should only be adopted outside of their country if they cannot be placed with a family in their own country.

ARTICLE 22 (refugee children)
If a child is seeking refuge or has refugee status, governments must provide them with appropriate protection and assistance to help them enjoy all the rights in the Convention. Governments must help refugee children who are separated from their parents to be reunited with them.

ARTICLE 23 (children with a disability)
A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled children and their families.

ARTICLE 24 (health and health services)
Every child has the right to the best possible health. Governments must provide good quality health care, clean water, nutritious food, and a clean environment and education on health and well-being so that children can stay healthy. Richer countries must help poorer countries achieve this.

ARTICLE 25 (review of treatment in care)
If a child has been placed away from home for the purpose of care or protection (for example, with a foster family or in hospital), they have the right to a regular review of their treatment, the way they are cared for and their wider circumstances.

ARTICLE 26 (social security)
Every child has the right to benefit from social security. Governments must provide social security, including financial support and other benefits, to families in need of assistance.

ARTICLE 27 (adequate standard of living)
Every child has the right to a standard of living that is good enough to meet their physical and social needs and support their development. Governments must help families who cannot afford to provide this.

ARTICLE 28 (right to education)
Every child has the right to an education. Primary education must be free and different forms of secondary education must be available to every child. Discipline in schools must respect children's dignity and their rights. Richer countries must help poorer countries achieve this.

ARTICLE 29 (goals of education)
Education must develop every child's personality, talents and abilities to the full. It must encourage the child's respect for human rights, as well as respect for their parents, their own and other cultures, and the environment.

ARTICLE 30 (children from minority or indigenous groups)
Every child has the right to learn and use the language, customs and religion of their family, whether or not these are shared by the majority of the people in the country where they live.

ARTICLE 31 (leisure, play and culture)
Every child has the right to relax, play and take part in a wide range of cultural and artistic activities.

ARTICLE 32 (child labour)
Governments must protect children from economic exploitation and work that is dangerous or might harm their health, development or education. Governments must set a minimum age for children to work and ensure that work conditions are safe and appropriate.

ARTICLE 33 (drug abuse)
Governments must protect children from the illegal use of drugs and from being involved in the production or distribution of drugs.

ARTICLE 34 (sexual exploitation)
Governments must protect children from all forms of sexual abuse and exploitation.

ARTICLE 35 (abduction, sale and trafficking)
Governments must protect children from being abducted, sold or moved illegally to a different place in or outside their country for the purpose of exploitation.

ARTICLE 36 (other forms of exploitation)
Governments must protect children from all other forms of exploitation, for example the exploitation of children for political activities, by the media or for medical research.

ARTICLE 37 (inhumane treatment and detention)
Children must not be tortured, sentenced to the death penalty or suffer other cruel or degrading treatment or punishment. Children should be arrested, detained or imprisoned only as a last resort and for the shortest time possible. They must be treated with respect and care, and be able to keep in contact with their family. Children must not be put in prison with adults.

ARTICLE 38 (war and armed conflicts)
Governments must not allow children under the age of 15 to take part in war or join the armed forces. Governments must do everything they can to protect and care for children affected by war and armed conflicts.

ARTICLE 39 (recovery from trauma and reintegration)
Children who have experienced neglect, abuse, exploitation, torture or who are victims of war must receive special support to help them recover their health, dignity, self-respect and social life.

ARTICLE 40 (juvenile justice)
A child accused or guilty of breaking the law must be treated with dignity and respect. They have the right to legal assistance and a fair trial that takes account of their age. Governments must set a minimum age for children to be tried in a criminal court and manage a justice system that enables children who have been in conflict with the law to reintegrate into society.

ARTICLE 41 (respect for higher national standards)
If a country has laws and standards that go further than the present Convention, then the country must keep these laws.

ARTICLE 42 (knowledge of rights)
Governments must actively work to make sure children and adults know about the Convention.

The Convention has 54 articles in total. Articles 43–54 are about how adults and governments must work together to make sure all children can enjoy all their rights, including:

ARTICLE 45
Unicef can provide expert advice and assistance on children's rights.

OPTIONAL PROTOCOLS
There are three agreements, called Optional Protocols, that strengthen the Convention and add further unique rights for children. They are optional because governments that ratify the Convention can decide whether or not to sign up to these Optional Protocols. They are: the Optional Protocol on the sale of children, child prostitution and child pornography, the Optional Protocol on the involvement of children in armed conflict and the Optional Protocol on a complaints mechanism for children (called Communications Procedure).

For more information go to
unicef.org.uk/crc/op

248

Appendix 2. NHS Ayrshire and Arran within Scotland's Health and Social Care Integration Partnerships
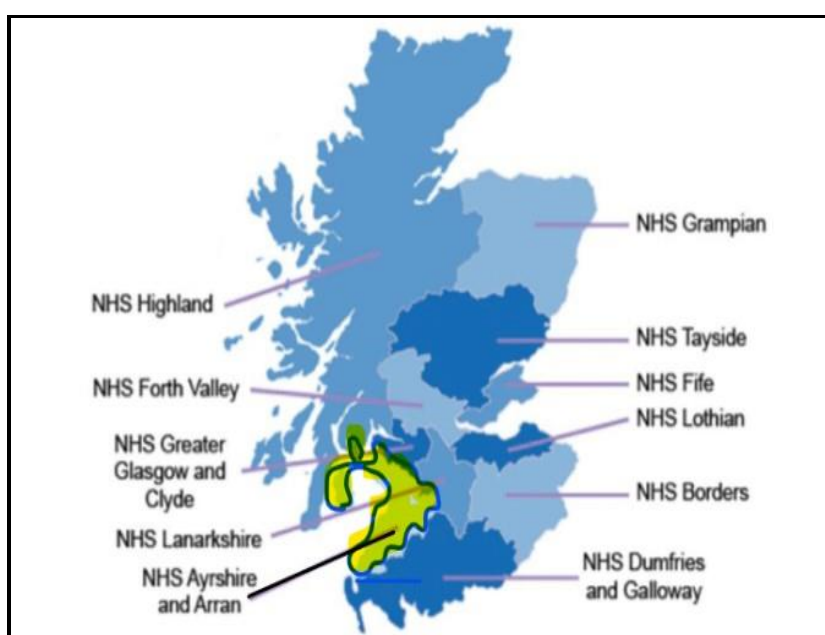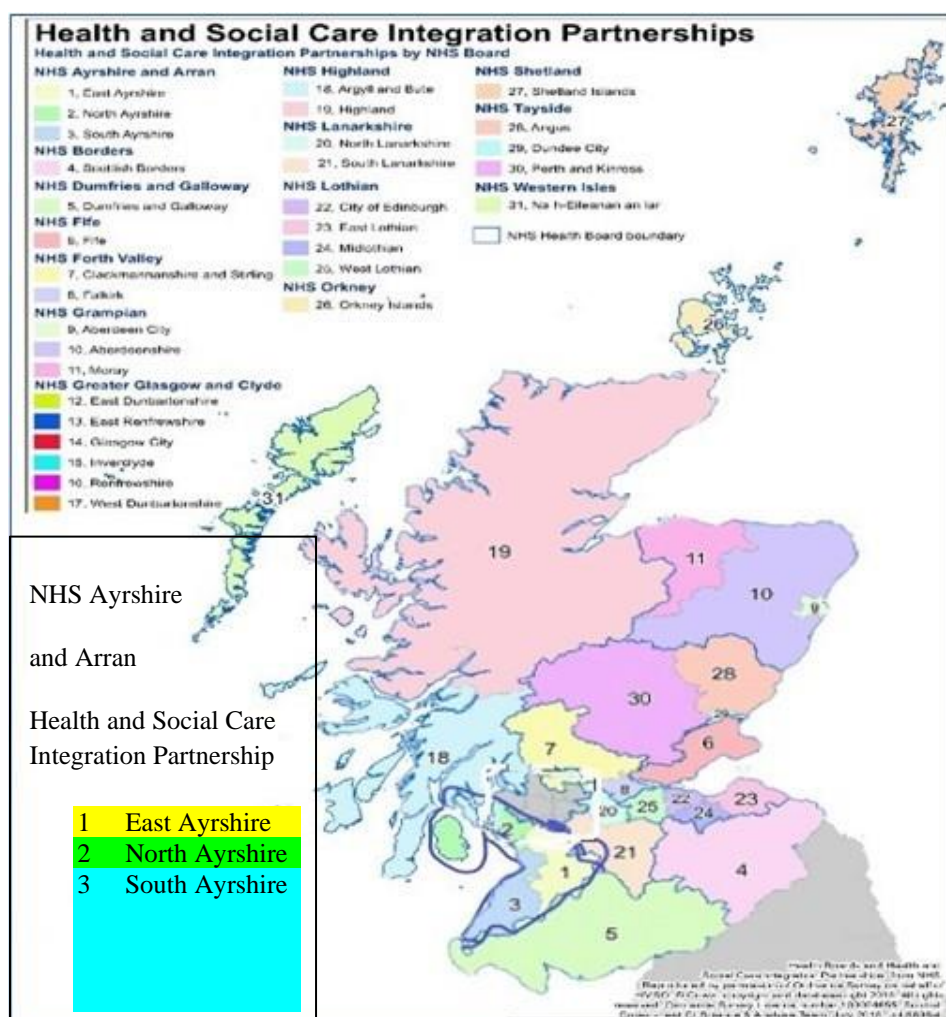
Appendix 3. Getting it right for every child (GIRFEC) National Practice Model Children and Young People (Scotland) Act 2014
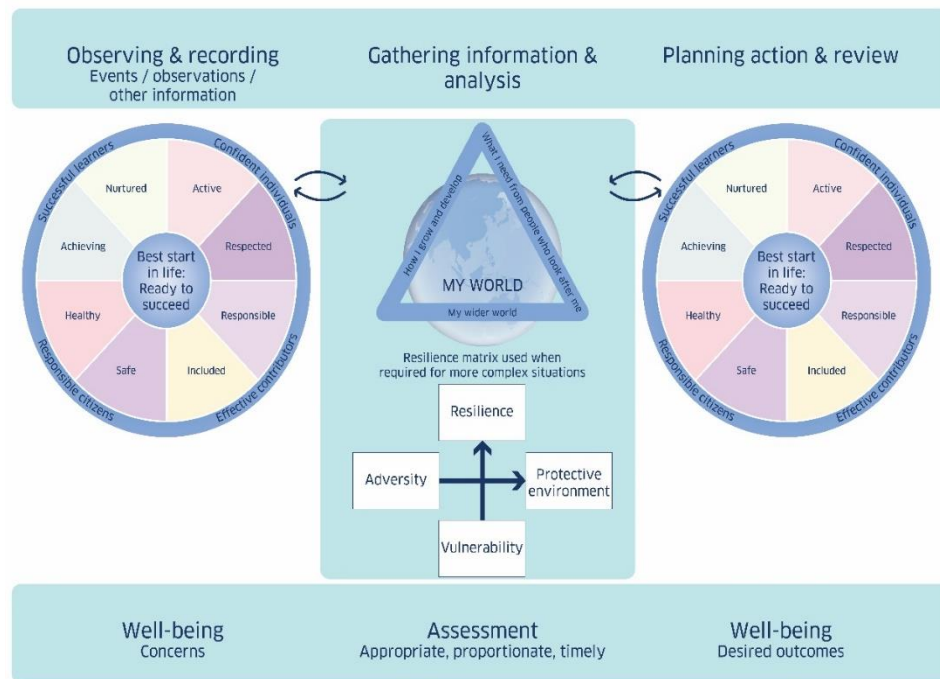
Appendix 4. ACE Pyramid- Early Deaths- chronic health and suicide
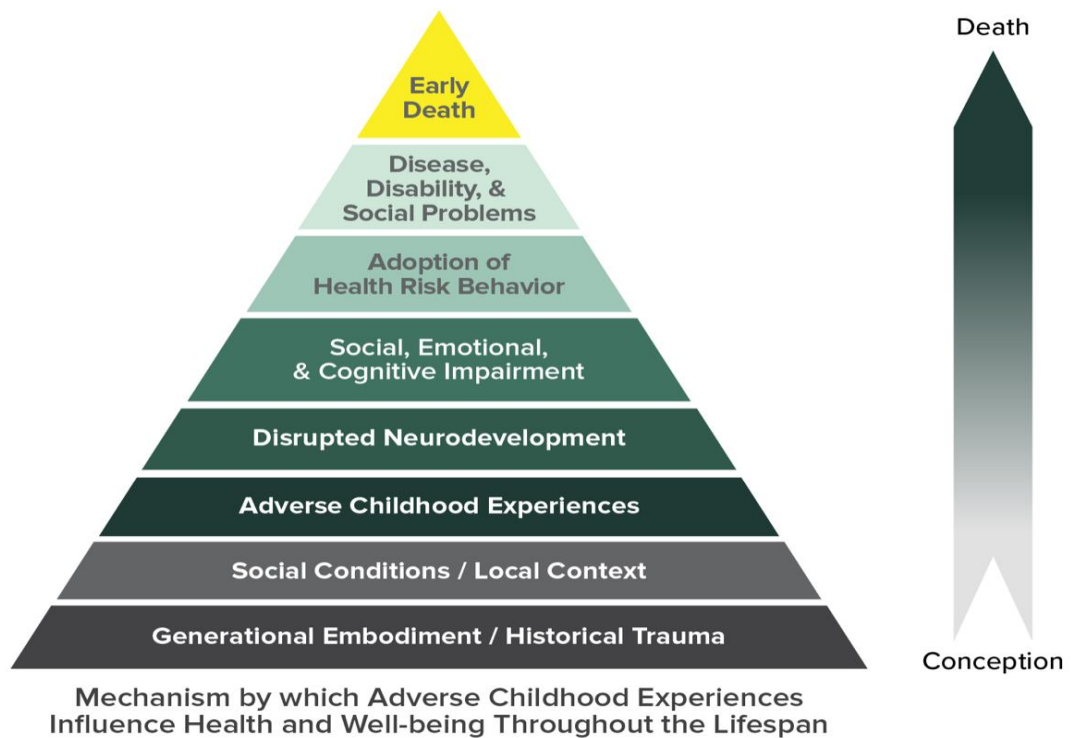
Mechanism by which Adverse Childhood Experiences
Influence Health and Well-being Throughout the Lifespan
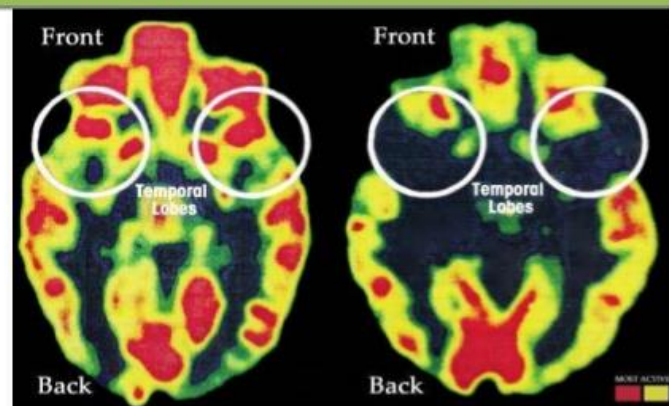
Courtesy of Dr. H.T. Chugani from the Children's Hospital of Michigan,
Wayne State University

Appendix 5. List of study documents submitted for ethical approval

IRAS Submission 16th January 2019 Jean A. Davies Professional Doctorate Student University of the West of Scotland

Mind Map and Project Plan: Preparation for research design-initial thoughts for consideration

The Letter that gives your permission. Children's Assent Letter for children aged 8 years to under 12 years. Version 4, 31st January 2019

Participant Information Sheet. Version 11 Child ages 8 to 15 years of all abilities, 31st January 2019

Participant Information Sheet. Version 10 Adult, 31st January 2019

Participant Information Sheet. Version 10a Adult accessible, 31st January 2019

Cover letter for Research Project (Version 2)

Confirm a favourable ethical opinion

Parent or Guardian Participant Consent Form Accessible. Version 1,
4th January 2019

Participant Consent Form Parent or Guardian Individual Interview.
Version 2, 12th January 2019

Child Participant Consent Form (12- 15 years)Version 8, 31st January 2019

Thank you letter to participants for contribution to Research Project. Version 1, 17th November 2018

Appendix 6. Gantt Chart April 2019 to September 2020

April May 2019	June July August	September October	November December	January February 2020	March April	May June	July August	September
Revisit the literature review	Transcribe interviews		Write Discussion chapter		Quality review all chapters	Act on feedback	Submit full chapters to Research Supervisors for review	Viva
Submit completed chapters of thesis to Research Supervisors: Methodology and Ethics	Analyse each transcript using advice in Smith, Flowers & Larkin (2012)	Continue familiarisation and analysis of transcripts		Write up Findings and Conclusion chapters		Quality review all chapters	Meet with Research Supervisors	Results
Collect data by completing 15 research interviews		Develop emergent themes searching for patterns/ connections	Submit full chapters to Research Supervisors for review		Check References and Appendices		Act on feedback	Resubmit if necessary
Listen to content of interviews, familiarise with data and initial noting anything of interest		Write Analysis and Results chapters	Meet with Research Supervisors Act on feedback	Meet with Research Supervisors Act on feedback	Submit full chapters to Research Supervisors for review	Meet with Research Supervisors Act on feedback	Resubmit for review Amend and submit completed thesis	Results

Appendix 7. Amended Gantt chart September 2020 to January 2022

September October 2020	November December	January February	March April	May June	July August	September	October November	December 2021 January 2022
Revisit the literature review Submit completed Methodology and Ethics chapters for review	Transcribe interviews Analyse each transcript-	Develop emergent themes searching for patterns/ connections	Write Discussion chapter	Write up Findings and Conclusion chapters	Quality review all chapters	Act on feedback	Submit chapters to Research Supervisors	Viva
Collect data by completing 15 research interviews	Continue familiarisation and analysis of transcripts	Write Analysis and Results chapters	Meet with Research Supervisors Act on feedback	Meet with Research Supervisors Act on feedback	Check References and Appendices	Quality review all chapters	Meet with Research Supervisors Act on feedback	Results Resubmit if necessary
Listen to content of interviews, familiarise with data and initial noting anything of interest		Submit full chapters to Research Supervisors for review			Submit full chapters to Research Supervisors for review	Meet with Research Supervisors Act on feedback	Resubmit thesis for review Amend and submit	Results

Appendix 8. Participant Information Sheet Version 11 children aged 8 to 15 years all abilities 4th January 2019

UWS UNIVERSITY OF THE
WEST *of* SCOTLAND

Hello, my name is Jean Angela Davies I am currently doing a planned piece of research work as part of my Professional Doctorate studies with the

University of the West of Scotland and this is a picture of me   My

contact details   01563 825652

b00297284@studentmail.uws.ac.uk

Title of Project:

What are the views and experiences of children with complex health needs and those of their families on the provision of healthcare?

You are invited to take part in the above study and before you decide if you want to take part it is important for you to understand why the research is being carried out and what it will involve.

Please take time to read everything carefully and talk to others about it if you wish. Please contact Jean Davies on 01563 825652 if you want to know more about the project.

What is the purpose of the project?

I want to find about your experiences of healthcare.

I would like to know about your complex health needs and if these affect your daily life.

The kinds of things I will ask you about are: -

- Your complex health needs

- Your experiences of healthcare

- Your typical day at school

- Any experiences you have had in hospital

- Anything else that you think is important about your experience of healthcare

Why have I been invited?

You have been invited because:
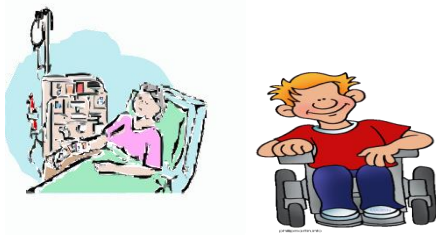
- You are a child aged between 8 years and 15 years

- You have a complex health need, for example, a gastrostomy and use a tube to help with feeding, or a tracheostomy and a tube to help with breathing

- You have help with your complex health needs

Do I have to take part?

- No, you do not have to take part. You are free to decide whether or not you wish to take part in the study.

Deciding to take part.

If you decide to take part please contact Jean Davies, the researcher, within 2 weeks of receiving this Participant Information Sheet. Jean can be contacted on 01563 825487.

Jean Davies can also be contacted through the Administrator at Ayrshire Maternity Unit, Crosshouse, Kilmarnock, KA2 0BE. Telephone number 01563 825487.

If you decide to take part, you will be asked to sign a form.

Deciding to leave the study.

If you decide to leave the study, anything collected about you will be destroyed.

Any healthcare support you get will not be affected if you decide not to take part in the study.

What will happen to me if I take part?

You will be asked to talk to Jean and this is called having an interview.
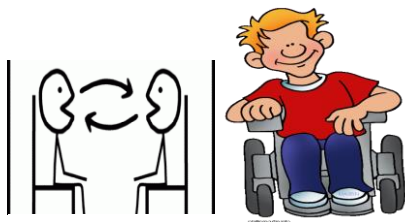
Who will be present at the interview?

You may decide to have your interview with Jean on your own, or that you would like your parent or guardian, helper or interpreter to be with you at your interview. Jean will make sure that everyone agrees about who will be at the interview and that everyone understands that children over 12 years old can make decisions for themselves if they have all the information they need to understand what is being asked of them.

If you need help with your interview because you communicate through an interpreter, British Sign Language, Talking Mats® or Makaton, your helper will be at your interview and your interview will be video recorded to ensure that your opinions are properly represented.

What happens in an individual interview?

Jean will meet with you so that you can tell her your story and talk to her about your health needs and care.

- The interview will take about 30 minutes at your home or at your school, wherever is best for you and your parent or guardian.

- Jean will say hello to you and will make you comfortable. You can let Jean know if you wish to stop or have a break and a drink.

- Your story will be recorded on tape or on an iPad with your permission. Written notes, called fieldnotes, can be taken of your interview (if you prefer).

- You can talk, use drawings, photos or something else, for example, Talking Mats®, British Sign Language, Makaton, or an interpreter, whichever way is best for you to tell your story.

- Consent is needed for the video recording of interviews where gestures (signs), pictures and symbols are used as the main methods of communication. These interviews are known as gestural-based interviews. Gestural based interviews use Talking Mats®, British Sign Language or Makaton and can include where help is given through an interpreter. Your interview will be video recorded to ensure that your opinions are properly represented.

- The recordings and fieldnotes will be privately stored on equipment at the university.

- The equipment will be kept in a locked room

- The recordings and fieldnotes will be destroyed after they have been used in the study report.
- Jean will not put your name in her research report or any other report or document connected with the study.
  This is to protect you and more about this can be found in the General Data Protection Regulations and Data Protection Act (GDPR and DPA, 2018).

- What you tell Jean is private unless you tell her something that worries her about you being harmed or might cause harm to you or others.
- If Jean is worried about harm or the risk of harm to you or others, these will be passed on to another person who might make further inquiries and might need to take action on the concerns. NHS Ayrshire & Arran Child Protection Team provide help and support for children who may be at risk or harm and Jean will contact this team for advice if she is worried.

What are the possible harms or risks of taking part in the study?

There are no known harms or risks to taking part in the study and care will be taken for your safety, comfort and security during the study. For example, you can stop the interview at any time if you are worried about anything or if you become tired, distressed, uncomfortable or upset. Jean will support you at the time and will get additional help for you from the NHS Health team if you need it.

What are the possible benefits of taking part?

You will be helping Jean to find out about children and their parents or guardians' experiences of healthcare.

The study may add to your knowledge about what it is like to live with and manage your

complex health needs and how this affects your healthcare. This information could make a

difference to how healthcare is provided in the future for children with complex health needs and their families.

What if something goes wrong?
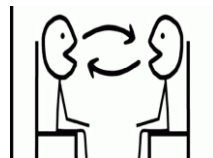
Care will be taken for your safety, comfort and security but you can stop the interview at any time if you are worried about anything, for example if you are tired, uncomfortable or upset.

You will have help straight away if you need it from people who know how to help you. There is a local complaints team in NHS Ayrshire & Arran, the Patient Relations and Complaints Department. Their address is PO Box 13, Eglinton House, Ailsa Hospital, Ayr, KA6 6AB. The telephone number is 01292 513620 and the email address is complaintsteam@aapct.scot.nhs.uk

If you think something is wrong about the study you can call Professor Rankin at the University of the West of Scotland on 0141 849 4274 or the Patient Advice & Support Service www.cas.org.uk   0800 9172127

The NSPCC has a complaints procedure and any complaints about a study can be made to the NSPCC.

You can email comments@nspcc.org.uk or call 020 7825 2500 and ask to speak to someone at NSPCC. Tell them that the name of the project is:

What are the views and experiences of children with complex health needs and those of their families on the provision of healthcare?

Please tell NSPCC your full name, contact details, and let them know how you would like to be contacted.

You could also write to the NSPCC Information Service at: Weston House 42 Curtain Road London EC2A 3NH

NSPCC's complaints' procedures can be found at: www.nspcc.org.uk/fighting-for-childhood/about-us/contact-us#complaints

What will happen to the results of the study?

Jean will send you a 'Thank you' letter for taking part in the study and a letter about what people said in the study report. The report will let people know about health services for children and their families.

Who is doing the research?

 The research is being done by Jean A. Davies, Professional Doctorate student at the University of the West of Scotland.

Who has looked at the study?

The study has been looked at by the University of the West of Scotland ethics committee.

Who do I get in touch with about the study?

If you would like to speak to someone other than Jean about the study, please call Professor Rankin at the University of the West of Scotland on 0141 849 4274.

Thank you for reading the Participant Information sheet and if you want to take part, Jean will ask you to sign an assent form if you are aged 8 years and not 12 years yet or a consent form if you are aged 12 years to 15 years.

You will be given a signed copy of your assent or your consent form.

Thank you again for taking the time to read this information sheet

Jean Angela Davies

Appendix 9. Participant Information Sheet (PIS) version 10 Adult

31st January 2019

Hello, my name is Jean Angela Davies and this is a picture of me

I am currently doing a planned piece of research work as part of my Professional Doctorate studies with the University of the West of Scotland

My contact details   b00297284@studentmail.uws.ac.uk   01563 825652

Title of Project:

A qualitative study to explore the views and experiences of children and young people with complex health needs and disabilities, and those of their families and carers on the healthcare services provided for them.

You are invited to take part in the above study and before you decide it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and to discuss it with others if you wish. Please contact Jean Davies on 01563 825652 if you would like more information about the project.

What is the purpose of the project?

In this project I want to find about you and your family's experiences of health care services. That is when you go a hospital or clinic to see a doctor, nurse or someone else.

I want to find out:

- about you
- how you would describe yourself and your health
- how you let someone know what you need
- how you feel when you ask someone something about your health
- how you feel when you see someone about your health

Why have I been invited?

You have been invited because you are a child or young person between the ages of 3 years and 19 years who has a complex health need or disability and you receive healthcare services.

Do I have to take part?

No, you do not have to take part. It is up to you to freely decide whether or not you wish to take part in the study. Once you have read all the information about the study and have understood everything that is involved in taking part you can decide whether to agree to participate or not.

If you decide to take part please contact Jean Davies, the researcher, within 2 weeks of receiving this Participant Information Sheet and the dated Cover letter. Jean, the researcher, will answer any questions you have and will ask you to sign a consent form. Children, young people and parents, guardians and carers will have separate consent forms and parents, guardians and carers' permission will be asked for before children and young people are asked to agree to the study, known as assent, and to then sign their consent forms.

You can withdraw from and leave the study at any time without giving a reason even if you agreed to take part and signed a consent form. If you leave the study you have the right to ask that any information collected about you be destroyed.

What will happen to me if I take part?

You will be invited to an individual interview.

Individual interview:

I would really to like to meet with you and your family so that we can talk about your healthcare experiences.

You can talk, use drawings, photos or something else that you think would be the best way to describe your thoughts and experiences.

The meeting will probably take about 30 minutes and would be held in a place convenient for you and your family. For example, at your local Children's centre, Community centre, at your home or at your school, whichever choice is best for you and your family. The interviews will be audio or video recorded with your permission.

What are the possible disadvantages and risks of taking part in the study?

There are no known risks or disadvantages to taking part in the study.

What are the possible benefits of taking part?

You will be helping the researcher to gather information about children, young people, parents, guardians and carers' experiences of healthcare which could influence how healthcare is provided in the future for children and young people with complex health needs and disabilities.

What if something goes wrong?

All care will be taken for your safety, comfort and security but you can ask to leave the focus discussion or stop the interview at any time if you are concerned about anything, for example if you or your child becomes tired, uncomfortable or upset. Immediate support for any problem arising will be given and further help will be available from persons with knowledge and skills appropriate to supporting children, young people, their parents, guardians and carers.

If you have any concerns or complaints about the way you have been approached or treated during the study, please contact Professor Jean Rankin at the University of the West of Scotland on 0141 849 4274 or the Patient Advice & Support Service www.cas.org.uk   0800 9172127

Will my taking part in the study be kept confidential?

The researcher will adhere to General Data Protection Regulation (GDPR, 2016), the Data Protection Act (1998) and the NHS and University policies of Confidentiality.

All information collected about you during the study will be anonymised by the researcher. This information will be kept securely in a locked fire-resistant cabinet and password protected personal computer accessible only by the researcher within researcher's office. The audio or video recording of your interview will be used by the researcher to analyse the information and no one else will have access to this.

A unique identifier will be used for you and this information will be anonymised. The audio or video recordings will be destroyed once the transcripts (a written or printed version of the information originally gained). Other information will be kept securely for 3 years following the study and then will be destroyed.

What will happen to the results of the study?

A summary of the findings of the findings of the study will be made available to you.

The findings will contribute to the evidence and information available about health services for children and young people and their families and carers which will

then be appropriately shared with healthcare service providers by written report, dissertation and publication.

Who is organising and funding the research?

The research is being organised by Jean A. Davies, Professional Doctorate student at the University of the West of Scotland. There are no additional funds available for this study.

Who has reviewed the study?

The study has been approved by the University of the West of Scotland ethics committee.

Thank you for taking the time to read this information,

Jean Angela Davies

If you would like to contact someone other than the researcher for further information, please call Professor Jean Rankin at the University of the West of Scotland on 0141 849 4274.

Thank you again for taking the time to read the Participant Information sheet and if you have decided to participate you will also be given a signed copy of the consent form.

Appendix 10. Participant Information Sheet (PIS) version 10a Adult accessible 4th January 2019

UWS UNIVERSITY OF THE WEST of SCOTLAND

Hello, my name is Jean Angela Davies and this is a picture of me

I am currently doing a planned piece of research work as part of my Professional Doctorate studies with the University of the West of Scotland

My contact details ✉ b00297284@studentmail.uws.ac.uk 📞 01563 825652

Title of Project:

What are the views and experiences of children with complex health needs and those of their families on the provision of healthcare?

You are invited to take part in the above study. Before you decide if you want to take part it is important for you to understand why the research is being carried out and what it will involve.

Please take time to read the following information carefully and to discuss it with others if you wish. Please contact Jean Davies on 01563 825652 if you would like more information about the project.

What is the purpose of the project?

I want to find about you and your family's experiences of healthcare.

I would like to know about your child's complex health need and if this affects your family's daily life.
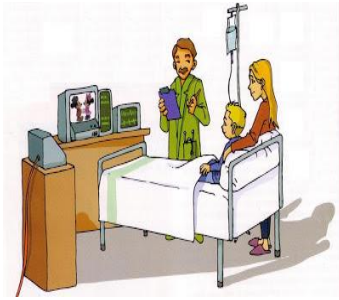
The kinds of things I will ask you about are: -

- Your child's complex health needs
- Your child's and your experiences of healthcare with your child
- Your child's typical day at school
- Any experiences you have had in hospital with your child
- Anything else that you think is important about your child's and your experience of healthcare

Why have I been invited?

You have been invited because:

- You are the parent or guardian of a child aged between 8 years and 15 years
- Your child has a complex health need, for example, a gastrostomy and uses a tube to help with feeding, or a tracheostomy and a tube to help with breathing
- Your child receives healthcare to help them with their complex health needs

Do I have to take part?

  No, you do not have to take part. It is up to you to freely decide whether or not you wish to take part in the study.

Deciding to take part.

If you decide to take part please contact Jean Davies, the researcher, within 2 weeks of receiving this Participant Information Sheet.

Jean Davies can be contacted on 01563 825487 or via the Administrator, Ayrshire Maternity Unit, Crosshouse, Kilmarnock KA2 0BE.

 If you decide to take part, you will be asked to sign a form.
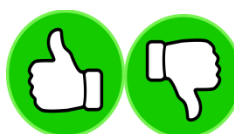
Deciding to leave the study.

You can withdraw from and leave the study at any time without giving a reason, even if you already agreed to take part.

If you decide to leave the study, any information collected about you will be destroyed.

Any healthcare support your child gets will not be affected if you decide not to take part in the study.

What will happen to me if I take part?

You will be invited to an individual interview.

Who will be present at the interview?

You may decide to have your interview with Jean on your own or with your child if preferred, your child's helper or interpreter can also be with you at your interview.

Jean will make sure that everyone agrees about who will be at the interview and that everyone understands that children over 12 years old can make decisions for themselves if they have all the information they need to understand what is being asked of them.

If you as a parent or guardian need help with your interview because you communicate through an interpreter, British Sign Language, Talking Mats® or Makaton, your helper will be at your interview and your interview will be video-recorded to ensure that your opinions are properly represented.

What happens in an individual interview?

Jean will meet with you and your child so that you can talk about your healthcare experiences.

- The interview will take about 30 minutes and would be held in a place convenient for you and your child. For example, at your home or at your school, wherever is best for you and your child.
- Introductions will take place and you will be made comfortable.
- You will be asked to let the researcher know if you wish to stop, have a comfort break or refreshments during the interview
- The interviews will be audio or video-recorded on tape or an iPad with your permission. Written notes, called fieldnotes, may also be taken during your interview.

- Your child can talk, use drawings, photos or something else, for example, Talking Mats®, British Sign Language or an interpreter, whichever way is best to describe their thoughts and experiences

- Consent is needed for the video recording of interviews where gestures (signs), pictures and symbols are used as the main methods of communication. These interviews are known as gestural-based interviews. Gestural based interviews use Talking Mats®, British Sign Language or Makaton and can include where help is given through an interpreter. Your child's interview will be video-recorded to ensure that their opinions are properly represented.

- The recordings and fieldnotes will be stored on encrypted equipment at the university especially for the purposes of the study.

- The equipment will be kept in a locked room

- The recordings and fieldnotes will be destroyed after they have been used in the study report.

- The researcher will anonymise your data in the report as required by the General Data Protection Regulations and Data Protection Act (GDPR and DPA, 2018).

- The information given to the researcher is private unless you tell the researcher something that raises a concern that there is harm, or a risk of harm to you or others

- If the researcher is worried about harm or the risk of harm to children or others, those concerns will be passed on to an appropriate professional who may need to make further inquiries and to take action on the concerns.

What are the possible disadvantages and risks of taking part in the study?

There are no known risks or disadvantages to taking part in the study and care will be taken for your safety, comfort and security during the study. For example, you can stop the interview at any time if you are worried about anything or if you become tired, distressed, uncomfortable or upset. Jean will support you at the time and will get additional help for you from the NHS Health team if you need it.

What are the possible benefits of taking part?

You will be helping the researcher to gather information about children and their parents or guardians' experiences of healthcare.

The study may add to your knowledge about what it is like to live with and manage your child's complex health need or needs and how this affects the healthcare provided.

This information could influence how healthcare is provided in the future for children with complex health needs and their families.

What if something goes wrong?

There is a local complaints team in NHS Ayrshire & Arran, the Patient Relations and Complaints Department. Their address is PO Box 13, Eglinton House, Ailsa Hospital, Ayr, KA6 6AB. The telephone number is 01292 513620 and the email address is complaintsteam@aapct.scot.nhs.uk

If you have any concerns or complaints about the way you have been approached or treated during the study, please contact Professor Rankin at the University of the West of Scotland on 0141 849 4274 or the Patient Advice & Support Service www.cas.org.uk   0800 9172127

The NSPCC has established a complaints procedure and any complaints about a study can be made to a NSPCC member of staff, volunteer, or local office. Alternatively, please email comments@nspcc.org.uk, or call 020 7825 2500 and ask to speak to an NSPCC staff member,

Further details of NSPCC's complaints' procedures can be found at: www.nspcc.org.uk/fighting-for-childhood/about-us/contact-us#complaints

What will happen to the results of the study?

A 'Thank you' letter for taking part in the study and a summary of the findings of the study will be made available to you.

The findings will contribute to the evidence and information available about health services for children and their families which will then be appropriately shared with healthcare service providers by written report, dissertation and publication.

Who is organising and funding the research?

The research is being organised by Jean A. Davies, Professional Doctorate student at the University of the West of Scotland. There are no additional funds available for this study.

Who has reviewed the study?

The study has been approved by the University of the West of Scotland ethics committee.

Who to contact about the study?

If you would like to contact someone other than the researcher for further information, please call Professor Rankin at the University of the West of Scotland on 0141 849 4274.

Thank you for taking the time to read the Participant Information sheet and if you have decided to participate, you and your child will be asked to sign an assent form or a consent form and you will be given a signed copy of the assent or the consent form.

Thank you again for taking the time to read this information sheet,

Jean Angela Davies

Appendix 11. Cover letter for research project (Gatekeepers)

UWS UNIVERSITY OF THE
WEST of SCOTLAND

18th May 2018

Jean A. Davies
Clinical Nurse Manager Paediatrics
Room 101B Children's Unit
University Hospital Crosshouse
Kilmarnock
KA2 0BE

✉ b00297284@studentmail.uws.ac.uk   ☎ 01563 825652

Reference: Cover letter for Research Project

Title of Project:

A qualitative study to explore the views and experiences of children and young people with complex health needs and disabilities, and those of their families and carers on the healthcare services provided for them.

Dear …………………..,

I am writing to you because I am currently undertaking a planned piece of research work as part of my Professional Doctorate studies with the University of the West of Scotland and would be most grateful for your support with this study.

Children, young people their families and carers will be invited to take part in the above
study and before they decide it will be important that it is fully understood why the research
is being carried out and what it will involve.
I have enclosed a Participant Information sheet which explains this and would
be very grateful if you could please take time to read the information carefully
and to discuss it with your colleagues and others if you wish.

Please contact me, the researcher Jean Davies on 01563 825652 if you are able to offer support for the study or you would like more information about the project.

Thank you for taking the time to read this letter.

Yours sincerely and kind regards,

[signature: J a Davies]

Jean Angela Davies

Appendix 12. The letter that gives your permission (Assent)

The Letter that gives your permission. Children's Assent Letter for children aged 8 years to under 12 years. Version 3, 4th January 2019

Participant number ☐   Name of Researcher Jean Angela Davies

Title of Project: What are the views and experiences of children with complex health needs and those of their families on the provision of healthcare?

To show your permission you can put your initials in each of the boxes below:

1. I have read the information letter with Jean, the person who is doing the study and Jean has answered all my questions about the study. I have read with Jean the Participant Information Sheet dated the 4th of January 2019 Version 10 and have been able to ask questions and these have been answered.

 👍 ☐ 👎 ☐

2. I know that I do not have to take part in the study if I do not want to, even if my parent or guardian agreed.
   If I take part I know that I can stop and leave the study at any time without saying why and I will not be asked to take part again. This will not make any changes to my healthcare or my rights as a child.

 👍 ☐ 👎 ☐

3. I know that Jean will video-record my interview on her research iPad.
   I know that what I tell Jean is private and that my real name will not be used in Jean's report written about the study. I know my video-recording will be deleted once Jean has written her report.
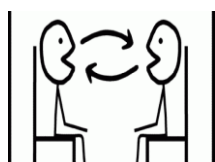
4. If I tell Jean something that makes her think that someone might hurt me or someone else, I know that Jean will have to protect me by passing on what is said to a suitable person who can help me. I know that Jean or another suitable person will help me if I become upset.

5. I want to take part in the study and to talk to Jean about my healthcare.

Name of Child	Signature	Date
_____	_____	_____

Note: Parent or Guardian's consent will also be required for this age group

Name of Researcher (and the name of the interpreter or signer if present and has participated in the consent process).

Name	Signature	Date
_____	_____	_____
_____	_____	_____

Parent or Guardian's name	Signature	Date
_____	_____	_____

Appendix 13. Child Participant Consent Form (12- 15 years) all abilities Version 8, 31ˢᵗ January 2019

Child Participant Consent Form (12- 15 years) Version 8, 31ˢᵗ January 2019

Participant number [ ]   Name of Researcher Jean Angela Davies

Title of Project:

What are the views and experiences of children with complex health needs and those of their families on the provision of healthcare?

Please initial each of the boxes below to show your agreement and consent:

1. I agree that I have read and understood the Participant Information Sheet dated the 31ˢᵗ of January 2019 Version 11 for the above study. I have been able to ask questions about the study and my questions have been fully answered.

2. I understand that it is my choice whether to take part in the study or not. I can stop
   and leave the study at any time, without giving any reason and this will not change
   or affect my health care or my rights as a child.

3. I agree for my interview to be video-recorded.

4. If something I tell the researcher makes her think I am at risk of harm, or others might be
at risk of harm, I know the researcher will have to protect me by passing on what is said
to a suitable person who can help me. The researcher or another suitable person will
help me if I become upset.

5. I agree to take part in the study and to speak to the researcher about my healthcare.

Name of Child   Signature   Date

_____   _____   _____

Note: Parent or Guardian's consent will also be required for this age group

Name of Researcher (and name of interpreter or signer if present and has participated in the consent process).   Signature   Date

_____   _____   _____

_____   _____   _____

Parent or Guardian's name   Signature   Date

_____   _____   _____

Participant number ☐   Name of Researcher: Jean Angela Davies

Title of Project:

What are the views and experiences of children with complex health needs and those of their families on the provision of healthcare?

Please initial each of the boxes below to show your agreement and consent:

1. I confirm that I have read and understand the Participant information Sheet Version 10 Adult, 31st January 2019 for the above study and have had the opportunity to ask questions and have had my questions answered to my satisfaction.   ☐

2. I understand that my child's participation is voluntary and that I am free to withdraw them at any time, without giving any reason, without their medical care or legal rights being affected.   ☐

3. I agree for my child's interview to be video-recorded   ☐

4. I agree for my child to take part in the above study.   ☐

Name of Parent or Guardian   Signature   Date

_____   _____   _____

Name of Researcher

(and interpreter or signer if

present and taking part in the

consent process).   Signature   Date

_____   _____   _____

1 copy for parent or guardian and 1 copy for researcher when completed.

Appendix 15. Participant Consent Form Parent or Guardian Individual Interview accessible version 2 12th January 2019

UWS UNIVERSITY OF THE WEST *of* SCOTLAND

Participant number ☐   Name of Researcher: Jean Angela Davies

Title of Project:

A qualitative study to explore the views and experiences of children and young people with complex health needs and disabilities, and those of their families and carers on the healthcare services provided for them.

Please initial each of the boxes below to show your agreement and consent:

1. I confirm that I have read and understand the Parent, Guardian or Carer Participant Information Sheet dated .... Version 4 for the above study and have had the opportunity to ask questions and have had those questions answered to my satisfaction.

👍 ☐   👎 ☐

I understand that my child's participation is voluntary and that I am free to withdraw them at any time, without giving any reason, without their medical care or legal rights being affected.

I understand that sections of any of my child's medical notes may be looked at by responsible individuals from NHS Ayrshire & Arran or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my child's records.

2. I agree for my child's views to be audio or video recorded.

3. I agree for my child to take part in the above study.

Name of Parent Guardian or   Date   Signature

Carer

_____   _____   _____

Name of Researcher

(or person taking consent   Date   Signature

if different from researcher

e.g. interpreter or signer).

_____   _____   _____

1 copy for parent, guardian or carer and 1 copy for researcher when completed.

Appendix 16. Thank you letter to participants

UWS UNIVERSITY OF THE
WEST *of* SCOTLAND

Jean A. Davies

17th November 2018   Care of the Administrator

Ayrshire Maternity Unit

Crosshouse

Kilmarnock

KA2 0BE

✉ b00297284@studentmail.uws.ac.uk   ☎ 01563 825487

Reference: Thank you letter to participants for contribution to Research Project. Version 1, 17th November 2018

Title of Project:

A qualitative study to explore the views and experiences of children with complex health needs and those of their families on the provision of healthcare.

Dear …………………,

I am writing to thank you for your valuable contribution to the study which explored the views and experiences of children who have complex health needs and those of their families on the provision of healthcare.

This piece of research work was completed as part of my Professional Doctorate studies with the University of the West of Scotland and I am very grateful for the time you have taken to take part in this study.

Very little research has been done previously with children who have complex health needs and because of your generous contribution to the study there is now more information available to inform the providers of healthcare what matters to children and their families regarding their health.

Your taking part in the study is confidential and the recordings made of your interview will be destroyed once the information has been written up (transcribed) into my research report. Your name will not be published in the report or used in or connected to any other report or publication. A copy of the report will be available for you if you wish to receive one.

I hope that you found the experience of taking part and giving your views worthwhile but if you felt upset or distressed in any way during your interview experience and this is something you could not talk about at the time but would like to speak to someone about it now, there is help and support available.

You can contact the researcher, Jean Davies through the Administrator of Ayrshire Maternity Unit, Crosshouse, Kilmarnock, KA2 0BE telephone 01563 825487 or Professor Jean Rankin at the University of the West of Scotland, Paisley Campus,

High Street, Paisley, Renfrewshire PA1 2BE telephone 0141 8494274.

If you prefer to speak to someone else support for children can be found at Childline, the national children's charity that provides a free and confidential counselling service. Childline's details are:

Childline freephone 0800 1111 Website: www.childline.org.uk

If you have concerns about any aspect of the study, or complaints about the way the study was undertaken, please note that the NSPCC has established a complaints procedure. Your complaint can be made to any NSPCC member of staff, volunteer, or NSPCC local office.

Alternatively, please email comments@nspcc.org.uk or call 020 7825 2500 and ask to speak to an NSPCC staff member and inform them that the name of the project is:

'A qualitative study to explore the views and experiences of children with complex health needs and those of their families on the provision of healthcare'.

To help the NSPCC respond to your comment or complaint effectively, please give your full name, contact details and let NSPCC know how you would like to be contacted.

You can also write to the NSPCC Information Service at: Weston House 42 Curtain Road London EC2A 3NH

Further details of the NSPCC complaints' procedures can be found at: www.nspcc.org.uk/fighting-for-childhood/about-us/contact-us#complaints

The NSPCC website can also be used to leave feedback on what has gone well.

Thank you again for being part of the study and for taking the time to read this letter.

Yours sincerely and kind regards,

Jean Angela Davies (signature)

Jean Angela Davies

Appendix 17. Confirmation of Favourable Opinion February 2019

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow
and Clyde

Professor Jean Rankin
University of the West of Scotland
High Street
Paisley
PA1 2BE

West of Scotland REC 4
Research Ethics
Clinical Research and Development
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow
G3 8SJ
(Formerly Yorkhill Childrens Hospital)

Date   6 February 2019
Direct line   0141 232 1808
E-mail   WoSREC4@ggc.scot.nhs.uk

Dear Professor Rankin

Study title: A qualitative study to explore the views and experiences
                          of children with complex health needs and those of their
                          families on the provision of healthcare.
REC reference: 18/WS/0228
Protocol number: 253492
IRAS project ID: 253492

Thank you for your submission of 6 February 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of

Appendix 18. Published original research regarding children with complex health needs, disabilities, and their families

Author Date and Origin	Research title and interest	Ethical Issues and Recruitment Population	Methodology and Method	Key Findings and Recommendation	Limitations
Bishop 2017 EThOS 801477 Doctoral Thesis UK H	Investigating prevalence and healthcare use of children with complex healthcare needs using data linkage: a study using multi-ethnic data from an ongoing prospective cohort, the Born in Bradford project CYP CA	Approved HBE LEC CYP DIS M CYP CA 0 to 5 years	Quantitative Review of PC and HB data	CA prevalent in children born to M over 34 years of age CRI significant in Bradford multi-ethnic population. FS	Coding systems Limited range of health conditions applied for at LEC HBE Time and resources

Davys et al. 2017 UK England	Fathers of adults who have a learning disability: Roles, needs and concerns CYP DIS Fathers	Repeated requests to Gatekeepers Adults DIS 7 Fathers M G	Qualitative IPA SSI	Fathers have difficulty with open emotion Concerns about CYP future Value family support Male stereotype FS	Small sample size Findings difficult to generalise
Diffin et al. 2018 UK Northern Ireland	The usefulness and acceptability of a personal health record to children and young people living with a complex health condition: A realist review of the literature. Personal Health Record	None noted	CHN DIS LLC	Realist, theory driven literature review FS LLC Search of 6 Databases 1946- 2018 9 articles reviewed CYP Personal Health Records have multiple benefits relating to self-advocacy, increased communication and empowerment	One study found LLC

Graham 2012 EThOS 590047	Children with Disabilities and Their families: Team working and the role of the key worker	Approved HBE LEC	Qualitative Grounded Theory FG	Delivery of services influenced by professional culture causes barriers No uniformity across providers, restrictive Inflexible KW. FS	Lack of F in study sample Lack of voice of CYP DIS Lack of representation of all team members caring for CYP
Hemsley et al. 2013 Australia	Parents and children with cerebral palsy discuss communication needs in hospital AAC COM CYP DIS	EA DO LOS FG CYP Able to only recruit up to 4 participants into each Minimum number advised for EA is 3 CHN- 10 M F NI 7 CYP NI 3 CYP FG	Qualitative Narrative Inquiry FG IGD AAC NI	CYP request direct communication with staff in own format QOL Frustration, communication, Support at school, social activities	SN and lack of diversity of population

				FS with younger children and at periods of transition	
Ilkhani 2013 UK	The inpatient hospital care delivery to disabled children and young people and those with complex health needs CYP CHN DIS NLS	Service Evaluation Approved by HB Using Care Quality audit tool Registered HS SS-14 Health Care Students- No number	Service evaluation through interview using Nominal Group Technique	CYP CHN DIS Lack of quality care Lack of HS KSE Lack of AAC COM barriers Limited time for care Training in CHN required Further audit	Audit cycle incomplete
Markham 2008 EthOS 500432 UK	The development and validation of a Quality of Life measure for children with speech language and communication needs. thesis	Approved HBE LEC	Qualitative Mixed methods FG 13 groups QOL tool 303 completed CYP	QOL Relationships School and Relaxation Clinical trial of QOL tool developed. FS	Newly developed tool not widely tested
McNeilly et al. 2015	The Participation of Disabled Children and	DO COM	Qualitative	CYP DIS do not receive information required for	Response rate from M F 24%

				QOL decision making Support for M F FS	Low numbers for FG Low generalisability
UK Northern Ireland	Young People: A Social Justice Perspective CRI CYP DIS M F HS Participation Independence Social Justice	Gatekeepers were reluctant, believe that CYP DIS unable to take part CYP DIS 18 CYP 77 M F 90 HS	Phenomenology Mixed Methods Surveys Interviews Talking Mats		
Misuk and Emmett-Gardner 2015 Korea	A Qualitative Inquiry of Korean Mothers' Perceptions of Grandparents' Roles and Support for Families of Children with Severe Disabilities CHN CRI CYP DIS - Severe M G	EA Numerous Gatekeepers 6 M	Qualitative Phenomenology SSI AR FN	Denial of disability Frustration Over-involvement Reduce parental stress Support from grandparents G M Opportunities to meet HS with KSE Seminars and workshops for families of CYP DIS FS	Subjectivity of data Potential bias of researcher Phenomenology deemphasises generalisability of SN findings affects transferability

Rabiee et al. 2005 UK England	Doing research with children and young people who do not use speech for communication COM CHN CYP NLS QOL M F	Negative attitudes from Gatekeepers CYP NLS 7 CHN 11 M F 50	Qualitative Talking Mats® Symbols Visual techniques	CYP NLS CHN can give their views when invited and using appropriate tools. Methods have wider applicability FS	Range and scope of tools and methods of communication
Shilling et al. 2012 UK	The experience of disabled children as inpatients: a structured review and synthesis of qualitative studies reporting the views of children, parents and professionals	None noted CYP COM QOC in hospital CHN CYP COM DIS HS M F	Structured literature review Search of multiple databases 32 papers reviewed and 8 synthesised	COM CYP M F requires improvement Paucity of qualitative studies prohibited distinctions between CHN DIS Lack of confidence in HS KSE Parent-led teaching programme for staff recommended	Majority of papers found report parents views resulting in reduced relevance of required criteria
Singer 2013	Perceptions of School Nurses in the Care of	LOS Underrepresented	Qualitative	Education provision on disabilities for staff	SSI and observational

292

America	Students with Disabilities AAC COM CYP DIS KSE QOC QOL	group of CYP 8 HS with individual nursing experience spanning 17-35 years	Narrative Inquiry SSI OG	Include HS in family and interdisciplinary meetings FS	guides not tested previously SN in one setting

Key: See ABBREVIATIONS

Key to terms used in Table 3

AAC- Augmentative and alternative communication CA- Congenital Abnormality CHN- Complex Health Needs COM- Communication CRI- Cultural Religious Issues	F- Fathers FC- Family Carers FG- Focus Groups FS- Further studies required H- Health HB- Health Board or Trust	KSE- Knowledge Skills Experience KW- Key Workers LEC- Local Ethics Committee LLC- Life Limiting Conditions LOS- Lack of studies on topic M- Mothers	QOC- Quality of Care QOL- Quality of Life SLN- Speech Language and Communication Needs SLT- Speech and Language Therapy SS- Support Staff

293

CYP- Children and Young People	HBE- Health Ethics Committee	NI- Narrative Interview	SW- Social Work Services
DIS- Disabilities	HS- Health Staff	NLS- No or Limited Speech	

Appendix 19. Interview Schedule Interpretative Phenomenological Analysis (IPA)

UWS UNIVERSITY OF THE WEST *of* SCOTLAND

Interview Guide for Child participants. Version 3, 4th January 2019

Interview guide for the child participants of:

What are the views and experiences of children with complex health needs and those of their families on the provision of healthcare?

Thank you for saying you will that you will talk to me and will take part in the interview. Our talk is private and whilst we are speaking we will be recorded on the tape and the iPad. The recordings will be destroyed when I have written up my report and your name with not be used in my research report or other documents.

If you tell me anything that makes me worry about your safety or anyone else's safety I will have to tell a suitable person who will make more enquiries about the concern and may need to take some action in relation to it.

Are you still ok for the interview to begin? Are you comfortable?

Please start by telling me about yourself and your family.

1. What is your understanding of a complex health needs?

2. Do you have complex health needs, if so, which complex health need/s do you have?

3. Does this affect you? If so, how does it affect you?

4. Do you think this affects your family and friends? If so, how do think this affects them?

5. Do you have help with your everyday needs?

6. Who helps you?

7. Tell me about your typical day at school?

8. Have you ever been in hospital?

9. Can you please tell me about being in hospital?

10. Is there anything else you would like to tell me?

Appendix 20. Interview Guide for Adult participants. Version 3, 4th January 2019

UWS UNIVERSITY OF THE WEST of SCOTLAND

Interview Guide for Adult participants. Version 3, 4th January 2019

Interview guide for the participants of:

 What are the views and experiences of children with complex health needs and those of their families on the provision of healthcare?

Thank you for agreeing to take part in the interview. Please note that the discussion is private and will be audio and video-recorded on tape and the iPad but the recording will be destroyed once I have written up my report. Your name with not be used in the research report or in any other documents. If you tell me anything that raises a child protection or a safety concern, I will pass that information on to a suitable person who will make more enquiries about the concern and may need to take some action in relation to it.

Are you still ok for the interview to begin? Are you comfortable?

Please start by telling me about yourself and your family.
1. What is your understanding of complex health needs?

2. Does your child have complex health needs? If so, please tell me about them.

3. Does this affect them? If so, how does this affect them?

4. Does this affect the rest of the family? If so, how does this affect them?

5. Does your child receive help for their complex needs? If so, what type of help?

6. Have you ever been in hospital with your child?

7. Can you please tell me about what happened during your time in hospital?

8. Is there anything else you would like to say?

Appendix 21. Talking Mats® interview schedule and questions

Thank you for saying you will that you will do a Talking Mat® with me, we will use the Children and Young People bundle and the Health and Well Being bundle. Your mat is completed in private but will be recorded by on the tape and iPad. A still photograph will be taken of the completed mat. The recordings will be destroyed when I have written up my report and your name with not be used in my research report or other documents.

If you tell me anything that makes me worry about your safety or anyone else's safety I will have to tell a suitable person who will make more enquiries about the concern and may need to take some action in relation to it.
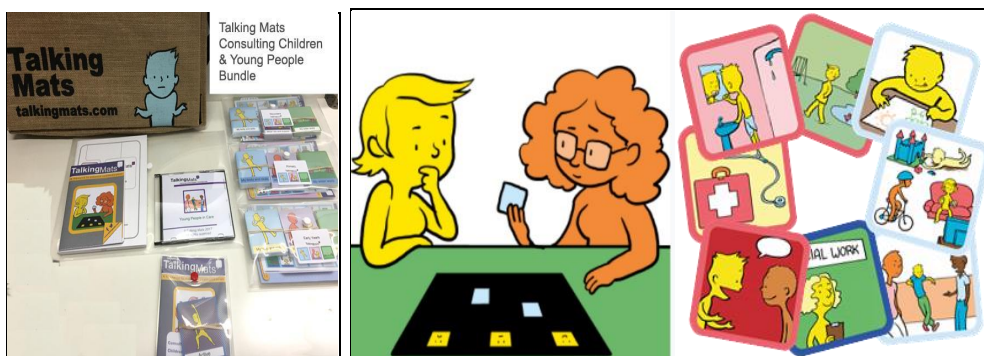
Are you still ok for the mat to begin? Are you comfortable?

Do you use Talking Mats in school?

We will use the cards to find out about what you think about everyday things at home, school and hospital.

Top Scale

Like, Happy or Enjoy: Do not like, Not Happy or Do Not Enjoy

'Thank you for doing your Mat today and here is copy for you.'

(Participant provided with a still photograph for future reference and use).

Appendix 22. Word Cloud formulated by ATLAS.ti 8 (2002) from anonymised transcripts uploaded to ATLAS.ti 8 Qualitative Data Analysis platform