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UNIVERSITY OF SOUTHAMPTON

FACULTY of HEALTH SCIENCES

The inpatient hospital care delivery to disabled children and
young people and those with complex health needs

by

Mahnaz Ilkhani

Thesis for the degree of Doctorate in Clinical Practice

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UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF HEALTH SCIENCES
SCIENCES

Doctorate in Clinical Practice

THE INPATIENT HOSPITAL CARE DELIVERY TO DISABLED
CHILDREN AND YOUNG PEOPLE AND THOSE WITH COMPLEX
HEALTH NEEDS

BY

Mahnaz Ilkhani

Introduction

Research suggests that parents of disabled children are dissatisfied with inpatient care delivery to their children.

Objectives

- To explore the inpatient care of disabled children
- To determine the rewards and challenges of working with disabled children and young people and those with complex health needs
- To analyse contemporary nursing curricula in order to ascertain areas of teaching pertinent to disabled children and young people and those with complex health needs
- To consider compliance with policy benchmarks for disabled children and young people and those with complex health needs

Methods

This project is part of a service evaluation for disabled children and their families that utilises different approaches. Three components of the project were designed:

1. To conduct focus group meetings using the Nominal Group Technique (NGT) with nursing staff
2. To conduct an in-depth content analysis of contemporary nursing curricula
3. To conduct an audit of compliance with policy benchmarks for disabled children and young people and those with complex health needs

Results

Four themes have been generated from the integrated data analysis of the current service evaluation, namely: effective communication, provision of training, provision of equipment, unfavourable environment.

Conclusion

This service evaluation has revealed that nursing staff need to improve their knowledge and expertise in the field of communication with disabled children and their families, and also enhance the quality of care delivered to this population. Additionally, it is vital that more equipment be provided, and the number of expert nursing staff caring for disabled children increased, in order to improve the quality of care for disabled children and their families.

List of Contents

ABSTRACT	ii
List of Contents	iii
List of Tables	ix
List of Figures	xi
DECLARATION OF AUTHORSHIP	xiii
Acknowledgements	xv
Definitions and Abbreviations.....	1
Chapter 1 : Background.....	1
1.1 Introduction.....	1
1.2 Introduction of the Chapter.....	3
1.3 Historical Background to Disability in Health Care and Terminology	3
1.4 Definition of Disability.....	4
1.5 Disability Rates and Effects of Disability on Use of Healthcare Facilities..	5
1.6 The Needs of Disabled Children and Their Families and Satisfaction with the Health System.....	7
1.7 Government Policy to Address Healthcare for Disabled Children	9
1.8 Knowledge Translation and Service Evaluation.....	11
1.9 Nurses' Role in Caring for Disabled Children and those with Special Health Needs	13
1.10 Health Care Support Workers Role in Caring to Disabled Children and Those with Complex Health Needs.....	14
1.11 Justification for the Focus of This Project.....	15
1.12 Chapter Summary	15
Chapter 2 : Literature Review and Critical Appraisal.....	17
2.1 Introduction.....	17
2.2 Literature Review	17
2.2.1 Literature Review Process.....	18
2.2.2 Searching Evidence.....	20
2.2.3 The Results of Systematic Searching	25
2.3 Critical Appraisal	46
2.3.1 Critiquing the literature.....	46
2.3.2 General Trends and Patterns in the Literature Review.....	56
2.3.3 Challenges for Nursing Staff in Caring for Disabled Children	58
2.3.4 Rewards for Nurses from Caring for Disabled Children	65

2.3.5: Search Focus: Parent/Carer Perspectives.....	66
2.3.5.1 Negative Attitudes.....	68
2.3.5.2. Communication.....	69
2.3.5.3. Partnership.....	70
2.4 Justification for This Study	73
2.5 The Service Evaluation Question and Objectives	73
2.5.1 Question.....	73
2.5.2 Objectives	73
2.6 Summary of the Chapter.....	74
Chapter 3 : Project Methodology.....	75
3.1 Introduction.....	75
3.2 Service Evaluation and Scholarship Activity	75
3.2.1 Dimensions of the Current Service Evaluation	77
3.2.2 Why Use Different Approaches for this Project?	78
3.2.3 Justification for Using Different Approaches for the Current Project	79
3.2.4 Steps for Conducting the Current Service Evaluation.....	80
3.2.5 Validity of the Current Service Evaluation	86
3.2.6 Limitations of the Current Service Evaluation	87
3.3 Section 1: The Nominal Group Technique	88
3.3.1 The Nominal Group Technique	88
3.3.2 The Nominal Group Technique Background.....	89
3.3.3 The Advantages of the Nominal Group Technique.....	89
3.3.4 NGT Difficulties	90
3.3.5 Rationale for Employing the NGT as a Service Evaluation Tool	90
3.3.6 The Role of the Investigator in the NGT	91
3.3.7 Composition of Participants	92
3.3.8 Recruitment Process for NGT Meetings in this Study.....	93
3.3.9 Location of the NGT Meetings.....	93
3.3.10 The Questions Posed.....	94
3.3.11 Time Required.....	94
3.3.12 Design of Voting Card.....	94
3.3.13 NGT Process with the Groups.....	95
3.3.14 Process of the NGT.....	96
Step 1: Silent Generation of Ideas in Writing	97
Step 2: Round-Robin Recording of Ideas	97
Step 3: Serial Discussion for Clarification.....	97
Step 4: Preliminary Vote of Item Importance	98
Step 5: Final Voting	98

3.3.15 Approval to conduct the Service Evaluation	99
3.3.16 Data Analysis of the NGT	99
3.3.17 Validity of the Current Nominal Group Technique	99
3.4 Section 2: Content Analysis of Nursing Curricula Relating to the Care of Disabled Children	100
3.4.1 What is Content Analysis?	100
3.4.2 History of Content Analysis.....	101
3.4.3 The Process of the Current Content Analysis	101
3.4.4 Nursing Education for Delivery of Care to Disabled Children and Young People and Those with Complex Health Needs.....	102
3.4.5 Nursing Curriculum Relating to Care for Disabled Patients	103
3.4.6 Questions for the Current Content Analysis.....	104
3.4.7 Objective of the Current Content Analysis	104
3.4.8 Sampling Strategy	104
3.4.9 Content Analysis of the Nursing Curricula	105
3.4.10 Trustworthiness of the Current Content Analysis	109
3.4.11 Limitations of the Current Content Analysis	109
3.5 Section 3: The Audit	110
3.5.1 Definition of an Audit.....	110
3.5.2 Advantages and Disadvantages of Conducting an Audit.....	110
3.5.3 Difficulties with Conducting an Audit	111
3.5.4 Differentiating Between Audit and Research	112
3.5.5 Aims and Objectives of the Current Audit.....	113
3.5.6 The Process of this Audit	114
3.5.7 Ethical Considerations.....	118
3.5.8 Data Analysis.....	119
3.5.9 External Validity	120
3.5.10 Pilot	120
3.5.11 Limitations	120
3.6 Summary of the Chapter.....	121
Chapter 4 : Results and Discussion	123
4.1 Introduction.....	123
4.2 Section 1: Nominal Technique Results.....	123
4.2.1 NGT Results for Question One	123
4.2.2 NGT Results for Question Two	129
4.2.3 Evaluation of the Nominal Group Technique.....	138
4.2.4 Limitations of the NGT	139
4.2.5 Summary of the Section	140
4.3 Section 2: Results of the Content Analysis	141

4.3.1 Primary Module Topics Related to Caring for Disabled Children within the Curricula in Three Universities.....	141
4.3.2 Deficiency of Material Related to Disability within Curricula.....	145
4.3.3 Discussion of Frequency of Terms within the Modules.....	151
4.3.4 Common Nomenclature Used within the Modules Examined.....	153
4.3.5 Learning Resources Identified Through Analysis of Curricula.....	155
4.3.6 Teaching Methods Used within the Curricula.....	157
4.3.7 Groups of Children and Young People with Disabilities Cited in the Curricula	160
4.3.8 Conclusions of the Content Analysis.....	161
4.3.9 Limitations of the Content Analysis	162
4.3.10 Summary of the Section	162
4.4 Section 3: Results and Findings of the Service Evaluation Audit	163
4.4.1 Introduction	163
4.4.2 Communication Benchmark Criteria (Score Range 0-10).....	163
4.4.3 Training Benchmark Criteria (Score Range 0-10).....	166
4.4.4 Multi-Agency Teamwork Benchmark Criteria (Score Range 0-10)..	168
4.4.5 Information Benchmark Criteria (Score Range 0-10)	172
4.4.6 Support Services Benchmark Criteria (Score Range 0-10)	175
4.4.7 Decision-Making Benchmark Criteria (Score Range 0-10).....	178
4.4.8 Key Worker Benchmark Criteria (Score Range 1-10).....	180
4.4.9 Assessment Benchmark Criteria (Score Range 0-10).....	182
4.4.10 Equipment Benchmark Criteria (Score Range 0-10).....	185
4.4.11 Palliative Care Benchmark Criteria (Score Range 0-10)	187
4.4.12 Bereavement Benchmark Criteria (Score Range 0-10)	189
4.4.13 Total Score of the Audit	191
4.4.14 Conclusion	193
4.4.15 Summary of the Section	193
4.5 The Results and Findings of Service Evaluation.....	194
4.5.1 Effective Communication	194
4.5.2 Provision of Training	196
4.5.3 Provision of Equipment	198
4.5.4 Unfavourable Environment.....	200
4.6 Summary of the Chapter.....	202
Chapter 5 : Overall Discussion.....	203
5.1 Introduction.....	203
5.2 Effective Communication.....	203
5.3 Provision of Training	208
5.4 Provision of Equipment.....	210

5.5 Unfavourable Environment	211
5.6 Summary of the Chapter.....	214
Chapter 6 : Conclusion and Recommendation.....	215
6.1 Introduction.....	215
6.2 Conclusion.....	215
6.3 Contribution of the current service evaluation to the development of scholarship in the area of caring for disabled children	216
6.3.1 Effective communication	216
6.3.2 Provision of training	217
6.3.3 Provision of equipment	217
6.3.4 Unfavourable environment.....	217
6.3.5 Feedback the Findings.....	218
6.4 Recommendations	218
6.4.1 Implications for Future Work.....	218
6.4.2 Implications for Practice	218
6.5 Utilising the Findings.....	220
6.6 Summary of the Thesis	221
List of References	223
Appendices	257
Appendix 1: Databases for Search.....	257
Appendix 2.1: Initial Studies Identified from Main Search.....	258
Appendix 2.2: The Steps of the Parahoo Model.....	265
Appendix 3	267
Appendix 3.1: Operational Definitions of Research, Clinical Audit and Service Evaluation	267
Appendix 3.2: Consent Form.....	269
Appendix 3.3: Literature Review of Content Analysis of Disability within Nursing Curricula	271
Appendix 3.4: Initial Study of Content Analysis of Papers.....	277
Appendix 3.5: Comparison between the Teaching Characteristics of the Programmes	281
Appendix 3.6: Content Analysis of Nursing Curricula	282
Appendix 3.7: Differences between Audit and Research	293
Appendix 3.8: Are the Children’s and Young People’s Units Disabled Friendly? A Preliminary Inquiry	295
Appendix 3.9: Care Quality Commission Essential Standards of Quality and Safety - Compliance Assessment Form.....	310
Appendix 4.1: Effective Communication Thematic Chart	316
Appendix 4.2: Provision of Training Thematic Chart.....	319
Appendix 4.3: Provision of Equipment Chart.....	323

Appendix 4.4: Unfavourable Environment Chart	325
Appendix 6.1 Executive Summary	326
Appendix 6.2 Permission Letter for Publication	334

List of Tables

Table 1.1 Barriers to high quality care for disabled patients during hospital stays	8
Table 2.1: Synonymous search terms	19
Table 2.2: Inclusion and exclusion criteria.....	20
Table 2.3: Database search (6 February 2013)	22
Table 2.4: Health policies relating to disability.....	24
Table 2.5 Final Critique of Selected Papers Relates to Nursing Staff Perspectives	35
Table 2.6 Final Critique of Selected Papers Relates to Parent Perspectives.....	45
Table 2.7 Strengths/Limitations Resulting from Critiquing Process	55
Table 2.8: Research about nursing perspectives towards care for disabled patients and their families	58
Table 2.9: Thematic Review of Parents' Perspectives of Care Delivery to Disabled Children and Their Families	72
Table 3.1The domains utilised within the service evaluation. Source: (Hanucharunkul 2009).....	77
Table 3.2: Measures of each aspects of the evaluation (adapted from (Health Knowledge 2012).....	78
Table 3.3: Strengths of using different approaches	79
Table 3.4: The advantages of the NGT	90
Table 3.5: The limitations of the NGT.....	90
Table 3.6: Characteristics of participants.....	93
Table 3.7: Content analysis benefits.....	100
Table 3.8: Differences between the three content analysis approaches. Adapted from Hsieh and Shannon (2005)......	102
Table 3.9: Selected modules from three UK universities relating to the study	105
Table 3.10: Advantages of conducting an audit	111
Table 3.11: Barriers and disadvantages of conducting an audit	112
Table 3.12: Segments of the Compliance Assessment Form.....	117
Table 3.13: Key informants who participated in the audit.....	118
Table 4.1: Statement responses to Question one from registered children's nurses.....	124
Table 4.2: Statement responses to Question one from HCSWs	125
Table 4.3: Comparison between the two groups' responses to Question one.....	126
Table 4.4: Registered children's nurses' responses to Question two	130
Table 4.5: HCSWs' responses to Question two	132

Table 4.6: Comparison of the responses of the two groups to Question two	132
Table 4.7: Primary module topics related to caring for disabled children and young people and those with complex health needs	142
Table 4.8: Curricula deficiencies related to caring for disabled children and young people and those with complex health needs	147
Table 4.9: Frequency of terms within the modules	151
Table 4.10: Common nomenclature within the modules examined	153
Table 4.11: Learning resources identified through analysis of curricula	155
Table 4.12: Comparison between universities in terms of teaching methods	157
Table 4.13: Groups with disabilities/special health needs addressed in nursing curricula.....	160
Table 4.14: Frequency of communication benchmark criteria	164
Table 4.15: Frequency of training benchmark criteria	167
Table 4.16: Frequency of multi-agency teamwork benchmark criteria.....	170
Table 4.17: Frequency of information benchmark criteria	173
Table 4.18: Frequency of support services benchmark criteria	176
Table 4.19: Frequency of decision-making benchmark criteria	179
Table 4.20: Frequency of key workers benchmark criteria.....	181
Table 4.21: Frequency of assessment benchmark criteria	184
Table 4.22: Frequency of equipment benchmark criteria.....	186
Table 4.23: Frequency of palliative care benchmark criteria.....	188
Table 4.24: Frequency of bereavement benchmark criteria	190
Table 4.25: Frequency of total score of benchmark criteria.....	192

List of Figures

Figure 1.1: Health policies related to disability.....	10
Figure 2.1: The current literature review synthesis.....	18
Figure 2.2: Flowchart of the results of literature searching which contributed to the service evaluation	26
Figure 3.1: The service evaluation design	83
Figure 3.2: Stage 1 of the service evaluation	84
Figure 3.3: Stage 2 of the service evaluation	85
Figure 3.4: Stage 3 of the service evaluation	86
Figure 3.5: Voting card	95
Figure 3.6: The five steps of the NGT	96
Figure 3.7: Coding steps (adapted from (Carley 1993)).....	106
Figure 3.8: The dendrogram for Module 2, University 2	108
Figure 3.9: Interaction between audits and research (adapted from Closs and Cheater (1996)).....	113
Figure 3.10: Stages of this audit	115
Figure 4.1: Bar chart for communication benchmark criteria	164
Figure 4.2: Bar chart for training benchmark criteria.....	167
Figure 4.3: Bar chart for multi-agency teamwork benchmark criteria.....	170
Figure 4.4: Bar chart for information benchmark criteria	173
Figure 4.5: Bar chart for support services benchmark criteria	176
Figure 4.6: Bar chart for decision-making benchmark criteria	179
Figure 4.7: Frequency of key workers benchmark criteria	181
Figure 4.8: Bar chart for assessment benchmark criteria.....	184
Figure 4.9: Bar chart for equipment benchmark criteria	186
Figure 4.10: Bar chart for palliative care benchmark criteria.....	188
Figure 4.11: Bar chart for bereavement benchmark criteria	190
Figure 4.12: Bar chart for total score of benchmark criteria.....	192
Figure 4.13: Communication key issue	195
Figure 4.14: Training key issue	197
Figure 4.15: Equipment key issue	199
Figure 4.16: Unfavourable environment key issue	201

DECLARATION OF AUTHORSHIP

I, Mahnaz Ilkhani

declare that the thesis entitled

The inpatient hospital care delivery to disabled children and young people and those with complex health needs

and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University;
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- Where I have consulted the published work of others, this is always clearly attributed;
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

Signed: M. Ilkhani.....

Date: 12 July 2013.....

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Definitions and Abbreviations

AAC	Augmentative and Alternative Communication Strategies
ACCN	Association of Chief Children's Nurses
BNI	British Nursing Index
CCN	Complex Communication Needs
CP	Cerebral Palsy
CSHN	Children with Special Health Needs
DDA	Disability Discrimination Act
DfES	Department for Education and Skills
DH	Department of Health
DRC	Disability Rights Commission
HCSWs	Health Care Support Workers
ID	Intellectual Disabilities
LTC	Long Term Conditions
M	Module
NGT	Nominal Group Technique
NMC	Nursing and Midwifery Council
NPSA	National Patient Safety Agency
NSF	National Service Framework
ONS	Office for National Statistics
SPSS	Statistical Analysis in Social Science
TDD	Telephone Device for the Deaf
UKES	UK Evaluation Society
U	University
WHO	World Health Organisation

Chapter 1 : Background

1.1 Introduction

The crucial goal of nursing is to deliver a high standard of care to patients (DiCenso et al. 1998). However, studies indicate that people with disabilities who have received inpatient care and their families are generally dissatisfied with the standards of care they receive, and some state that hospital experiences can even be quite distressing (Iacono & Davis 2003; Liptak et al. 2006).

A group of families of children with complex health care needs who had received care in the local children's unit situated within a large district general hospital were not happy with the standard of care provided to them. Some of these families wrote letters to their Primary Care Trust explaining their concerns about the care they had received at the hospital.

In due course the Primary Care Trust wrote to the medical director of the Childrens' unit asking him to investigate these complaints. The medical director asked the matron of the unit to fully scrutinize the care pathway experiences of children and their families' admitted with complex health conditions. The matron approached a member of the local university child health nursing team who had experience of designing service evaluations to ask for assistance in illuminating the care experiences of this group of families.

After discussion with the clinical governance committee of the children's unit a service evaluation strategy was developed which sought to comprehensively examine all aspects of care delivery to this group of children. The original plan incorporated interviews with parents of children with complex health care needs but the ethical complexities and the time necessary to do this was beyond the time frame allocated to the post graduate student who undertook the service evaluation. Hence a partial service evaluation was conducted which incorporated 3 distinct components. The first component involved nurses and health care assistants and sought to identify from their perspective the rewards and challenges of delivering care to disabled children. It was hoped that the outcomes of this component of the service evaluation would assist in

Chapter One

improving care standards by helping staff recognise the challenges and to use the rewards as motivational prompts to enhance care delivery. Findings from this first component revealed that nursing staff are concerned about their training in this area. Therefore, the second component of this service evaluation is a content analysis of the contemporary curricula, related to care delivery to this population. This analysis provided a detailed understanding of how nursing schools arrange and approach training in caring for disabled children. It was conducted on seven modules on children with disabilities and special health needs from undergraduate children's nursing courses at three UK universities. According to Scullion (1999), worthwhile insights emerge from the analysis of curriculum documents. The final component of this service evaluation was firstly the design and construction of a specific audit tool for measuring compliance to agree optimum benchmarks of care and secondly the completion of an audit of all areas of the children's unit where children with disabilities receive care. The results of this audit will inspire recommendations which may help to improve standards of care for this group of patients.

Chapter one provides a brief outline of the background and rationale for the chosen topic: care delivered to children with special needs. Chapter two presents an in-depth literature review of the perspectives of nursing staff and parents of disabled children on delivery of care to children with disabilities and special needs. The methodology of the project is presented in chapter three. This chapter provides an overlook of the definition of the service evaluation, dimensions, steps, validity and limitation. Additionally, the three components of the current service evaluation are described in full; the NGT process is defined and the NGT design, recruitment process, data collection, analysis procedures and approvals are set out. Sections two and three of the chapter focus on the full details of the content analysis and audit. Chapter four concentrates on results and discussion of the three components of the current service evaluation: the NGT, content analysis and audit. Additionally, this chapter presents the overall findings of the service evaluation. Chapter five summarises the overall discussion, with focus on four key issues generated from the service evaluation: effective communication, provision of training, provision of equipment and unfavourable environment. Chapter six provides a conclusion and recommendations.

1.2 Introduction of the Chapter

This chapter provides a brief outline of the background and rationale for the chosen topic: the delivery of inpatient hospital care to disabled children and young people and those with complex health needs. This chapter will commence with the history and definition of disability, examine disability rates and the effects of disability on the use of healthcare facilities, and discuss the needs of disabled children and their families and satisfaction with the health system. It will conclude with an examination of nurses' and Health Care Support Workers' (HCSWs) roles in caring for disabled children and those with special health needs.

1.3 Historical Background to Disability in Health Care and Terminology

Homer (8th century BC) recounted the story about the god, Hephaestus, being thrown out from Mount Olympus by his mother due to his physical disability (Kazantzakis & Kakridis 1997). For many centuries, disabled people have experienced persecution, abuse and discrimination (Oliver & Barnes 1996; Stiker 1999). The Romans performed infanticide on disabled infants (Barnes 1994). In Sparta, disabled children were left to die in a deep hole (Matziou et al. 2009). Disability has been associated with notions of submission, pity, sadness and evil. In the Bible, disability is connected to sin and possession by the devil. Many of the miracles of Jesus involved disabled people (Stiker 1999). Humphries and Gordon (1992) state that disability was still considered a curse or punishment from God at the beginning of the 20th century. In more recent European history, during the Nazi regime (1930s-1940s), disabled people were disadvantaged due to the notion of 'improving the human race' and thus stigmatised (Snyder & Mitchell 2006b).

The term handicap originated from the phrase 'cap-in-hand'; this idiom dates from 1504, when Henry VIII legally allowed injured soldiers to beg in the street (DePoy & Gilson 2011). In the early 20th century, the term was used to describe individuals with bodily impairments; doctors instead used the term 'disabled' as they considered it more respectful. The prefix 'dis' represents a lack of health, well-being and ability to interact with the environment (DePoy & Gilson 2011).

Chapter One

In the UK, the Disability Discrimination Act (DDA) was introduced in 1995 in order to combat discrimination against disabled people in health service provision (Department of Health (DH) 2009). Unfortunately, even under this law, disabled children are still sometimes treated with prejudice and stigma by those in healthcare (Joachim & Acron 2000; Matziou et al. 2009).

In the UK, nursing training in mental deficiency officially commenced after the enactment of the Mental Deficiency Act in 1913. The syllabus for nursing education in learning disability originally focused on care and support for people with intellectual disabilities (ID) (Turnbull 2004); ultimately, the Royal College of Nursing (1982) enriched the purpose of learning disability nursing by adding the autonomy of patients with learning disability (LD) to the syllabus (Sweeny & Mitchell 2009).

1.4 Definition of Disability

The DDA defines disability as a physical or mental deficiency which has a long term impact on people's ability to carry out their normal daily activities (Fawcett 2003). This definition was criticised by Gooding (2000) due to the support of the medical model.

Within this study, the term 'children with special health needs' (CSHN) refers to children and young people who suffer serious and on-going physical, psychological and/or social problems (Taylor 1995), as well as requiring health and related services which are not usually needed by their healthy counterparts (McPherson et al. 1998). This definition has a health professional context; nevertheless it is acceptable for disabled young people and their families (DH 2004).

Children with disabilities, on whom this study focuses, are a sub-group of children with special health needs. The World Health Organisation (WHO 2011) states that disability is the interaction between disabled people and environmental factors. The WHO provides a social-environment model and describes how disability can impact on the capability of individuals to enjoy a normal lifestyle with regards to their age, gender, social and cultural situation (Newacheck et al. 2004; Sen & Yurtsever 2007b), which may in turn impact on their sense of fulfilment in life (Goodall 1995).

Disability is an inclusive term for impairments, activity limitations and restrictions (WHO 2011). A child's disability can take the form of either one

limitation or a combination of physical, developmental, cognitive and affective deficits (Parkes & Clarke 2006). Disabilities that have considerable impact on the function and development of children include cerebral palsy, spina bifida, muscular dystrophy, spinal muscular atrophy, metabolic disorders and genetic syndromes (Parkes & Clarke 2006).

1.5 Disability Rates and Effects of Disability on Use of Healthcare Facilities

More than one billion people, about 15% of the world's population, are living with some form of disability (WHO 2011). Across the UK, 7.3% of children (Blackburn et al. 2010) or one in 20 children under 16 years old are reported as disabled (Office for National Statistics (ONS) 2004). These children experience higher levels of poverty and are at an increasing personal and social disadvantage compared with their healthy counterparts (Blackburn et al. 2010). The reason for the increase in the rate of disability among the population is the growth of chronic health conditions (WHO 2011).

Disabled children experience a higher incidence rate of health deficits including respiratory and gastrointestinal problems, coronary heart disease, cancer, accidents, hypertension, epilepsy, sensory impairments, osteoporosis, schizophrenia, dementia, dysphagia, dental disease, musculoskeletal problems and nutritional problems. Many of these conditions go unidentified, which leads to health needs being unmet (Sowney & Barr 2006; Sowney & Barr 2007). Additionally, disabled children experience a greater occurrence of behavioural problems and anxiety/depressed moods (Houtrow et al. 2011). Gallaher et al. (2002) reported that CSHN are greater users of health services. Studies conducted by MENCAP (1998) into people with intellectual disabilities (ID) found that they were admitted to hospitals much more often than their healthy counterparts, Furthermore, in the USA, Houtrow et al. (2011) found that disabled children require more special care, therapy services, assistive devices, medical supplies and equipment; this results in a unique challenge for those who contribute to their care (Kibirge & Mahon 2004).

Walsh et al. (1997) stated that both the frequency of admissions and length of stay for disabled patients had risen significantly; these findings have been confirmed by numerous studies (Walsh et al. 1997; MENCAP 1998; Sowney & Barr 2006). The Disability Rights Commission (DRC) (2006) reported that

Chapter One

disabled patients are 2.5 times more likely to have health problems and four times more likely to die from preventable diseases than their healthy counterparts. In contrast, health problems related to smoking, alcohol and use of illegal drugs are unusual for this population (Cooper et al. 2004).

Increasing experience of acute and chronic illnesses in this group of people leads to more frequent admittance to acute wards than their healthy counterparts (Walsh et al. 1997; MENCAP 1998; Sowney & Barr 2006). Mahon and Kibirge (2004) investigated the frequency and reasons for referrals of CSHN to a paediatric assessment unit in the UK between 1997 and 2001. The findings of this research indicated that CSHN have a higher frequency and length of hospital admission than their healthy peers, and it was concluded that this group of children presents a unique challenge to those involved in their care (Kibirge & Mahon 2004).

Cooper et al. (2004) believed that the health needs of disabled people are a challenge for healthcare systems. Newacheck and Inkelas (2004) conducted a survey in order to examine healthcare costs for children with disabilities in the USA. The findings demonstrated that the 7.3% of children who were disabled used health services more often than their peers without disabilities.

Additionally, they had more than four times the number of hospitalisations ($P<.001$) and spent eight times more days in hospitals ($P<.001$) than the healthy children; their hospital treatment cost was also higher (\$2,669 vs \$676).

In the UK, the National Health Service (NHS) and social services claim that hospital costs for individuals with ID are approximately £3,000 billion per year (DH 2003). Furthermore, the costs of supporting children with autism were estimated to be £2.7 billion per year (Knapp & Hall 2009).

Increases in hospital admissions, longer hospital stays and early deaths among people with learning disabilities might be due to a lack of knowledge, skills and confidence, as well as negative attitudes, on the part of the healthcare professionals who treat disabled people (Slevin & Sines 1996; Lennox et al. 1997; McConkey & Truesdale 2000; Iacono & Davis 2003).

1.6 The Needs of Disabled Children and Their Families and Satisfaction with the Health System

Research has shown that people with disabilities have greater healthcare needs than their healthy counterparts (Kirk 1999; Liptak et al. 2006; Sowney & Barr 2006). This point is highlighted by Glasby's (2002) research. Glasby found that some people with learning disabilities were receiving poor quality care, and that health services did not always meet their needs. The national and international evidence suggests that mainstream services are inadequate for the needs of disabled patients (Kirk 1999; Liptak et al. 2006; Sowney & Barr 2006). This was emphasised by a British Government document (NHS Management Executive 1992). In addition, the UK Government supported calls to prioritise the improvement of healthcare for disabled patients (HM Treasury & Department for Education and Skills (HM Treasury & DfES) 2007).

Patient satisfaction is an important measurement of quality of care (Donabedian 1992; Sowney & Barr 2007). Studies indicate that disabled people receiving care in general hospitals, and their families, are dissatisfied with many aspects of the care received (Fox & Wilson 1999; Iacono & Davis 2003; Phua et al. 2005; Liptak et al. 2006; Sowney & Barr 2006). In the USA, Ngui and Flores (2006) found that the prevalence of dissatisfaction with healthcare among the parents of CSHN was 8%; for problems with accessing services, it was 25%. Meanwhile, the experiences of disabled patients within general hospitals in the UK were reported as rather negative (Sowney & Barr 2006), and the care given to them as insensitive (Northway 1997; Balandin et al. 2001; Hahn 2003). Some are afraid of treatment (Balandin et al. 2001; Hahn 2003), while others report being disrespected and blamed for being ill by healthcare professionals (Alex & Whitty-Rogers 2012).

The barriers to proper quality of care for disabled patients have been identified in the literature presented within Table 1.1

Chapter One

- Lack of sufficient knowledge and clinical skills (Glasby 2002; Sowney & Barr 2006; Lunsky et al. 2008; Weiss et al. 2009)
- Attitude of disrespect and blame for being ill from healthcare professionals (Alex & Whitty-Rogers 2012)
- Inappropriate nursing care plan (Fox & Wilson 1999)
- Lack of empathy and understanding from hospital staff (Dinsmore & Higgins 2011)
- Lack of confidence in nursing staff (McConkey & Truesdale 2000; Glasby 2002; Phua et al. 2005; Avis & Reardon 2008), which likely leads to distrust and negative views of disabled patients and their families (Baxter et al. 2000)
- Dependence on caregivers (Hayes & Kjioux 1984; Iacono & Davis 2003; Sowney & Barr 2007; Lunsky et al. 2008)
- Inadequate equipment and supplements (Kirk 1999; Iacono & Davis 2003)
- Negative attitudes towards disabled people (Slevin & Sines 1996; McConkey & Truesdale 2000; Iacono & Davis 2003; Lewis & Stenfert-Kroese 2010)
- Lack of effective communication skills and reassurance from nurses (Cumella & Martin 2000; Balandin et al. 2001; Hahn 2003; Iacono & Davis 2003; Phua et al. 2005; Sowney & Barr 2007; Avis & Reardon 2008; Lunsky et al. 2008)
- Not enough time for care delivery by nurses (Balandin et al. 2001; Hahn 2003; Drainoni et al. 2006c)
- Requirement to utilise high cost services (Coughlin et al. 2002)
- Reduction in quality of care (Cumella & Martin 2000; Glasby 2002; Iacono & Davis 2003; Phua et al. 2005)
- Absence of information exchange (Iacono & Davis 2003; Phua et al. 2005)
- Difficulties with admissions process (Phua et al. 2005)
- Inadequate coordination of different service providers (Drainoni et al. 2006a)
- Inaccessibility of health services (Drainoni et al. 2006a)
- Unwillingness to deliver care and support (Kirk 1999; Roberts 2001; Iacono & Davis 2003; Drainoni et al. 2006a)

Table 1.1 Barriers to high quality care for disabled patients during hospital stays

People with disabilities have reported that the skills of healthcare professionals are inadequate for meeting their needs. They are four times as likely to be dissatisfied with care delivery and almost three times more likely to record being ignored than people without disabilities (WHO 2011). Lindsay et al. (2010) highlight that people with learning disabilities often do not receive the healthcare they require. Children with CSHN and their families may have

different health-related needs than their healthy counterparts. It is argued that the care delivered to CSHN should cover their fundamental, developmental and social needs (Balling & McCubbin 2001; Hewitt-Taylor 2005b).

Surveys have highlighted shortfalls in inpatient services (DH 2001). Scullion (1999a, 1999b) claimed that disabled people might be receiving a lower quality of nursing service than able-bodied patients.

The White Paper 'Aiming high for disabled children: better support for families' pointed out that insufficient support for disabled children leads to unfulfilled lives (HM & DfES 2007). Therefore, the NHS needs to pay closer attention to the disabled population (Scullion 1999b).

1.7 Government Policy to Address Healthcare for Disabled Children

Government decisions and performances relating to the sustenance and improvement of health among the people is defined as health policy (Blakemore & Griggs 2007). Quality of care, satisfaction with care and accountability for the value of healthcare are the British government's highest priorities for health policy (Lohr et al. 1998; Taylor 2013). Policies influence nursing work as they affect daily work (Kenny 2002; Taylor 2013).

Enabling children with disabilities to access mainstream health services is a key goal for health policy (Brown & Guvenir 2009; Taylor 2013); furthermore, the British government aims to improve and support the ordinary lives of people with learning disabilities via advocacy and a person-centred approach, and to meet their needs (DH 2001b; Brown et al. 2010). For instance, the White Paper 'Aiming High for Disabled Children: Better Support for Families' and 'Valuing People Now' (DH 2009) emphasised the importance of accessible health services for disabled children to the reduction of inequalities (DfES 2007).

There is a range of health policy and guideline documents related to disability (see details below):

- Aiming High for Disabled Children: Best Practice to Common Practice (DCSF & DH 2009)
- Aiming High for Disabled Children: Better Support for Families (DfEs & DH 2007)
- Better Care: Better Lives (DH 2008)

Chapter One

- Disabled Child Standard, National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and Those with Complex Health Needs (NSF) (DH 2004)
- Nothing About Us Without Us (DH 2001a)
- Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs (DH 2007)
- Together from the Start - Practical Guidance for Professionals Working with Disabled Children (Birth to Third Birthday) and Their Families (DfES & DH 2003)
- Valuing People: a New Strategy for Learning Disability for the 21st Century (DfES & DH 2001b)

Valuing People Now: a New Three-Year Strategy for People with Learning Disabilities (DH 2009)

Figure 1.1 shows some of the health policies related to disability.

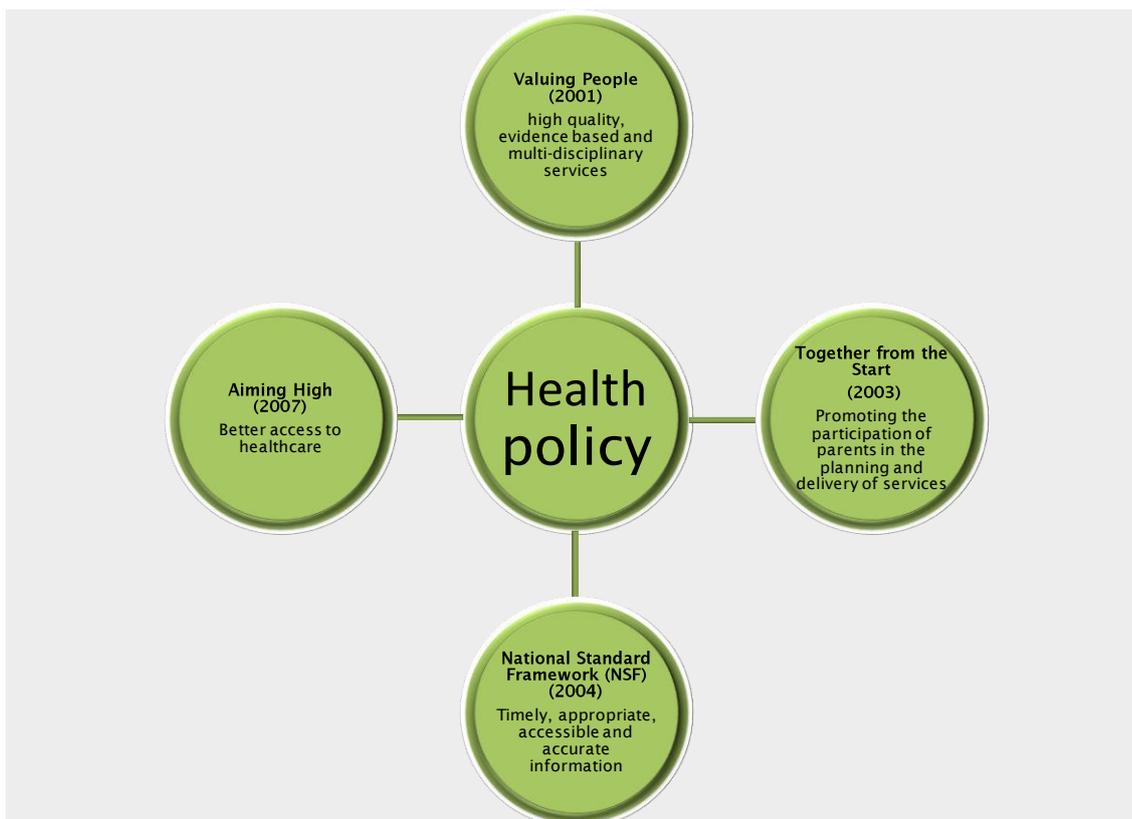


Figure 1.1: Health policies related to disability

1.8 Knowledge Translation and Service Evaluation

This is important to stress that high-quality findings from audits and service evaluations are not always put into practice, and many patients may not consistently receive high standards of care (Kong et al. 1998; Gabbay & May 2004; Le May & Holmes 2012; Nowicki & Siviour 2013). Promoting the uptake of audits and service evaluations can lead to improved quality and effectiveness of healthcare provision (Sitzia & Harlow 2002; Straus et al. 2009; Nowicki & Siviour 2013) and contribute to positive outcomes for patients (Ward et al. 2009). The WHO emphasises collaboration between knowledge producers and consumers with the aim of improving health (Ward et al. 2012; Nowicki & Siviour 2013). Additionally, Lord Darzi's report on the NHS stressed the importance of putting service evaluations and other activities into practice (Ward et al. 2012). Oliver (2012) noted that gathering and disseminating reliable evidence from service evaluations is a step towards offering optimal care. Furthermore, service evaluations can create change in clinical practice (Kumar 2007). The NHS Wirral Research & Development Team (2009) pointed out that service evaluations are a way to share information, views, decision-making and responsibilities.

Translating knowledge into action is defined as a dynamic and complex process which supports and promotes the effectiveness of health services (Straus et al. 2009) and enhances the awareness of stakeholders (Nowicki & Siviour 2013).

Interaction between clinicians and academic experts encourages policy-makers to adopt knowledge from service evaluations (Kumar 2007). The UK Particle Physics and Astronomy Research Council (PPARC) stated that successful translation of knowledge into practice is a two-way street (PPARC 1996). However, this two-way 'exchange process', in which investigators can learn from decision-makers and vice versa, has led to a cultural shift (Kumar 2007). Lavis et al. (2003) believed that this cultural shift can facilitate the transfer of knowledge to practice and promote decision-making. For example, Professor Kate Gerrish has contributed to a joint project between the University of Sheffield and Sheffield Teaching Hospital NHS Foundation Trust, using audit and service evaluation findings in order to improve the quality of care for patients (National Institute for Health Research 2000). Graham et al. (2013)

Chapter One

noted that all relevant scientific study can improve the uptake of service evaluation findings into practice. Clinical audits, service evaluations and practice development produce applicable information that can be used to develop healthcare provision and inform decision-makers (Jeffs 2006).

Hollander et al.(2009) noted that service evaluations can be used as a tool for decision-making. It is a requirement for evaluators and decision-makers to discuss the new knowledge that will be produced before the service evaluation is undertaken. Policy-makers and administrators will need to know how the knowledge will be developed (Hanucharunkul 2009).

Foy et al. (2002) and Graham et al. (2013) suggested that strategies such as audits can have a great impact on changing professional and organisational behaviour outcomes and therefore have a direct effect on practice.

Additionally, according to Gerrish and Mawson (2006), clinical audits and service evaluations affect the quality and effectiveness of patient care and the development of practice. It is hoped that the current service evaluation has produced knowledge which will lead to improved care delivery to disabled children and their families.

The profession of nursing is based on scholarship and academic process (Meric et al. 2002), which is defined as intellectual activities relating to studies in a particular field or area of knowledge (Bernier 2002). Scholarship requires high standards of excellence, rigorous science and systematic and flexible approaches which lead to the generation, representation and communication of knowledge (Starck 1996; Pearson 2004).

Boyer (1990a) proposed four dimensions of scholarship: discovery, integration, application and teaching (see Table 1.2).

Dimensions of Scholarship	Description
Discovery	Original study which leads to the establishment of a national institute of nursing studies
Integrative	Synthesis of different types of sciences and knowledge; these are then integrated, which contributes to holistic and multi-disciplinary care (Beattie 2000)
Application	Focus on practices which provide a bridge between practice and theory (Beattie 2000)
Teaching	Successful transfer and communication of scholars' knowledge to students

Table 1.2: Dimensions of scholarship. (Source: Beattie 2000, Boyer 1990)

Boyer (1990b) noted that the third concept of application relates to nurses' scholarship in practice. The current service evaluation has produced information and new knowledge relating to care delivery to disabled children, with the aim of promoting care for this population and attempting to generate recommendations for improving their services. Wright (1993) identified that clinical scholarship activities may be used toward advancement of practice.

1.9 Nurses' Role in Caring for Disabled Children and those with Special Health Needs

Nurses are one of the most significant human resources within health services (Gieter et al. 2006) and their influence on organisational performance is unquestionable (Hampton & Hampton 2004) due to their focus on human beings (Benner & Wrubel 1989). Sheerin (2008) listed the responsibilities of nurses as medication administration, psychological and physical support, behavioural-cognitive therapy, communication with family caregivers for disabled patients and assisting patients to cope with their situation. They also have a duty of developing plans and coordinating healthcare services and thus decreasing failures and gaps within services utilised by disabled people (Tommet et al. 1993). Tommet et al. (1993) found that all participants in their study believed that the role of nurses was essential, due to their focus on the families of disabled children. Wang and Barnard (2004) stated that young people with complex health needs and their parents were in a difficult situation. Zigler and Lang (1992) identified that insufficient professional skills acted as a barrier to providing adequate care and meeting disabled children's

Chapter One

needs. Esine and Yurtsever (2007a) found that more than half of families with disabled children were not receiving sufficient support from nursing staff. Glasper (2007) emphasised that disabled children and young people should receive high quality, evidence-based care. The DH (2004b) claimed that this care should be delivered by trained and committed nurses (Newhill & Korr 2004) with both a range of medical and technical skills and sufficient knowledge and competency to deliver constant care and support (Hewitt-Taylor 2010) and deliver it respectfully (Hewitt-Taylor 2008). Flexible and innovative approaches should be taken in order to give disabled children empowerment to develop their capabilities (Camus 2008; Kay et al. 1995) and promote positive self-esteem and self-confidence (Hewitt-Taylor 2008); this is directly influenced by high quality provision. Northway (1997) argued that modern nursing still needs to develop, and that more emphasis should be placed on the needs of disabled people.

1.10 Health Care Support Workers Role in Caring to Disabled Children and Those with Complex Health Needs

Health Care Support Workers (HCSWs) are a vital part of the nursing care team within the UK health service (Department of Health and Social Security, DHSS, 1987). The Information Centre (2009) reported that there were 45,678 HCSWs employed across the UK by 2008, performing basic nursing care such as personal care, assisting with nutrition, toileting and mobility (Fowler 2003) and supporting the physical and emotional concerns of patients (Bach et al. 2012). Fowler (2003) noted that HCSWs make a significant contribution to patient care; they are also extremely committed to their duties (Thornley 2000) and help to increase organisational effectiveness (Buchan & Dal Poz 2002). Although they are the lowest-paid, least professionally-trained (Hile & Walbran 1991) and least powerfully-positioned (Vail et al. 2010) healthcare workers, they form the majority of the workforce in hospitals (Fowler 2003). Care of children with complex needs is planned and supervised by registered children's nurses (RNs), and HCSWs often contribute to their day to day needs (Hewitt-Taylor 2004). However, there has been a paucity of research into the role of HCSWs and their experiences relating to care of disabled children. Therefore, for this particular study, the perceptions of registered children's nurses and HCSWs have been collected by using the Nominal Group Technique

(NGT), in order to ascertain the challenges and rewards of working with disabled children.

1.11 Justification for the Focus of This Project

The topic of this project was precipitated by dialogue with a parent of a disabled child regarding the standards of inpatient care their child received whilst in hospital. Service evaluation into the weaknesses and strengths of hospital care for children with disabilities has been limited. The increasing rate of children with disabilities and complex health needs is an indication (Smeltzer et al. 2005) that this topic is important and needs greater attention. The accumulation of knowledge of different aspects of care for disabled children will contribute to a more in-depth understanding of their care needs. Additionally, the investigator may be able to identify ways of improving the experience of general hospital care for disabled children and their families, with the hope of enhancing nursing care delivery to these patients. Additionally, a greater understanding of the perspective of RNs and HCSWs is needed.

1.12 Chapter Summary

This chapter has provided an overview of the background literature concerning the care of children with disabilities in order to understand the issues surrounding care delivery to this population. The following chapter will review the relevant literature pertinent to the delivery of care to disabled children.

Chapter 2 : Literature Review and Critical Appraisal

2.1 Introduction

This chapter presents the search evidence concerning inpatient care delivery to children with disabilities. The investigator searched thoroughly and relevant evidence was then accessed and critically appraised.

The method for searching and selecting the literature will be described. Following this, the literature will be presented in two main parts: first, the general themes and patterns will be identified and the evidence base discussed, and secondly, parents' and nurses' views on the delivery of care to children with disabilities will be explored. Gaps within the evidence base will be identified and utilised in order to develop the preliminary service evaluation questions and objectives.

2.2 Literature Review

A literature review is a scientific approach which identifies and describes the existing knowledge related to the problem under examination, recognises the gaps in knowledge, and provides an explanation of how the current study might generate new knowledge (Burns & Grove 2007; Clarke 2007). A review of the relevant literature has been undertaken in order to explore the current evidence base underpinning contemporary knowledge of the delivery of inpatient care to children and young people with disabilities and those with complex health needs.

The quality of any literature review may be judged by certain characteristics: it should be comprehensive, connected with up-to-date references, transparent, balanced and without bias. It should contain effective analysis and synthesis and be well-organised, well-presented and potentially replicable (Hart 1999; Polit & Beck 2006). A search of the literature was carried out three times, twice prior to data collection, in order to obtain a general view of the service evaluation under examination: this was repeated before writing the discussion chapter. This point is addressed by Polit and Beck (2006).

Chapter Two

2.2.1 Literature Review Process

The literature review process has sequential steps, in order to provide a framework for a study. The results of any literature review should explain about how the proposed study contributes to the existing body of knowledge (Levy & Ellis 2006). This study followed the nine steps required for an effective literature review as suggested by Parahoo (2006) and Polit and Beck (2008). The flowchart for the current literature review is shown in figure 2.1.

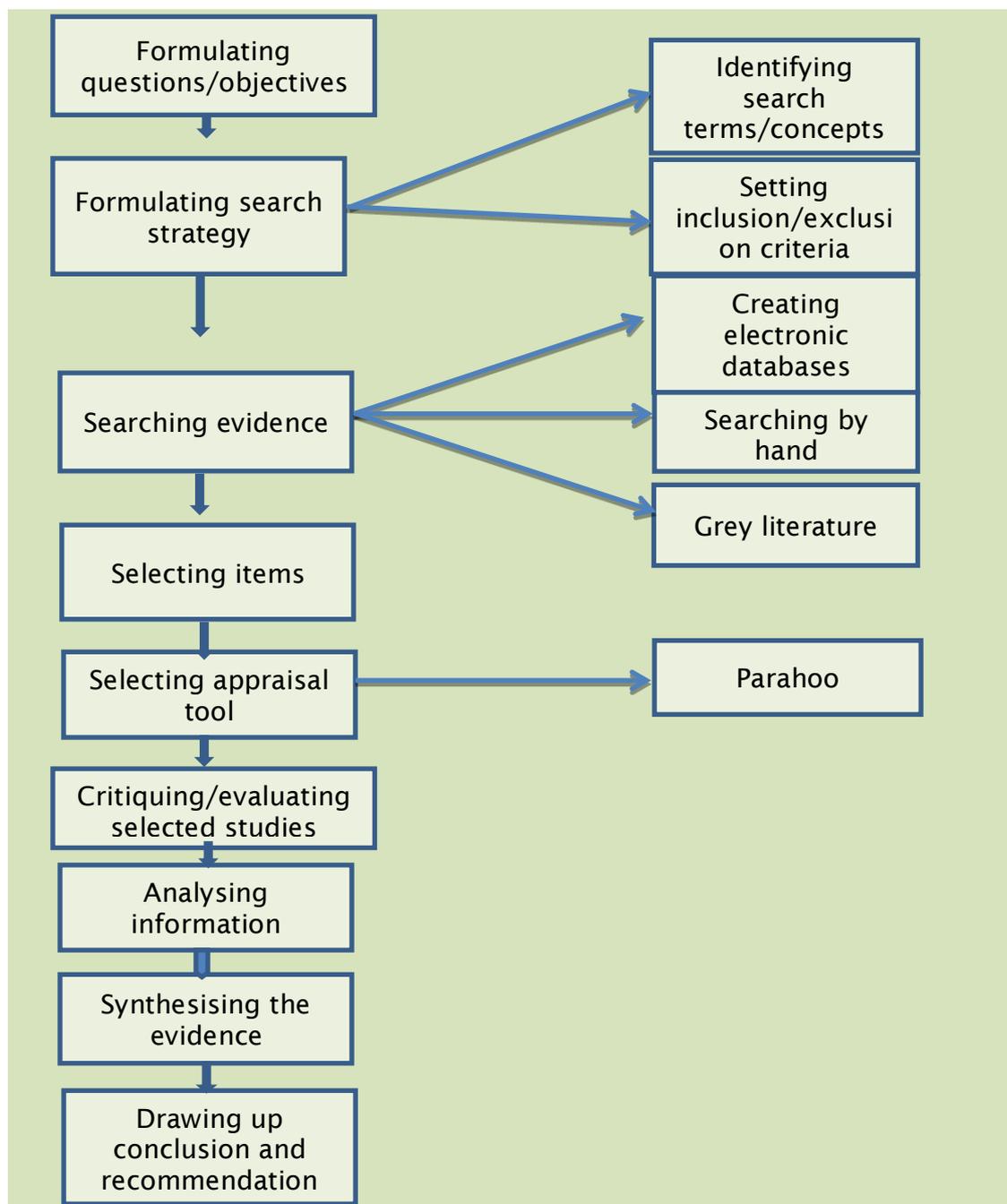


Figure 2.1: The current literature review synthesis

2.2.1.1 Identifying Search Terms/Concepts

Recognition of search words is a requirement in searching studies (Glasper & Rees 2012). The 'keywords' or search terms refer to a specific word or phrase for searching relevant literature from databases (Levy & Ellis 2006). For this service evaluation, six keyword concepts and alternative terms synonymous with each concept are identified and summarised in Table 2.1.

Concept group 1: To identify rewards or caregiving. Use term 'rewards'	Concept group 2: To identify the challenges of caregiving. Use term 'challenges'	Concept group 3: To identify who is the care deliverer to disabled children. Use term 'nurse'	Concept group 4: To identify who is being cared for. Use term 'disabled children'	Concept group 5: To identify where disabled children are being cared for. Use term 'hospital'	Concept group 6: To identify what care is delivered to disabled children. Use term 'care'
Rewards*	Challenge*	Nurses*	Disabled children*	General hospital*	Care*
Reward*	Challenges*	Nursing staff*	Children with learning disabilities*	Hospital*	Care deliverer*
Advantage*	Difficulties*	Nurse*	Children with intellectual disabilities*	Inpatient service*	Care delivery*
Honour*	Negative*	Health care support worker*	Children with developmental disabilities*		
Recognise*		Health care auxiliary*	Children with complex health needs*		
Positive*		Care giver*			
		Health care professional*			

Table 2.1: Synonymous search terms

Chapter Two

2.2.1.2 Setting Inclusion/Exclusion Criteria

The literature review commenced in 2010 and has been regularly updated. The year 1990 was chosen as the commencement date for the search as long-stay institutions were then being closed (DH 1990).

In addition, there is a large body of literature on particular issues faced by disabled children, such as access to health services. Although these articles were studied in order to gain background knowledge, they are not included in this review. The inclusion and exclusion criteria are presented in Table 2.2.

Inclusion criteria	Exclusion Criteria
<ol style="list-style-type: none">1. Literature that examines factors that influence general hospital care for people with learning disabilities2. Articles written in English3. Articles published between January 1990 and January 20134. Research articles5. Literature reviews6. Health policies related to the topic of study	<ol style="list-style-type: none">1. Studies of factors that influence primary healthcare for people with learning disabilities2. Studies published before 19903. Unpublished 'grey literature' (such as posters presented at conferences, health board communications, departmental projects)4. Articles not written in English5. Literature on particular issues faced by disabled children, such as access to health services

Table 2.2: Inclusion and exclusion criteria

Truncation (using a term with * after the word) and Boolean (using AND/OR with the terms) methods were applied in order to narrow the search.

2.2.2 Searching Evidence

Electronic databases, general internet searches (with the same keywords) and searching by hand were employed to identify the relevant studies.

2.2.2.1 Electronic Databases

Electronic databases can assist in a broad literature search by allowing access to published literature related to the study questions under examination (Glasper & Rees 2012).

Brazier and Begley (1996) recommended Medical Literature Online (MEDLINE) as the premier bibliographic database for any subject related to nursing studies. In addition, Burnham and Shearer (1993) concluded that a combination

of Cumulative Index of Nursing and Allied Health Literature (CINAHL) and MEDLINE databases would provide the best results for nurse researchers. The databases searched for this study were:

- Allied and Complementary Medicine Databases (AMED)
- CINAHL
- Excerpta Medica Database (EMBASE)
- MEDLINE
- PsycINFO
- The Cochrane Library
- Thesis UK Database
- Web of Knowledge (Appendix 1).

Table 2.3 presented the last search databases related to subject.

Chapter Two

	Search terms	CINAHL	MEDLINE	Web of Knowledge	EMBASE	AMED	PsycINFO	Cochrane Library
1	Disabled children.mp or Children with learning disabilities or Children with intellectual disabilities or Children with developmental disabilities or Children with complex health needs	3,981	7,375	47,632	1,205	269	11,917	1,040
2	Hospital.mp. or General hospital or inpatient services	161,238	2,437,435	2,258,444	39,791	1143	210,447	141,084
3	1+2	82	1,103	2,957	1	0	556	0
4	Nurses.mp. or Health care professional or Caregiver or Health care support workers or Health care auxiliary or Nursing staff	55,407	185,239	429,199	180,903	4530	78,489	7,694
5	3+4	9	70	435	0	0	49	5,784
6	Care.mp. or Care delivery	709,078	1,417,091	3,798,420	2,228,480	47,717	291,281	102,043
7	6+5	9	54	414	0	0	38	0
8	Rewards.mp or Honour.mp or Advantages.mp	11,624	126,652	971,209	0	2,233	83,600	7,935
9	8+7	0	0	1	0	0	0	0
10	Challenges.mp or Challenge.mp or Difficulties.mp	84,323	361,499	394,416	3,725	7,938	203,740	7,417
11	10+7	0	6	36	0	0	0	0
Total		28	16	46	0	26	19	25

Table 2.3: Database search (6 February 2013)

2.2.2.2 Grey Literature

Unpublished literature such as PHD theses and literature not published by traditional publishing companies is known collectively as grey literature (Glasper & Rees 2012). Grey literature is a term often used to describe publications not produced commercially and they would not be attributed ISBN numbers as such. These might include policy publications from external bodies such as Royal Colleges or from government departments. Although health care policies are published in paper format many are now widely available via the world wide and this has now become the principal repository of grey literature (Glasper & Rees 2012). One aspect of the service evaluation was to use standards from a variety of health policy documents related to the care of disabled children and young people and those with complex health needs to develop an audit tool.

2.2.2.2.1 Health Policies

Health policies are the decisions and performances of government and other agencies that relate to improvement and sustenance of health among the population (Blakemore & Griggs 2007). The British government through the department of health and others aims to improve the lives of disabled people and meet their needs. Therefore, a range of health policies and guideline documents relating to disabilities have been produced, which have been utilised in the development of the audit tool for this service evaluation (see Table 2.4 for a selection of examples).

Health policy relating to disability	Brief of policy
Aiming High for Disabled Children: Best Practice to Common Practice (DCSF & DH 2009)	<p>The aim of the policy is to improve service provision for disabled children and their families, increasing equality and providing opportunities for them.</p> <p>The main aim of this policy is partnership with disabled children and their families at all levels, which will lead to improvement in service provision.</p>
Better Care: Better Lives (2008)	This policy aims to improve children's palliative care services by promoting data sources, arranging joint working,

Chapter Two

Health policy relating to disability	Brief of policy
	enhancing needs assessment and support groups, supporting inequality and providing the best possible care in the appropriate setting.
Disabled Child Standard, National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and Those with Complex Health Needs (NSF) (DH 2004)	The goal of this framework is to provide and coordinate high quality and family-centred service provision for children and young people who are disabled or have complex health needs. The framework is based on assessing disabled children's needs, promoting social inclusion and allowing them to lead a fulfilled life. It focuses on timely, appropriate, accessible and accurate delivery of information, as well as multiagency transition, early identification of needs and provision of a high standard of evidence-based care delivered by well-trained and competent staff.
Together from the Start - Practical Guidance for Professionals Working with Disabled Children (Birth to Third Birthday) and Their Families (DfES & DH 2003)	These guidelines focus on the initial assessment needs of disabled children between birth and three years old. Additional foci include providing multi-agency support, delivering better access to information for families, enhancing professional knowledge and competence, reviewing and developing services and promoting partnership across agencies.
Valuing People Now: a New Three-Year Strategy for People with Learning Disabilities (DH 2009)	This policy addresses the needs of people with learning disabilities and special health issues. It is based on personalisation of services, ensuring that the right level of support, information and advocacy is given to patients. The document promotes inclusion in all aspects of social life and giving people control over decisions made about their life, as well as providing appropriate information for disabled people, which will lead to independent and fulfilled lives.

Table 2.4: Health policies relating to disability

2.2.3 The Results of Systematic Searching

Parents' perspectives provide a better understanding of the care delivered to disabled children during hospital admission and the challenges they face. Therefore, the literature search process was divided into two sections: parents' and nurses' perspectives on care delivery to disabled children. All articles identified by the main search were read and logged in a table (table 2.5 and Table 2.6). The contents of each article were related to that article's country of origin, and the outline of the study was reviewed. A summary flowchart of the systematic search process is illustrated in Figure 2.2 which shows that the initial papers numbered 193. A scan of the titles and abstracts eliminated 113 papers; a further 45 papers were excluded after they were read whole. A total of 35 papers met the inclusion criteria, and were divided into two groups: parents' perspectives (n=18) and nursing perspectives (n=17).

Chapter Two

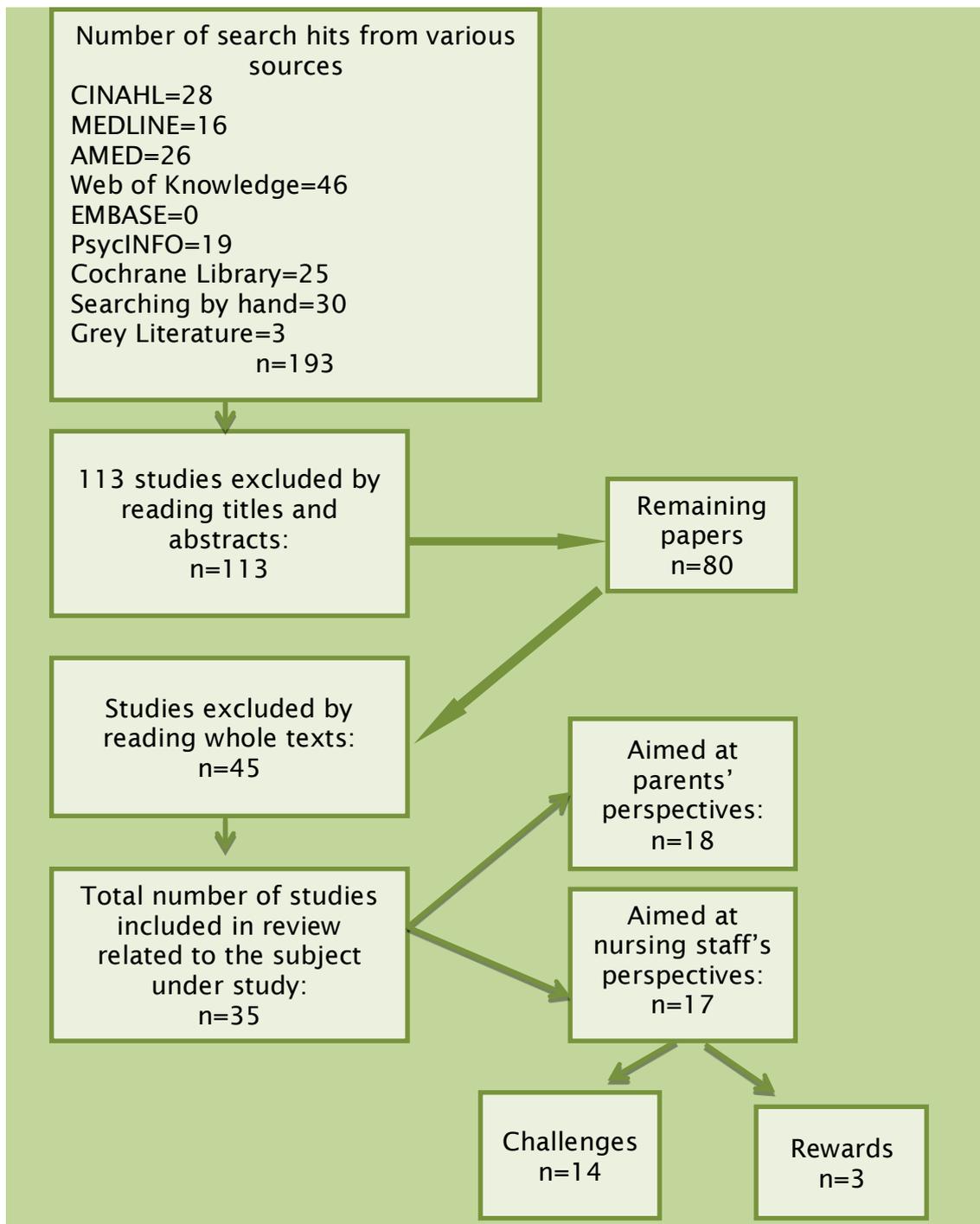


Figure 2.2: Flowchart of the results of literature searching which contributed to the service evaluation

2.2.3.1 Final Critique of Selected Papers

All retrieved papers are logged in Table 2.5 and Table 2.6 (colour coded), which follows a special grid designed by Savage and Callery (2000). This grid is helpful as a first stage in critiquing the selected papers from the literature review and in providing a summary of these papers (Glasper & Rees 2012).

Chapter Two

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
Lunsky et al. (2008) Canada (Toronto)	To identify clinical and systemic issues relating to emergency psychiatry services for people with intellectual disabilities, from the perspective of hospital staff	Emergency psychiatry staff (n=44) from six high volume general hospitals in Toronto	A qualitative methodology by means of focus groups was conducted. Content validity: Questions were developed via a panel with expertise in this field. Reliability: For inconsistencies, notes from the two research team members were synthesised immediately after each focus group. In addition, the records were reviewed by a third researcher who did not participate in the focus groups. Analysis: The narrative data were analysed and emerging themes were identified.	The main challenges identified by hospital nurses during A&E visits were: 1 Lack of information on available services 2 Lack of knowledge and experience relating to dual diagnosis 3 Misunderstanding of clients and caregivers about the aim of A&E 4 Insufficient background information about patients 5 Limited respite and residential placement 6 Lack of communication with service providers or caregivers 7 Caregiver burnout 8 Time-consuming population 9 Unfavourable hospital environment 10 Complex medical issues
McConkey and Truesdale (2000) Ireland	1. To explore nurses and therapists' experiences relating to past contact with people with learning disabilities 2. To determine their willingness for future contact	A total of 1008 persons took part in the study, including post-qualified nurses (n=269), therapists (n=169), staff working in	The survey contrasted the reactions of nurses and therapists to their contact with people with learning disabilities. Reliability and validity: Reliability and validity were not mentioned. Analysis: Statistical Package for the Social	Both nurses and therapists were significantly less confident in working with a patient who had learning disabilities in comparison to one with physical disabilities. Previous contact may affect further contact in a practice environment.

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
		learning disability services (n=270) and undergraduate students (n=261)	Sciences (SPSS) used.	
Ford and Turner (2001) Australia	To explore nurses' experiences of caring for children with special needs and their families	Four nurses caring for children with long term or chronic illnesses	Gadamerian hermeneutic phenomenology and feminist research principles were the approaches used. Interviews were held with experienced children's nurses. Reliability and validity: Reliability and validity were not mentioned. Analysis: The phenomenological transformative processes were used to generate themes.	The four themes revealed were special relationships, multiple dimensions of expertise, development of trust between nurses and families and feelings of frustration and guilt.
Sowney and Barr (2007) Ireland	To explore the challenges experienced by nurses in A&E who provide care to adults with intellectual disabilities	Nurses (n=27)	Five focus groups were conducted, one in each of five acute general hospitals across Northern Ireland, in order to explore the challenges experienced by nurses in A&E wards relating to caring for disabled patients. Reliability and validity: Reliability and validity were not mentioned. Analysis: Colaizzi's (1978) procedural steps were	Six themes were identified from the data: 1. Good practice 2. Respect for individuals 3. Lack of nurses' knowledge 4. Reliance on carers 5. Communication difficulties 6. Difficulties gaining consent Communicating with people with intellectual disabilities was the biggest challenge for nurses within A&E wards.

Chapter Two

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
			used for data analysis.	
Sowney and Barr (2006) Ireland	To explore the experiences of nurses in A&E who care for people with intellectual disabilities	Accident and emergency nurses (n=27) from five hospitals in Northern Ireland	Focus groups were conducted with nurses caring for people with intellectual disabilities. Reliability and validity: Reliability and validity were not mentioned. Analysis: Colaizzi's (1978) procedural steps were used for data analysis.	This paper focused on two themes: lack of knowledge relating to intellectual disability and reliance on carers. Nurses who worked in A&E departments needed to be educated about the needs of people with learning disabilities. Participants felt fear and vulnerability due to their lack of knowledge, which led to an over-dependence on patients' informal carers and receiving criticism about their performance.
Lewis and Stanfert-Kroese (2010) UK	To investigate the attitudes and emotional reactions of nursing staff working in general hospitals towards caring for patients with learning disabilities	Registered general nurses (n=34), a student nurse (n=1) and nursing assistants (n=13)	This study utilised a self-reported, vignette-style questionnaire which included attitude and emotional scales. Reliability and validity: Reliability was established via a test/retest process. Analysis: SPSS version 11 was used. Cronbach's alpha was used for test/retest reliability, along with Spearman's rho correlation coefficient.	Nursing staff reported less positive attitudes and more negative emotions towards care for a patient with a learning disability compared to a patient with a physical disability.
Hewitt-Taylor (2005b) UK	To determine the education and training needs of those who care deliver to children	Care managers (n=21)	This was a questionnaire survey on a good range of organisations involved with the care of children with complex health needs. Validity and reliability:	The respondents noted that technical and medical aspects of care do not dominate over psychological elements.

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
	with complex health needs outside the hospital setting		The questionnaire was piloted. Analysis: Descriptive statistics were used.	
Chung and Corbett (1998) UK	To compare burnout between nursing staff who worked with challenging behaviour in hospital and those who worked in a community unit	Hospital staff (n=26) and staff from the community unit (n=12)	Two groups of staff assessed their clients' behaviour by using the Aberrant Behaviour Checklist followed by interviews. Analysis: An independent t-test was used to examine some factors in both groups of staff. Kendall correlation coefficients were used to examine relationships between the staff and those factors. Validity and reliability: This was not mentioned.	The hospital staff were dissatisfied with their salaries and found less enjoyment in contact with their clients. They also felt that their training was insufficient. Additionally, they felt emotionally exhausted and experienced more depersonalisation. A positive relationship between staff burnout and management issues was found.
Hatton et al. (1999) UK	1. To investigate which factors relate to general distress, job strain and work dissatisfaction 2. To investigate factors which are directly or indirectly related to general distress, job strain and work dissatisfaction	Staff working in UK community-based services for learning disabilities (n=450)	The study was a survey by questionnaire. Analysis: The study used descriptive analysis, by means of mean and standard deviation, and regression analysis. Validity and reliability: Validity and reliability was not mentioned.	The findings showed that in general, stress related to wishful thinking, work-home conflict and role ambiguity. Job strain was related to factors such as wishful thinking, a lack of staff support, alienated commitment, role ambiguity, low job status and long hours of work. Work satisfaction was also related to low job status, support from supervisors, influence over work decisions, alienated commitment, support from colleagues and older staff's age.

Chapter Two

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
Hemsley et al. (2008c) Australia	To explore the views of hospital and disability service staff relating to the roles and needs of family carers of adults with CP and complex communication needs (CCN) in hospital	Six hospital and disability service staff	A focus group was conducted with six participants working in hospital and disability services. Validity and reliability: Not directly mentioned, but intra-reliability was provided by both researchers conducting transcription and analysis. Analysis: Content themes were used.	Participant emphasis was on family carers' expertise and their role in communication support, advocacy, and providing information. Additionally, staff believed that the attempt to provide ideal care had failed. The researchers noted that the family carers provided valuable support during hospitalisation in terms of communication, advocacy, protection, information exchange, direct care and emotional support.
Slevin and Sines (1996) Ireland	1. To investigate the attitudes of nursing staff towards people with learning disabilities 2. To compare the attitudes of graduate nurses and non-graduate nurses	Nurses (n=31)	This was a triangulation approach by means of an attitude questionnaire (n=31), followed by in-depth interviews with 10 nurses. Validity and reliability: A pilot study was undertaken. Validity was assessed by the triangulation approach. Analysis: Content analysis was used.	1. Negative attitudes towards learning disability people were higher than the expected level. 2. Graduate nurses had more positive attitudes towards ID people than non-graduate nurses.
Matziou et al. (2009) Greece	To investigate the attitudes of paediatric nurses and nursing students towards disabled children	Paediatric nurses (n=123), first year nursing students (n=228) and post-diploma nurses (n=90)	This was a cross-sectional design, using a paediatric 'attitude towards disabled person' scale (ATDP). Validity and reliability: The researcher used a valid and reliable tool. Analysis: SPSS version 13.0 was used. A two-factor ANOVA for comparing attitudes across gender and professional status,	1. Nurses' attitudes towards disabled children were poor. 2. Those with higher education levels obtained higher scores.

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
			a Cronbach's alpha for internal consistency and a Scheffe's hoc for comparing different professional groups were all utilised.	
Glaysher (2005) UK	To review services delivered to disabled patients with the aim to improve these services	A hospital with membership of the local Learning Disability Health Action Planning	This was a review of services for disabled patients, conducted by a team of service advisors including four members with learning disabilities from one local hospital. Validity and reliability: Not mentioned. Analysis: Only the views of the reviewer were reported.	1. The reviewer found that layout and navigation across the hospital was poor. 2. It was recommended that the environment should be improved and made friendlier, in accordance with the hospital staff's perspectives.
Gieter et al.(2006)	To determine rewards for nurses and categorise these rewards	Nurses (n=20)	This study was a mixed method study. In-depth semi-structured interviews conducted with nurses, followed by completing a questionnaire. Validity and reliability Inter-rater reliability or reproducibility provided by conducting categorisation process by two authors independently Analysis Firstly, discourse analysis conducted by using software package ATLAS.ti 5.0. Then qualitative data analysed by content analysis. Non-parametric statistical technique was performed by using SPSS package	Three major categorised rewards revealed by this study, include: financial, non-financial and psychological. The data shows a number of psychological and non-financial rewards which are significant include: valued job security, promotion possibilities, and working for a good reputation hospital. There were identified as rewards for nurses.

Chapter Two

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
			version 12.0.	
Hemsley et al.(2001)	To explore perceptions and experiences of nurses who are working with patients with severe communication problems.	Nurses (n=20)	This study is a qualitative study by means of conducting interviews with 20 nurses who are working with patients with severe communication impairments. Validity and reliability Two different researchers involved with interviews and analysis the data. Analysis The data were analysed quantitatively and descriptive, and then the themes generated.	The results showed that nurse-patient communication is a challenge for nurses, in terms of difficulties in understanding patients, due to the lack of access and use of the communication system.
Bakker et al.(2000b)	To investigate association between the experience of work stress and burnout among nurses	Female nurses (n=207)	This research was a cross-sectional study. The researchers utilise multi-questioners to measure intrinsic and extrinsic effort, occupational rewards and burnout Inventory. Validity and reliability Cronbach's alpha used for the internal consistency. Analysis SPSS package was used. The analyses of variance were conducted with ERI and intrinsic effort.	This research shows that nurses who experienced an effort-reward imbalance (ERI) had suffered more of burnout that those who did not experience such an imbalance. Burnout among nurses with ERI more relative to high intrinsic effort in their job and control over job conditions.
Backer et al. (2009)	To identify research relating to experiences of secondary healthcare for disabled patients	Thirteen studies retrieved by this systematic review of the literature.	A systematic review of the literature (n=13) carried out between 1990-2008 Effective analysis and synthesis of the literature conducted were well-organised.	<ul style="list-style-type: none"> The influencing factors on the experiences of hospital care for disabled patients were identified, including: the carer's role, the attitudes, knowledge and

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
				<p>communicative style of health staff, and the physical environment.</p> <ul style="list-style-type: none"> The authors provided recommendations for improving hospital care for disabled patients.

Table 2.5 Final Critique of Selected Papers Relates to Nursing Staff Perspectives

Chapter Two

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
Avis and Reardon (2008) UK	To explore parents' views on how their children with additional needs have been cared for by hospital nursing staff, with a focus on how these needs have been identified and met	12 parents of children with additional needs	This was a qualitative methodology using a purposive sampling strategy. The participants were recruited from one National Health Service (NHS) Children's Centre in the East Midlands. Reliability and validity: Reliability and validity were not mentioned. Analysis: A pragmatic thematic analysis of the data was used.	<ol style="list-style-type: none"> 1. Four themes were generated: prior experiences of parents relating to hospital care, including the process of being told the original diagnosis; communication with staff; nurse-parent relationships; and perceptions of nurses and nursing care. 2. A lack of practical and emotional support from nursing staff. 3. The lack of trust and confidence among nursing staff. 4. The parents acknowledged that they were deemed the 'experts' by nurses. Therefore, the nursing staff relied on them to continue caring for their children rather than negotiating.
Perkins (1993) UK	To identify the emergence process and trajectory as described by parents	Parents of hospitalised or recently hospitalised children aged two to 13 years with cognitive impairments and a variety of disabling conditions (n=23)	This study was a qualitative study which aimed to explore parental caregiving experiences.	This study generated a theory about how the characteristics of the parent caregiver can help nurses create caregiving partnerships.

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
Dinsomre (2011) UK	To investigate the levels of access to services in hospital for patients with ID in Merseyside	Parents or carers of ID patients (n=13) who had any hospital experience in Merseyside from March 2007	First, a pilot study was conducted and feedback was obtained, relating to the content and face validity of the questionnaire, from a number of professionals. During the second stage of the piloting process, 100 questionnaires were distributed to nursing staff on four wards across two NHS Trusts. 15 respondents were asked to complete the Reliability and validity: A draft of the interview structure was formulated and piloted by a person with ID. Analysis: Thematic analysis was used. questionnaire again one week later.	11 themes emerged, including: 1. Special learning roles 2. Annual health checks 3. Placements 4. Involvement of families/carers 5. After leaving hospital 6. Medication 7. Complaints 8. Provision of easy-to-read information 9. Patient passports 10. Flexibility in staff attitudes Participants also claimed that they needed greater empathy and understanding from hospital staff when the latter were dealing with patients with ID. The majority of participants were unconvinced that the staff they encountered had either received specialist training in caring for people with ID or had much experience.
Hayes and Kjiiox (1984) Canada	To examine the views of parents of children with long-term disabilities relating to hospitalisation	Parents of disabled children and children with cancer (n=40)	This involved interviews conducted with parents during hospitalisation of their children. This study utilised stress theory as its background.	1. Parents noted that the hospitalisation experience required many adaptations for them, especially in terms of their parenting role. 2. Sharing the care of their child with healthcare professionals was

Chapter Two

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
				<p>a positive experience.</p> <ol style="list-style-type: none"> 3. The primary source of parental role stress was loss of control over the whole situation. 4. Parents believed that their views as 'experts' ought to be considered. They also expressed that they were advocates for their children. 5. The parents emphasised open, clear and honest communication during delivery of information. The researchers claimed that staff and parents have different views about children's hospitalisation. Open communication and acceptance by staff could ease relationships and lessen stress between staff and parents. Furthermore, an improvement in the negotiation process with parents regarding their children's care should be considered by staff. 6. The researcher emphasised that caring can be shared. 7. Parents required time at the beginning of each hospitalisation to assess the situation and adapt their parenting role.
Phua et al. (2005)	1. To measure the level of satisfaction	40 parents of children with CP	This study was a cross-sectional study.	Parents of able-bodied children were more satisfied with the

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
Australia	with inpatient hospital care as perceived by parents of children with a disability, specifically CP, compared with parents of children without a disability 2. To identify the areas of parental concern and dissatisfaction	and 90 parents of able-bodied children	Reliability and validity: Face content, constructed validity and internal consistency were obtained. Analysis: Analysis was performed using STATA 8 (Stata Corporation, 2003). The demographic data were compared using Pearson's chi-squared, Fisher's exact probability and Student's t-tests.	hospitalisation than parents of children with CP ($P < 0.0001$).
Iacono and Davis (2003) Australia	To obtain data on the prevalence of problems with receiving adequate care in hospitals for adults with LD in Victoria	Participants had developmental disabilities and were aged 18 years or over (n=328)	The questionnaire was developed in consultation with staff from a disability organisation. A group of adults with physical disabilities participated in a focus group to discuss the content and wording of the questionnaire. The questionnaire was in the form of a small booklet, with COMPICs1 (picture symbols) inserted to represent each of their areas of need. The questionnaire (n=1022) was distributed to three disability organisations. Interviews were then conducted (n=11). Reliability and validity: Reliability and validity was not mentioned.	<ol style="list-style-type: none"> 1. The themes that emerged included reliance on carers, the negative attitudes of hospital staff and the lack of skills and knowledge relating to developmental disabilities. 2. Many patients' needs were not met, in particular getting to the toilet (39%), getting their medication on time (22%) and getting enough to drink (18%). Others included getting enough to eat and being able to move from the hospital bed when needed. 3. Participants reported that hospital staff were very helpful and intent on meeting their

Chapter Two

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
			Analysis: SPSS was utilised to analyse the results of the questionnaire. The transcripts of the interviews were entered into N5 (2000, QSR International). The data were then analysed for emerging themes.	needs.
Sen and Yurtsever (2007) Turkey	To determine the difficulties experienced by families with disabled children	The mothers of handicapped children referred to one public and two private rehabilitation centres in a Turkish province (n=103)	This was a descriptive study by means of a personal information form constructed by the investigators. Reliability and validity: This was not mentioned. Analysis: Descriptive statistics were used.	<ol style="list-style-type: none"> 1. Families received more support from their own family members. 2. The families needed more professional support from nurses. 3. The mothers of disabled children experienced high levels of stress.
Hewitt-Taylor (2008a) UK	To explore parents' perceptions of their children with complex health needs and their experience of communication, play, socialising and learning	Parents of children with complex health needs (n=14)	This involved semi-structured interviews. Validity and reliability: Transcript reports were returned to participants for confirmation of accuracy. Data analysis: Data analysis was inductive. Codes were generated from the data gathered, and then clustered into categories.	<ol style="list-style-type: none"> 1. Parents often felt that their child's efforts at communication were not valued. 2. Play and socialising were more challenging for the participants' children than their healthy peers due to their physical needs. 3. Parents reported a mixed experience of inclusion in education settings.
Fox and Wilson (1999) UK (Nottingham)	To explore parents' experiences of general hospital admission for adults with learning	10 parents of children with special needs from a day centre	A qualitative methodology with a purposive sampling strategy was used. Reliability and validity: Reliability and validity were not	The parents believed that the staff were not responding in a sensitive manner to their needs, and so they continued the basic nursing care of their children in hospital without

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
	disabilities		mentioned.	negotiating with the staff. The parents put emphasis on the communication skills among nurses. Additionally, it was emphasised that the 'learning curve' should be facilitated during the initial nursing assessment.
Weiss et al. (2009) Canada	To understand the experience of caregivers working with adults with ID and mental health issues from caregivers' perspectives	One group of unpaid caregivers (i.e. family members) and two groups of paid caregivers	A qualitative design using focus groups with caregivers was set out. Caregivers were recruited through flyers distributed to all agencies that provide services to individuals with ID. Reliability and validity: The inter-rater reliability of the themes was provided by a third researcher (SM) who did not attend the focus groups and who was blind. Validity was not mentioned. Analysis: Thematic analysis was used.	Caregivers identified a number of issues, including a lack of appropriate services, respect, knowledge, expertise, diagnostic overshadowing and overmedication.
Kirk (1999) Manchester-UK	<ol style="list-style-type: none"> To explore the experiences of families with a technology-dependent child caring at home To identify problems and good 	24 parents of children who were dependent on technology and with 4 children themselves, 38 health professionals	<ul style="list-style-type: none"> Qualitative interviews were conducted with the parents of children who were dependent on technology and the children themselves and professionals involved in supporting the families at home. These families were recruited via three specialist children's 	The research revealed particular problems in relation to the purchasing and provision of short-term care and specialist equipment/therapies in the community.

Chapter Two

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
	<p>practice in the purchasing, delivery and coordination of services</p> <p>3. To assess the appropriateness and adequacy of support services,</p>		<p>hospitals in the north of England, with the assistance of nurse specialists and hospital consultants.</p> <p>Reliability and validity</p> <ul style="list-style-type: none"> Reliability and validity not mentioned <p>Analysis:</p> <p>A computer package (NUD*IST) was used as a tool to support the coding and exploration of the data generated.</p>	
Liptak et al. (2006) USA	<p>To evaluate the perceptions of families with disabled children regarding their primary care physicians</p> <p>To determine differences</p>	Families of children with disabilities(n=121)	<p>300 survey were mailed to families with disabled children during 2003-2004, which included a Multidimensional Assessment of Parental Satisfaction for Children with Special Needs.</p> <p>Reliability and validity</p> <p>The researchers utilised a valid tool for measuring satisfaction of parents relates to care received by their physician.</p> <p>Analysis</p> <p>SPSS version 10 was utilised to analyse.</p>	<p>Parents with disabled children articulated that general care provided by health team was very good but less happy with certain area of care, such as: physician ability to in touch with parents and answer their question, understanding of the impact of child's condition on the family and provided guidance for prevention. Families of children with autism was dissatisfied more and believed that their needs unmet.</p>
Hewitt-Taylor (2008b) UK	To explore the provision of support for young people with complex health needs	One teenager with complex health needs and her family	<p>A qualitative case study of a teenager with complex health needs and her family by means of a semi-structured interview.</p> <p>Analysis</p> <p>A constant comparative analysis was</p>	<p>The findings emerged from the study shows that:</p> <ol style="list-style-type: none"> Young people with disability and their families often have difficulties with obtaining support

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity used.	
				<ol style="list-style-type: none"> 2. Lack of short-break 3. Difficulty in allowing adolescent to take their own choices and risks 4. Exhaustion of parents due to meeting their child's needs 5. Flexible health staff schedule time working 6. The personalised service provision
Brown and Guvenir (2009) UK	To investigate the experiences of children, their carers and nursing staff relating to their hospital admission	Children with disabilities (n=2) Carers of disabled children (n=13) Nursing staff (n=13)	A qualitative study by means of semi-structured interview was utilised for describing the phenomena relating to the experiences of children with disabilities and their carers during hospital admission. Reliability and validity Not mentioned Analysis Thematic analysis was used.	Five themes emerged from the data analysis: <ol style="list-style-type: none"> 1. Child, carer and staff anxiety 2. Preparedness for admission 3. Difficulties managing the child's behaviour 4. Carer presence during the admission 5. Ward environment and individual room.
Cumella and Martin (2004a) UK	<ul style="list-style-type: none"> • To define important issues for people with learning disabilities • To identify innovations and solutions for these problems 	40 people (disabled people and their carers, the health care team, and managers) participated in each consensus conference.	This research was an exploratory study conducted in two consensus conference with two sessions. Reliability and validity Not mentioned Analysis Thematic analysis was used.	Three main themes emerged from the first session: <ol style="list-style-type: none"> 1. Improving the exchange of information between individual disabled patients, their carers and the hospital staff 2. Improving support for family carers 3. Generating and sustaining improvement in care delivery to

Chapter Two

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
				<p>disabled patients</p> <p>The second session revealed some suggestions about the ways of improving hospital care for this population, including:</p> <ol style="list-style-type: none"> 1. Improved hospital information about patients 2. Preparation for admission 3. Staff training for better communication 4. Improving information about choices within the hospital 5. More collaborating with family carers 6. Improving the hospital environment 7. Specialist support the staff
Milner et al. (1996) UK	<ol style="list-style-type: none"> 1. To develop a parent's satisfaction checklist 2. To determine the criteria for which items important for parents 	39 parents of children with cerebral palsy who were all living in an inner district London	<p>Semi-structure interviews conducted based on a quality and good practice questionnaire developed by reviewing the literature.</p> <p>Reliability and validity Face validity obtained by reviewing the questionnaire by the participants.</p> <p>Analysis Quantitative data were analysed by using Epi-Info.</p>	<p>52% of parents were highly or fairly satisfied with care they received. The area of concerns revealed by parents including:</p> <ol style="list-style-type: none"> 1. The standards of news breaking 2. Early follow-up 3. Delivering information 4. Supply and repair of equipment
Roberts (2001) UK	<ol style="list-style-type: none"> 1. To explore family carers' experiences of nursing services 2. To determine 	205 family carers with disabled person	<p>A survey by means of a mailed questionnaire conducted.</p> <p>Reliability and validity Did not mention.</p> <p>Analysis</p>	<ol style="list-style-type: none"> 1. Family carer's provided examples of bad and good nursing practice and influencing factors. 2. Professional skills, information and knowledge was rated as

Author (Year) Country	Aim(s) of study	Methodological issues		Relevant/key findings
		Sample	Design, data collection and analysis, rigour, reliability and validity	
	factors which influence on the quality of the nursing service 3. To ascertain family carers' perspective on the future contribution of nursing services for care and support of people with disabilities		Did not mention.	important, followed by caring and understanding nature, the ability to listen to families, building up a good relationships. 3. Lack of relevant skills, poor attitude towards family carers and the person with disabilities noted as bad nursing practice.
Balandin et al.(2001) Australia	To explore the experiences of patients with cerebral palsy and complex Communication needs (CCN) in hospital.	Adults with cerebral palsy and CCN (n=10)	Interview protocol developed by 3 nurses and 3 disabled patients. Six questions were included within the protocol, and then structured interviews conducted for ten adults with cerebral palsy and CCN. Reliability and validity Pilot interviews with 2 participants conducted. Analysis The data analysed quantitative and qualitative.	The participants suggested two strategies for improving the hospital communication experience: 1. Communication Preparation for adults with cerebral palsy and complex communication needs (CCN) before hospitalisation. 2. Providing training and support for nurses in order to have an effective communication due to nurses not knowing how to use augmentative or alternative communication (AAC)

Table 2.6 Final Critique of Selected Papers Relates to Parent Perspectives

Chapter Two

2.3 Critical Appraisal

The process of assessing and analytically evaluating evidences in terms of trustworthiness, reliability and relevance to the topic under study is called critical appraisal (Parkes et al. 2001; Barker 2010a; Glasper & Rees 2012).

2.3.1 Critiquing the literature

In order to provide reliable conclusions about the data generated from the papers reviewed, a critiquing tool described by Parahoo was utilised (Appendix 2.4). The result of critiquing process and the identification of strengths and limitations are presented in table 2.7.

Study	Strengths	Limitations
Avis and Reardon (2008)	<ol style="list-style-type: none"> 1. The study used qualitative research; the interviews yielded rich and detailed information about nursing care from the view of parents of children with special needs. 2. The researchers acted as a release for parents, providing an opportunity to talk about their views and experiences and to be heard by an impartial listener. 3. Ethical consideration was mentioned. 	<ol style="list-style-type: none"> 1. The study was carried out on a small sample of 12 parents about their experiences of hospital care for their child. 2. All the parents were recruited through one respite care children's centre. 3. The study was based on only the parents views, not on broad views of all involved sectors including nursing staff. 4. No pilot study done.
Fox and Wilson (1999)	<ol style="list-style-type: none"> 1. The study used qualitative research; its semi-structured interviews yielded rich and detailed information about parents' experiences of general hospital admission for adults with learning disabilities. 2. A two-hour pilot interview was carried out before developing the semi-structured interviews. 3. The researcher provided recommendations relevant to practice. 4. Ethical consideration was not mentioned. 5. A good explanation was provided with details on discussion and results of the study. 	<ol style="list-style-type: none"> 1. The sample was small and may not be representative of the population. 2. Participants were selected from a day centre population and may not represent the wider population of people with learning disabilities on general hospital wards. 3. The two-year period for hospital exposure is long and recall bias is likely. 4. Nursing staff were not contacted, so only one side of each story is available. 5. Those agreeing to participate may have had a particularly bad experience, which made a more lasting impression.
Lunsky et al. (2008)	<ol style="list-style-type: none"> 1. The focus groups conducted involved a variety of emergency staff. 2. Questions for the research were developed via a panel with expertise in health research and intellectual disability. 3. Ethical consideration was mentioned. 	<ol style="list-style-type: none"> 1. Other perspectives (e.g. clients, paid and unpaid caregivers) were not included in this research. 2. With a single facilitator, there is a possibility that it may have hindered the diversity of responses from hospital staff. 3. There is a need for substantive data, not only on the characteristics of the individuals the hospitals are serving but also on what happens to these individuals in A&E (e.g. information on restraint use, percentage of individuals with intellectual disabilities in hospital).

Chapter Two

Study	Strengths	Limitations
		<p>4. Focus groups were conducted within six high volume hospitals in an urban setting, and so findings cannot be generalised to emergency departments in more rural locations or to settings where specialist services and expertise are more readily available.</p>
Weiss et al. (2009)	<ol style="list-style-type: none"> 1. This was the first study in Canada to examine the concerns of caregivers of adults with ID who use hospitals. 2. The results are likely relevant to a broader range of contexts. 	<ol style="list-style-type: none"> 1. This was a focus group pilot study; samples were small and may not be representative of the majority of individuals with ID and mental health problems. 2. Representativeness was limited to urban and suburban. Locations did not extend to people living in rural settings.
Kirk (1999)	<ol style="list-style-type: none"> 1. The researcher considered broad perspectives from professionals working in the primary healthcare sector, as well as disabled children and their parents. 2. The research was conducted in the UK and investigated the needs of such families and their perceptions of the services supporting them at home. 3. A good explanation was provided with details on discussion and results of the study. 	<ol style="list-style-type: none"> 1. Participants were recruited from three children's hospitals in the north of England, therefore data cannot be generalised. 2. Ethical consideration was not fully mentioned.
McConkey and Truesdale (2000)	<ol style="list-style-type: none"> 1. The size of the sample was significant. 2. The participants included nurses, therapists and undergraduate and postgraduate students 	<ol style="list-style-type: none"> 1. The study focused on staff undertaking further professional training and may not be representative of the wider nursing population. 2. The participants were only recruited from Ulster University. 3. The researcher assessed what respondents said they would do rather than their actual behaviour with people who have learning disabilities. 4. There were no direct observations to

Study	Strengths	Limitations
Ford and Turner (2001)	<ol style="list-style-type: none"> 1. This study presented one possible way of interpreting the participants' experiences and exploring their stories, revealing the complexity of the phenomenon of caring for children with special needs. 2. The study generated questions regarding notions of increased involvement and over-involvement as well as questions about how experiences of increased involvement differ to relationships of over-involvement and when increased involvement might become problematic. 	<p style="text-align: center;">operationalise performance.</p> <ol style="list-style-type: none"> 1. The sample was small (only 4 nurses) and may not be representative of the population. 2. The researchers were colleagues with the participants.
Sowney and Barr (2007)	<ol style="list-style-type: none"> 1. A good explanation was provided with details on discussion and results of the study. 2. Ethical consideration was mentioned. 3. The sampling was quite adequate: a purposive sample of nurses working within the accident and emergency departments of five general hospitals across Northern Ireland. 4. The use of focus groups is a valuable method to encourage a number of opinions to be heard and validated. 	<ol style="list-style-type: none"> 1. The sample may only be representative of the population of Northern Ireland, and so findings cannot be generalised to all nurses in accident and emergency services. 2. Too many participants in focus groups reduce the opportunity for all opinions to be heard.
Sowney and Barr (2006)	<ol style="list-style-type: none"> 1. A good explanation was provided with details on discussion and results of the study. 2. Ethical consideration was mentioned. 3. The sampling was quite adequate: a purposive sample of nurses working within the accident and emergency departments of five general hospitals across Northern Ireland. 4. The use of focus groups is a valuable method to encourage a number of opinions to be heard and validated. 5. A recommendation was provided. 	<ol style="list-style-type: none"> 1. The sample may only be representative of the population of Northern Ireland and so findings cannot be generalised to all nurses in accident and emergency services. 2. Too many participants in focus groups reduce the opportunity for all opinions to be heard.

Chapter Two

Study	Strengths	Limitations
Lewis and Stanfert-Kroese (2010)	<ol style="list-style-type: none"> 1. Ethical consideration was mentioned. 2. The pilot study, reliability and validity was explained. 3. A good explanation was provided with details on the results of the study. 4. The researcher developed a vignette style self-report questionnaire which was a novel approach to measuring attitudes. 5. A recommendation was provided for further studies. 	<ol style="list-style-type: none"> 1. The response rate was 50%.
Dinsomre and Higgins (2011)	<ol style="list-style-type: none"> 1. Pilot study was explained 2. A good explanation was provided with details on the results of the study. 	<ol style="list-style-type: none"> 1. The sample may only be representative of the population of Merseyside and so findings cannot be generalised to all health services. 2. The researcher assessed what clients said they would do rather than using another approach such as observation. 3. The process of interviews and analysis of data was not well explained.
Hewitt-Taylor (2008b)	<ol style="list-style-type: none"> 1. All nursing staff and parents who were involved with the support of one family participated in this study. 2. Ethical approval was obtained. 3. Implications for practice were provided. 	The findings were not intended to be generalisable.
Hewitt-Taylor (2008a)	The aim was to explore individuals' perceptions and experiences.	<ol style="list-style-type: none"> 1. The intention was not to achieve generalisability. 2. Parents' views did not necessarily reflect the child's views.
Iacono and Davis (2003)	<ol style="list-style-type: none"> 1. The researchers used a mixed methodology. First, they developed their questionnaire by using a focus group and consultation with knowledgeable staff; they then conducted the questionnaire and interviewed participants. 2. A good explanation was provided with details on discussion and results of the study. 3. A new instrument was constructed (questionnaire). 	<ol style="list-style-type: none"> 1. The generalisability of the results from the present study is limited in light of the poor response rate. A higher response rate (119 of the total 328 respondents) could have been achieved by a more targeted approach, a strategy that was difficult to implement because of problems with the client databases. 2. The researcher assessed what respondents said

Study	Strengths	Limitations
		<p>they would do rather than their actual behaviour with people who have learning disabilities.</p> <ol style="list-style-type: none"> 3. Reliability and validity were not mentioned. 4. The questionnaire was developed specifically for this study and had not been previously validated.
Phua et al. (2005)	<ol style="list-style-type: none"> 1. The study compared two group of parents: parents of able-bodied children and parents of children with CP. 2. A new instrument was constructed (questionnaire). 3. Face, content and some construct validity was achieved by the development of a parental satisfaction questionnaire. 4. A measure of the internal consistency reliability of each domain was performed as a part of this study. 5. A pilot study was conducted. 6. A good explanation was provided with details on discussion and results of the study. 	<ol style="list-style-type: none"> 1. The questionnaire was developed specifically for this study and had not been previously validated. 2. A test-retest was not conducted. 3. The generalisability of the results from the present study is limited as it was conducted in only one hospital.
Chung and Corbett (1998)	<ol style="list-style-type: none"> 1. The study compared two groups of staff: staff in hospital-based bungalows and in a community unit. 2. Two methods were utilised for the study: a self-constructed staff questionnaire and an interview. 3. The characteristics of their clients were considered. 4. A good explanation was provided for the findings. 	<ol style="list-style-type: none"> 1. Generalisability of the study was limited due to a small sample. 2. Dissimilarity between the clients' characteristics. 3. Ethical approval, validity and reliability of the study were not mentioned.
Hayes and Kjiiox (1984)	<ol style="list-style-type: none"> 1. A qualitative method was utilised for describing a phenomena relating to nursing concerns. 2. A good explanation was provided for the findings. 3. A good size sample was used (n=40). 4. Stress theory was applied for the background of the study. 	Two groups were recruited for the study: parents of children with cancer and parents with disabled children. Their opinions were not compared.
Hatton et al. (1999)	1. This study conducted regression analysis with a	1. A single method was utilised.

Chapter Two

Study	Strengths	Limitations
	<ul style="list-style-type: none"> 1. wide range of factors related to staff outcomes. 2. A good number of direct care staff were recruited for sampling. 3. The survey included staff in residential and non-residential services. 4. A path analysis was applied. 	<ul style="list-style-type: none"> 2. There was a low response rate (44%). 3. Validity and reliability of the study were not mentioned. 4. Sub-groups such as young staff were not considered. 5. Only health agencies were considered in this study, not different agency sectors.
Sen and Yurtsever (2007)	<ul style="list-style-type: none"> 1. The sample size was good (n=103). 2. The researcher constructed the tool for this study. 3. A good explanation was provided for the results. 4. Ethical approval was mentioned. 5. Application to nursing practice was mentioned. 	<ul style="list-style-type: none"> 1. Only a descriptive study was utilised; in this case a mixed methods or qualitative approach would have provided more in-depth data. 2. Validity and reliability instruments were not mentioned. 3. The researcher did not conduct a pilot study.
Hemsley et al. (2008c)	<ul style="list-style-type: none"> 1. Ethical approval was mentioned. 2. The participants included both hospital staff and disability services. 3. Good explanations were provided for the results of the study. 4. Transcription and analysis was conducted by both researchers. 	<ul style="list-style-type: none"> 1. The sample was small (n=6). 2. Validity and reliability were not mentioned. 3. Participants were recruited through only one agency, related to care provision to adults with disabilities.
Liptak et al.(2006)	<ul style="list-style-type: none"> 1. Good explanations were provided for the results. 2. The researchers used a valid instrument. 3. The survey translated into Spanish aiming to encourage non-English language speakers to correspond. 4. The additional data analysis was conducted for sub-group dominants. 	<ul style="list-style-type: none"> 1. The researchers used a convenience sample which cannot be representative of all parents with disabled children. 2. Provided a very brief recommendation 3. Only a descriptive study was utilised; in this case a mixed method or qualitative approach would have provided more in-depth data relating to satisfaction levels expressed by families with disabled children. 4. The approach was a mailed survey. 5. The response rate to survey was %44.
Bakker et al.(2000)	<ul style="list-style-type: none"> 1. The researchers used multi-questionnaires 2. Good explanation was provided for the results. 3. .Provided practical implications 	<ul style="list-style-type: none"> 1. Participants were all one gender and mostly younger than 30 years old. 2. The research conducted in a local area.

Study	Strengths	Limitations
		<ul style="list-style-type: none"> 3. Ethical approval was not mentioned. 4. The design of study was cross-sectional which cannot provide a deep interpretation of potentially causal effects. 5. The lack of objective measures of deficiency in health or functional capacity.
Gieter et al. (Gieter et al. 2006)	<ul style="list-style-type: none"> 1. Two different methods utilised by the researchers: semi-structure interviews and questionnaire 2. The researchers constructed the questionnaire by conducting a literature review. 3. Provided a good background 4. Provided organisation recommendation. 	<ul style="list-style-type: none"> 1. Validity of questionnaire was not mentioned. 2. Ethical approval was not mentioned.
Backer et al. (Backer et al. 2009)	<ul style="list-style-type: none"> 1. Provided recommendations for enhancing hospital care for disabled patients. 2. Inclusion criteria provided 3. Provided transparency of search process 4. A number of themes generated from search 5. Well-presented tables 	<ul style="list-style-type: none"> 1. Based more on the UK research
Balandin et al.(2001)	<ul style="list-style-type: none"> 1. Developed the interview protocol by contributing 3 nurses alongside 3 disabled participants. 2. Pilot interviews conducted. 3. The ethical approval was mentioned. 4. Implications for further research were provided. 	<ul style="list-style-type: none"> 1. The participants recruited from a private organisation. 2. The participants admitted to different wards which may effect the results. 3. The participants were not currently hospitalised or be in the hospital which may effect their memories and experiences. 4. The sample was small (n=10).
Hemsley et al.(2001)	<ul style="list-style-type: none"> 1. A pilot study was conducted 2. The participants recruited from 4 hospitals in Sydney from different wards. 3. Good explanation was provided for the results. 4. Two different researchers involved with interview and analysis the data which reduce the risk of bias 5. Provided a couple of nursing implications 	<ul style="list-style-type: none"> 1. Did not provide organisational implications. 2. The ethical approval was not mentioned. 3. The researchers did not use any model for analysis of the qualitative data.

Chapter Two

Study	Strengths	Limitations
Cumella and Martin (2004a)	<ol style="list-style-type: none"> 1. Collected a diverse range of experiences from different sectors who are involved with the subject of the study 2. Give the voice to disabled patients and their carers 3. Use information to develop policies and improve clinical practice 	<ol style="list-style-type: none"> 1. Not provided detailed and comprehensive explanation about data analysis 2. The ethical approval was not mentioned. 3. Did not provide organisational implications. 4. No recommendation for further studies. 5. Perhaps conducting some individual interviews could provide more in-depth information
Hewitt-Taylor (2008b)	<ol style="list-style-type: none"> 1. Ethical approval was mentioned. 2. Good explanation was provided for the data analysis and the results. 3. Provided some recommendation for improving transition process for teenager with complex health needs. 	<ol style="list-style-type: none"> 1. The findings could not be generalised due to sample size. 2. Not providing any information from different streams that impact on the quality of support.
Milner et al. (1996)	<ol style="list-style-type: none"> 1. The researchers constructed a new instrument for satisfaction of parents with disabled children 2. 71% response rate. 3. Provided good tables for presenting the data. 4. Face validity obtained. 	<ol style="list-style-type: none"> 1. Ethical approval was not mentioned. 2. Gathering data limited to an inner district of London. 3. No organisational recommendation provided 4. No suggestion for further studies provided.
Roberts (2001)	<ol style="list-style-type: none"> 1. Provided practical recommendation for nurses. 2. Provided good explanation of the results. 	<ol style="list-style-type: none"> 1. Low response rate (22%). 2. Not provided detailed and comprehensive explanation about data analysis 3. Only a descriptive study was utilised; in this case a mixed method or qualitative approach would have provided more in-depth data relating to the subject of the study
Brown and Guvenir (2009)	<ol style="list-style-type: none"> 1. A qualitative study was utilised for describing the phenomena relating to the experiences of children with disabilities. 2. The researchers recruited carers, children and nursing staff. 3. Ethical approval, validity and reliability were mentioned. 4. A good explanation was provided for the results. 5. Children admitted for less than 24 hours were 	<ol style="list-style-type: none"> 1. Due to the small size of the study, the conclusion cannot be generalised. 2. The study utilised a single method only. 3. Not very comprehensive and detailed explanation about the data analysis was provided.

Study	Strengths	Limitations
	excluded from the sampling, therefore, only children with more prolonged health needs were considered within the study. 6. Some suggestions were made for further studies.	

Table 2.7 Strengths/Limitations Resulting from Critiquing Process

Chapter Two

2.3.2 General Trends and Patterns in the Literature Review

2.3.2.1 Country of Origin

35 papers were identified and classified as primarily being about care delivery to disabled children during admission to hospital. Within these 35, the majority of papers originated from the UK (58.6%) and Australia (13.7%), followed by Ireland (10.3%), Canada (10.3%), Greece (3.4%), and Turkey (3.4%). Although the number of children with disabilities has increased significantly around the world, it is apparent that this area has been searched more in the UK than in other countries.

2.3.2.2 Papers Focus: Nursing Staff's Perspectives

17 papers were identified as relating to nursing staff's experience of care delivery to disabled children; 14 of these related to challenges and three to rewards for nurses from care delivery to disabled children and their families.

2.3.2.3. A Summary of the Main Themes from the Literature Relating to Nurses Perspectives of Care Delivery to Disabled Children and Their Families

A literature review was undertaken in order to identify the main themes relating to this topic as discussed in the 17 papers; these are summarised in **Error! Reference source not found.** The literature was categorised into 10 road themes:

- Communication difficulties
- Provision of information
- Lack of support
- Reliance on carers
- Working with People with complex health needs including learning or intellectual disabilities
- Dissatisfaction and strains of the job
- The physical environment
- Negative attitudes towards patients with learning disability
- Limited time and problems with assisting patients with learning disability
- Expert parents

Theme	Research findings related to the theme
Communication difficulties	Misunderstanding of clients and caregivers about the role of service (Lunsky et al. 2008) Communication difficulties (Sowney & Barr 2006; Sowney & Barr 2007; Lunsky et al. 2008) Special relationships (Ford & Turner 2001) Developing trust between nurses and families (Ford & Turner 2001)
Provision of information	Lack of information about available services (Lunsky et al. 2008) Insufficient information available about client background (Lunsky et al. 2008)
Lack of support	Lack of support from colleagues and supervisors (Hatton et al. 1999) Lack of staff support (Hatton et al. 1999)
Reliance on carers	Reliance on carer to provide care in hospital in terms of communication, advocacy, protection of information exchange, direct care and emotional support (Sowney & Barr 2006; Sowney & Barr 2007; Brown & Guvenir 2009)
Working with people with complex health needs including learning or intellectual disabilities	Insufficient training (Chung & Corbett 1998) Lack of knowledge and experience (Sowney & Barr 2006; Sowney & Barr 2007; Lunsky et al. 2008) Lack of confidence in working with LD patients (McConkey & Truesdale 2000)
Dissatisfaction and strains of the job	Time-consuming (Lunsky et al. 2008) Longer shifts (Hatton et al. 1999) Shortage of nursing staff (Chung & Corbett 1998) Dissatisfaction with salary (Chung & Corbett 1998) Burnout (Chung & Corbett 1998; Lunsky et al. 2008) Influence on work decisions (Hatton et al. 1999) Increasing capacity of staff to provide care (Brown & Guvenir 2009) Role ambiguity (Hatton et al. 1999) Low-status job (Hatton et al. 1999) Feelings of frustration and guilt (Ford & Turner 2001) Lack of good practice (Sowney & Barr 2007) Difficulties with gaining consent (Sowney & Barr 2006; Sowney & Barr 2007)
The physical environment	Inappropriate hospital environment (Lunsky et al. 2008) Limited respite and residential placement (Lunsky et al. 2008)
Negative attitudes toward patients with learning disabilities	Less positive attitudes towards patients with LD (Lewis & Stenfert-Kroese 2010) More negative emotions towards patients with LD (Lewis & Stenfert-Kroese 2010) Alienating commitment (Hatton et al. 1999)
Limited time and problems with assisting patients	Not enough time to assist patients with learning disabilities (Hemsley et al. 2008c)

Chapter Two

Theme	Research findings related to the theme
with learning disabilities	
Expert parents	Expert parents (Ford & Turner 2001)

Table 2.8: Research about nursing perspectives towards care for disabled patients and their families

2.3.3 Challenges for Nursing Staff in Caring for Disabled Children

Nursing staff who work with disabled children and their families confront a variety of rewards and challenges in their work. Ford and Turner (2001) noted that nursing is a caring profession and that the relationship between nurse and patient can be challenging. In the literature, only 14 papers could be identified from the last 15 years that explored these challenges (Slevin & Sines 1996; Chung & Corbett 1998; Hatton et al. 1999; McConkey & Truesdale 2000; Ford & Turner 2001; Hemsley et al. 2001; Glaysher 2005; Hewitt-Taylor 2005a; Sowney & Barr 2006; Sowney & Barr 2007; Hemsley et al. 2008c; Lunsky et al. 2008; Matziou et al. 2009; Lewis & Stenfert-Kroese 2010); nine of the 14 were conducted in the UK and Ireland. Of these papers, six were of a qualitative design, five were of a quantitative design, two were mixed methods and one was a review of service. The sample size in the papers reporting qualitative research was typically less than 50, with the majority of studies being far smaller. This limitation in population size means that it is inappropriate to generalise the findings.

2.3.3.1 Communication Difficulties

The importance of direct nurse-patient communication has been highlighted by several studies (Hart 1998a; Balandin et al. 2001; Hemsley et al. 2001). Four studies identified communication difficulties between nursing staff and disabled patients and their families (Ford & Turner 2001; Hemsley et al. 2001; Sowney & Barr 2007; Lunsky et al. 2008).

Sowney and Barr (2007), whose study utilised focus groups, revealed that problems with communication constitute the most significant challenge for nurses delivering care to patients with learning disabilities within A&E wards. The researchers concluded that difficulty with communication has negative

effects on patients' needs, as it means that patients are not informed appropriately about their health status and that nurses are unable to gain valid consent. Additionally, staff's lack of understanding of patients with learning disabilities may have further negative effects on patients such as decreased autonomy, less cooperation, fear and stress. The sampling process was reasonably acceptable for a qualitative study, but as the study was confined to Northern Ireland, the data could not be generalised to all A&E departments. Additionally, no intellectual disability nurses were included. This research provided enough data analysis, discussion and rationale for the study to be well understood, and also provided deep information.

Ford and Turner (2001) used in-depth interviews to understand children's nurses' experiences of caring for children with special needs and their families. The researcher found that special relationships formed with this group of patients are different than those with other patients, meaning that nurses are more involved with them than usual. One participant gave a statement relating to this special relationship: 'you get to know them and their families'. Two major limitations of this study were a small sample size and the fact that the participants were the researchers' colleagues.

Hemsley et al. (2001) conducted interviews with 20 Australian nurses caring for patients with severe communication impairments. Nurses felt that the difficulties related to caring for these patients include lack of time available to communicate with patients, lack of access to augmentative and alternative communication (AAC) resources and lack of familiarity with using them. The findings suggested that more training for nurses in this field is necessary. The researchers used a purposive sample with inclusion criteria, which had an effect on the credibility of this study. Additionally, half of the participants had training in this area, but their response was not compared with that of the other half. Therefore, the findings of these studies showed that communication with disabled patients is important and that nurses need more training.

2.3.3.2 Provision of Information

Cumella and Martin (2000) held two conferences in London and Sheffield, followed by two workshops in hospitals; there were 40 participants in each meeting, including learning disability patients and their supporters, professional teams and health service managers. The researchers found that

Chapter Two

hospital admission is a traumatic and intimidating experience for disabled patients, particularly due to a lack of comprehensive information delivered by hospital staff. They recommended tackling the problems faced by disabled patients based on the data obtained; however, they did not determine which of the recommended solutions would be clinically or organisationally effective.

Sowney and Barr (2007) argued that the health service needs to be more active in producing documents for patients with learning disabilities. Inadequate time for gathering information about patients was noted by Lunsky et al. (2008). Furthermore, many researchers have emphasised the importance of accessible and user-friendly information (Backer et al. 2009).

Another challenge revealed by Lunsky et al. (2008) was insufficient information about a patient's background. The researchers conducted focus groups with hospital staff members (n=44). The findings were based only on emergency staff perspectives; there were no other sectors involved, such as patients. Therefore, the perceptions of patients with disability were not explored. In addition, this study had a single facilitator, which may have influenced the diversity of responses from hospital staff.

2.3.3.3 Lack of Support

Lack of staff support as a factor in job strain while working with patients with learning disabilities was identified by Hatton et al. (1999), who used a postal questionnaire to survey staff who worked with these patients (n=450). The aim of the study was to investigate the factors related to general distress, job strain and work dissatisfaction. Job status, support from supervisors and colleagues and influence on work-related decisions were all identified as factors in job satisfaction. The researchers only used a single method to explore the topic under investigation. Furthermore, although the questionnaire was constructed by the researchers and widely distributed, the response rate was low (44%). (Polit and Beck (2006) reported that a response rate of more than 65% is desirable for a postal questionnaire.) However, a good number of direct care staff were included in the sample and the survey included staff from residential and non-residential services.

2.3.3.4 Working with People with Complex Health Needs Including Learning or Intellectual Disabilities

Training and improving the knowledge of nursing staff are strategies that would promote quality of care and enhance attitudes towards people with learning disabilities (Slevin & Sines 1996; Cumella & Martin 2000; McConkey & Truesdale 2000). A quantitative survey was conducted by Hewitt-Taylor (2005b) to identify the education and training needs of nurses caring for children with complex health needs from the hospital managers' perspective. Responses to the questionnaire used in this study revealed that 85.7% of care managers believed that the technical and medical aspects of care are more dominant than the psychosocial aspects. This research article provided an adequate background to the study, discussion and results. However, it was not comprehensive, as only one questionnaire was used. Three different sources were selected for sampling, but the target groups were entirely composed of care managers, who were not directly involved in care activities. The identity and role of the person responsible for distributing the questionnaire was not made clear. In addition, the study had a medical and technical bias due to there being very little focus on the psychosocial aspects of training. A number of studies have highlighted a lack of staff knowledge and limited expertise in caring for patients with learning disabilities (Slevin & Sines 1996; Hart 1998b; Fox & Wilson 1999; Iacono & Davis 2003). Sowney and Barr (2006) noted that lack of knowledge and competence may lead to fear and vulnerability on the part of staff.

McConkey and Truesdale (2000) conducted a survey in Ireland with the aim of exploring nurses' and therapists' experiences of contact with people with learning disabilities. The results showed that both nurses and therapists are significantly less confident in caring for a patient with a learning disability than one with a physical disability. The researchers did not mention anything about either the validity or reliability of the questionnaire. Moreover, the study was focused on staff who were undertaking further professional training; therefore, the sample may not have been representative of the wider nursing population. The findings focused on what respondents had said, rather than deriving from direct observation of actual performance. However, the sample size was significant.

Chapter Two

2.3.3.5 Dissatisfaction and Strains of the Job

Chung and Corbett (1998) reported that the hospital staff in their study were dissatisfied with their salaries and did not enjoy contact with their patients as much as members of the comparison group who worked in the community unit. The hospital staff felt emotionally exhausted and depersonalised. Additionally, a positive relationship between staff burnout and management issues was explored. The strength of this study was the use of two information-gathering methods: a self-constructed staff questionnaire and an interview. However, no explanations were provided concerning the ethical considerations, validity and reliability of the study.

2.3.3.6 The Physical Environment

Backer et al. (2009) noted that physical environment may provide additional difficulties for people with learning disabilities. Glayser (2005) found that the physical environment of the hospital did not lend itself well to a positive experience for patients with learning disabilities during hospital admission, due to factors such as poor layout and navigation. This review was conducted in only one local hospital providing services for disabled patients. However, reviewers included four members with learning disabilities, trained for the purpose of the review. Limited facilities in wards, which impacted on nurses' performance, were reported by Brown and Guvenir (2009). Additionally, an inappropriate hospital environment was recognised to be a challenge for nursing staff by Lunskey et al. (2008).

2.3.3.7 Negative Attitudes toward Patients with Learning Disabilities

Negative attitudes among healthcare professionals towards people with learning disabilities have been reported several times (Slevin & Sines 1996; Matziou et al. 2009; Lewis & Stenfert-Kroese 2010; Shama & Stenfert-Kroese 2010). It is argued that the attitudes of nursing staff towards caring for these patients are extremely important and may affect the quality and effectiveness of the care provided (Shama & Stenfert-Kroese 2010).

Lewis and Stenfert-Kroese (2010) investigated the attitudes and emotional reactions towards caring for patients with learning disabilities reported by nursing staff working in general hospitals in the UK by employing a self-report

questionnaire. The reliability of the study was provided by a test/retest element to the questionnaire and a pilot study. The sample consisted of registered nurses (n=34), one student nurse and nursing assistants (n=13). The response rate was low (50%). Nursing staff who participated in this study reported more negative attitudes and emotions when caring for a patient with a learning disability compared to caring for a patient with a physical disability.

These findings were confirmed by Slevin and Sines (1996), who reported negative attitudes from healthcare professionals towards people with learning disabilities. This study used an attitude measurement questionnaire, conducted with a random sample of nurses in a general hospital (n=31). Their attitudes towards patients with learning disabilities were examined, and the attitudes of graduate and non-graduate nurses were compared. This was followed by an in-depth interview with a sub-sample (n=10). The result of these negative attitudes was overdependence on carers. This in turn led to a reduction in the need for nurses to be involved with caring for patients (Slevin and Sines 1996; Scullion 1999; Weiss et al. 2009). Additionally, the results showed that more educated nurses (graduates) had better attitudes towards patients with learning disabilities than non-graduate nurses. Therefore, improving knowledge may affect nurses' attitudes toward these patients. This study involved nurses working in the general setting, meaning that comparison with the field of disability is difficult. However, two methods were employed. According to Martin et al. (2010), data collection using multiple methods provides more information, which leads to a better interpretation of the data.

This need for further training was corroborated by the study of Matziou et al. (2009). This was a comparative study between nursing students (n=228), post-diploma student nurses (n=90) and paediatric nurses (n=123), aimed at investigating the attitudes of nurses toward disabled children. Overall, nurses' attitudes appeared to be negative. The researchers suggested that nursing education in this field is poor and needs to be reconsidered in order to achieve more positive attitudes towards this population. The methodology of this research was weak as the design was cross-sectional, which meant that the examination of the effectiveness of nursing education on students' attitude was not adequate. Additionally, some variables, such as previous work and contact with disabled patients, were not examined. However, the questionnaire had a good rate of internal consistency (0.80).

Chapter Two

2.3.3.8 Reliance on Carers/Family

Families and carers are good sources for supporting intellectually disabled people, due to their existing knowledge of their needs and behaviour (Backer et al. 2009). Therefore, negotiation with families and carers during hospital admission of a patient with learning disability is essential (Fox & Wilson 1999), and caring can be shared (Hayes & Kjioux 1984). Dependence on carers was one theme identified by the study carried out by Sowney and Barr (2006).

Hemsley et al. (2008c) carried out a focus group with six participants working in hospital or disability services. Participants noted that a gap existed between ideal care and what was actually available. The researchers emphasised dependence on family carers in hospital, and noted that communication, advocacy, protection, direct care and emotional support were all issues that required attention. In light of the small number of participants (n=6) involved in this study, and the fact that they were recruited from only one agency, the results cannot be generalised. However, participants were recruited from both hospital and disability services. Inter-rater reliability was provided for this study, as transcription and analysis of the results were undertaken by both of the researchers.

2.3.3.9 Limited Time and Problems with Assisting Patients with Learning Disabilities

Ford and Turner (2001) studied paediatric nurses' (n=4) experiences of caring for children with special needs (from birth to six years) and their families in an acute care setting in Australia; the information was gathered by means of semi-structured interviews. Four themes were generated from this study. One challenge that emerged quite clearly was the time available to assist and care for patients with special care needs. Staff were only able to deliver the more immediate care needs of patients, and could not provide holistic care, which is considered vital to high quality care. The nurses experienced frustration and feelings of guilt due to the gap between parents' and nurses' expectations of the child's care needs. Two major limitations of this study were i) a small sample size and ii) the fact that the participants were the researchers' colleagues.

Power and Sharp (1988) drew up their data from two separate studies using the same questionnaire (Maslach Burnout Inventory). The authors reported that workload is a stressor for nurses caring for patients with learning disabilities. The questionnaire required reliability and viability, as the authors noted. However, these studies included criteria, due to selected samples of staff working with people with learning disabilities. 'Working too hard on my job' was a burnout factor identified by Hastings et al. (2004).

2.3.3.10 Expert Parents

The notion of expert parents, presented in Ford and Turner's (2001) study under the theme 'multiple dimension of who is expert', was described by participants in this study as a period of transition in terms of role change.

2.3.4 Rewards for Nurses from Caring for Disabled Children

Only three papers from the last 12 years have been identified in the literature relating to rewards for nurses caring for disabled children (Ford & Turner 2001; Gieter et al. 2006; Hewitt-Taylor 2008a). Only a small part of Ford and Turner's study focused on these rewards. Gieter et al. (2006) researched the rewards for nurses by means of interviews and a questionnaire (n=20). The data revealed three main reward categories: financial, non-financial and psychological. The findings showed that aside from financial rewards, a number of psychological and non-financial rewards were also significant for nurses, such as appreciation of their work by others, compliments and contact with patients. This study was conducted in a general setting not specific to working with disabled patients. However, the mixed method design provided richer information, although the sample size was too small. Bakker et al. (2000a) found that imbalance or lack of reward in whatever form leads to emotional exhaustion and depersonalisation and impacts negatively on personal accomplishment. Hewitt-Taylor (2008a) reported that the most significant rewards from nurses' relationships with children are being able to communicate with them, meeting not only medical and technical needs but also providing holistic care at all times, being entrusted with the care of other people's children, acting as a coordinator and facilitator and providing support for the whole family.

Chapter Two

Ford and Turner (2001) revealed that parents' observation of nurses' practice leads to a trusting relationship, with a therapeutic outcome for the family. Haas et al. (1992) emphasised parent/nurse partnerships in caring for children with special healthcare needs as both important and valuable. Various studies of the rewards of caring for disabled children provide a suitable field for this study.

2.3.5: Search Focus: Parent/Carer Perspectives

It has been well acknowledged in the literature that disabled children receiving inpatient care and their families are dissatisfied with many aspects of that care (Fox & Wilson 1999; Iacono & Davis 2003; Phua et al. 2005; Liptak et al. 2006; Sowney & Barr 2006). It is apparent that most carers of this population are the children's parents; therefore, their perspective about care delivery to children with disabilities is, or least should be, valued. This body of literature represents the views of parents and families (14/18), service users or patients (2/18) and mixed groups (2/18). These studies mainly used a qualitative approach by means of interview (11/18) or questionnaire (5/18); only two (2/18) used mixed methods, a questionnaire followed by a focus group with disabled adult patients. Most of the qualitative research studies made use of a sample of less than 20 people.

Dinsmore (2011) interviewed carers and relatives of patients with learning disabilities (n=13) in the UK. The study highlighted that patients with learning disabilities wanted to see greater empathy and understanding from hospital staff. In addition, the research indicated families' particular dissatisfaction with inappropriate delivery of information and inadequate empathy from the health professional team. This research did not provide sufficient background context or a review of literature. The research was based only on the clients' perspectives, rather than using other approaches such as observation to explore the problem. On the other hand, the interview process, data analysis and details of the results of the study were well explained. Due to the sample size, demographic details and recruitment from local learning disability charities, the findings cannot be generalised to all the health services.

Despite general dissatisfaction with hospital staff, there is research-based evidence that shows a level of satisfaction in some areas. Iacono and Davis (2003) conducted a mixed methods study in Australia. The researchers

investigated whether the needs of people with developmental disabilities were being met during hospitalisation. Overall, a group of adults with physical disabilities (n=328) responded to the questionnaire, which was followed up by a limited number of interviews (n=11). The participants reported general satisfaction with the care. In contrast, reliance on support from parents emerged as a result of nurses' lack of skills and time. However, the generalisability of this study was limited in light of the poor response and difficulties with distributing the questionnaire. The larger context of the role of hospital staff and their supporters needs to be considered. Although a detailed discussion of the results of the study was included, the specific questionnaire developed for the study had not been validated.

Phua et al. (2005) carried out a cross-sectional study on parents of children with Cerebral Palsy (CP) (n=40) and parents of able-bodied children (n=90), aiming to measure the level of satisfaction with inpatient hospital care in Melbourne by means of a parental satisfaction questionnaire. Overall, parents of children with CP were more dissatisfied ($P<0.0001$) with the hospitalisation than their 'healthy' counterparts. Considerable differences were found in four of the areas assessed: the admissions process ($P=0.0002$); the care that their child received ($P<0.0001$); confidence in communication with doctors and nurses ($P<0.0001$); and their personal experience of hospitalisation ($P=0.0076$). A new questionnaire, which had good face content, construct validity and internal consistency, was compiled for this study. A pilot study was conducted. However, as all the participants were recruited on the second or fourth day of admission, the findings may have been limited to short term hospitalisation experiences.

Brown and Guvenir (2009) conducted semi-structured interviews with carers of children (n=13), nursing staff (n=13) and two children with learning disabilities. Their aim was to describe the experience of hospital admission for children with disabilities. Five themes emerged from this study. All participants expressed their anxiety about the hospital admission; also, the carers felt that staff were not well-prepared for meeting children's needs and managing their challenging behaviour during admission. The staff heavily relied on parents to meet the basic needs of their children. The parents also reported that the physical environment of the ward was not appropriate. This study provided

Chapter Two

some suggestions for further studies and has some clinical validity and reliability. However, the small sample size means that generalisability of this study is limited.

In the UK, Fox and Wilson (1999) conducted semi-structured interviews with the parents of young adults with learning disabilities (n=10). The study showed that at least half of the parents interviewed were dissatisfied with the level of care delivered to their children. Additionally, the parents believed that the staff were unresponsive to the children's needs; therefore, the parents were required to continue delivering care to their child. The researchers provided good recommendations relevant to practice. However, in light of the sample used in this study, the findings may not accurately represent the population. In addition, it is likely that there is recall bias as the study took place two years after the hospital experience.

2.3.5.1 Negative Attitudes

Negative attitudes towards people with learning disability have been reported often among healthcare professionals (Perkins 1993; Hart 1998a; Fox & Wilson 1999; Shama & Stenfert-Kroese 2010). It is argued that attitudes of nursing staff towards care for patients with learning disabilities are extremely important and may affect the quality and effectiveness of care (Shama & Stenfert-Kroese 2010).

One of the themes which emerged from the qualitative study by Fox and Wilson (1999) was the attitudes of the nurses. The researchers mentioned that the parents were concerned that the nursing staff did not understand the nature of their children's disabilities. In addition, negative attitudes from the hospital staff make for stressful experiences for patients and caregivers (Slevin & Sines 1996). Improving attitudes among nursing staff has been recommended by many researchers (Scullion 1999b; Shama & Stenfert-Kroese 2010).

A qualitative study carried out by Weiss et al. (2009) aimed to understand the experience of caregivers and adults with learning disability and mental health issues. The study took place in Canada using focus groups with unpaid (i.e. family members) and paid caregivers (i.e. staff from community agencies). The researcher used a thematic analysis and identified various issues from

caregivers' perspectives; the main issue identified was a lack of respect for the knowledge and expertise of caregivers. This study was limited to urban and suburban locations; it had inter-reliability and a pilot study was conducted. The researchers recommended that contact with patients with ID during training would improve positive attitudes among nursing staff (Slevin & Sines 1996). In addition, contact with disabled people in a pre-service clinical environment could raise levels of positive attitudes, empathy and competence when delivering care to children with learning disability (Wilson & Merrill 2002; Sanders et al. 2007).

2.3.5.2. Communication

Avis and Reardon (2008) designed a qualitative study to explore parents' views about how their children with additional needs had been cared for by hospital nursing staff. The sample was 12 parents of children with additional needs. It was concluded that parents' concerns related to developing a trusting relationship with the nurses delivering care to their child. This finding was confirmed in the study by Simons et al. (2002) regarding parental involvement in children's pain care. The most significant finding of that study was the relationship between difficulty with communication and frustration in parents and nurses. It was concluded that good communication is an essential part of quality of care. This study provides rich and detailed information about nursing care from parents' perspectives. However, the sample was small, recruited through only one respite children's centre and did not include all sectors relevant to children with special health needs.

Furthermore, parents often felt that their child's attempts to communicate were not valued (Hewitt-Taylor 2008). It has been proposed that stigmatising and negative attitudes among professionals have affected communication between hospital staff and patients (Barr 1999).

McConkey and Truesdale (2000) investigated reactions of nurses and therapists toward learning disability patients within the health services by using a questionnaire. The participants were only recruited from Ulster University. The findings show that both nurses and therapists had less confidence in working with ID patients than patients with physical disabilities. The study focused on staff who were in the process of undertaking

Chapter Two

professional training; therefore, it may not be representative of the broader nursing population. The findings also focus on what respondents said rather than researchers directly observing actual performance. On the other hand, the sample size was significant.

2.3.5.3. Partnership

Perkins (1993) conducted a qualitative study of the parental caregiving experience of 23 parents of hospitalised or recently hospitalised children (two to 13 years of age) with cognitive impairments. The researcher suggested that nurses and parents need detailed information about each other's backgrounds, expectations, goals, opinions and their roles during the child's hospitalisation in order to facilitate and create a partnership (Perkins 1993). The study revealed that hospitalisation is a stressful experience for parents. This was corroborated by the cross-sectional study of Phua et al. (2005) in Melbourne. The study showed that parents of disabled children in hospital displayed a much higher mean score on the Perceived Stress Scale (Ford & Turner 2001). Parents often have a sense of their experience being devalued or disregarded during their child's hospitalisation (Robinson 1985), exhaustion due to their child's needs (Hewitt-Taylor 2008), and a feeling of fear and distress (Cumella & Martin 2000).

Sen and Yurtsever (2007) carried out a descriptive study in Turkey in order to determine the difficulties experienced by families of disabled children. The researchers stated that having a disabled child is a critical condition that impacts on parents' psychological, social and economic status. They believed that nurses are professionals who can provide support during this distressing time and help them to cope with their difficulties.

If nurses were more willing to provide the extra help that severely disabled children require, the level of stress that parents experience during their child's hospitalisation may be reduced significantly. Roberts and Lawton (2001) studied severely disabled children (n=40,000) and found that more than 70% generally needed extra care with each of the following activities: washing, dressing, meal times, during the night and keeping occupied.

Parents are increasingly recognised as a valuable source, due to their capacity to plan their child's care and be a part of the supervision of the services

(DeGeeter et al. 2002; Simeonsson et al. 1995). The findings of the study conducted by Sowney and Barr (2006) supported the need for care to be shifted from dependence on nurses to a more collaborative approach with emphasis on promoting healthy relationships with parents. A significant number of studies revealed 'dependence on caregiver' as a stressor for parents (Fox & Wilson 1999; Lunsky et al. 2008; Hayes & Kjioux 1984).

There is a mutual misunderstanding about parents and nurses' responsibilities and different expectations of the parenting role (Ford & Turner 2001; Darbyshire 1995). These findings are supported by the work of Hayes and Kjioux (1984), which showed that parents understand their role in their hospitalised child's care differently to health professionals and that most parental stress is related to the gap between them and the healthcare workers. Hayes and Kjioux (1984) utilised a qualitative method to describe the phenomena under examination, with two groups of parents of disabled children and cancer patients (n=40); however, a comparison between groups was not carried out. The researchers suggested that improving nursing care could be achieved by better understanding parents' views of their hospital-related stress and its causes

Chapter Two

The main themes that emerged from the literature review are presented below (Table 2.9).

Communication difficulties	Lack of communication skills among staff (Fox & Wilson 1999; Avis & Reardon 2008; Hewitt-Taylor 2008a) Nurse-parent relationship (Avis & Reardon 2008) Lack of negotiation with parents (Hayes & Kjioux 1984; Avis & Reardon 2008) Partnership between nursing staff and parents (Perkins 1993) Insufficient empathy from healthcare professionals (Dinsmore & Higgins 2011) Space between health professionals and parents (Hayes & Kjioux 1984)
Knowledge and expertise of nursing staff	Lack of nursing expertise related to care for disabled children (Avis & Reardon 2008; Weiss et al. 2009) Lack of knowledge and skill among nursing staff (Iacono & Davis 2003; Weiss et al. 2009) Inappropriate nursing care plan (Fox & Wilson 1999) Lack of trust and confidence among nursing staff during care delivery to disabled patients (Avis & Reardon 2008) Diagnostic overshadowing and overmedication (Weiss et al. 2009) Lack of special training for nursing staff related to care of disabled people (Dinsmore & Higgins 2011)
Meeting children's and their families' needs	Lack of sensitivity to their needs (Fox & Wilson 1999) Not meeting patients' and their families' needs relating to getting to the toilet, getting their medication and moving from the bed (Iacono & Davis 2003) Lack of emotional support from nursing staff (Avis & Reardon 2008) Lack of respect for disabled people and their families from nursing staff (Weiss et al. 2009) Dissatisfaction on the part of disabled people and their families (Phua et al. 2005; Liptak et al. 2006)
Environment and equipment	Difficulties with equipment and provision of short term care (Kirk 1999) Inadequate space/ward environment (Brown & Guvenir 2009)
Dependence on families	Reliance on parents (Fox & Wilson 1999; Iacono & Davis 2003) Expert parents (Avis & Reardon 2008)
Others	Patient passports (Dinsmore & Higgins 2011) Lack of services for disabled patients (Weiss et al. 2009) Nursing staff not ready for admission of disabled patients (Brown & Guvenir 2009) Negative attitudes from staff (Iacono & Davis 2003) Child, carer and staff anxiety during hospital admission (Brown & Guvenir 2009) Difficulties with managing the child's behaviour (Brown & Guvenir 2009)

Table 2.9: Thematic Review of Parents' Perspectives of Care Delivery to Disabled Children and Their Families

2.4 Justification for This Study

Several studies have been conducted into health service provision for disabled patients, but there is a paucity of studies concerning nurses' perspectives and experiences. Service evaluation into the weaknesses and strengths of in-hospital care for children with disabilities has been limited. The literature from the last 23 years has emphasised that parents of children with disabilities are dissatisfied with hospital care. The majority of the literature overlooks parent or patient perspectives. There is a lack of service evaluation that explores all sectors involved in caring for children with disabilities.

While there is some research looking at the challenges, there is a distinct lack of literature examining the rewards of caring for children with disabilities; as such, this service evaluation has aimed to understand the aspects of caring for disabled children with greater emphasis on nursing experiences.

2.5 The Service Evaluation Question and Objectives

This project was designed to contribute to a greater understanding of inpatient care delivery to disabled children and young people and those with complex health needs.

2.5.1 Question

To what extent do children with complex disabilities and their families receive optimal care during hospital admission?

2.5.2 Objectives

- To explore the quality of inpatient care of disabled children
- To determine the rewards and challenges of working with disabled children and young people and those with complex health needs
- To analyse contemporary nursing curricula in order to ascertain areas of teaching pertinent to the care of disabled children and young people and those with complex health needs

Chapter Two

- To consider levels of compliance with policy benchmarks for disabled children and young people and those with complex health needs

2.6 Summary of the Chapter

This chapter has summarised the literature review process and presented a critique of selected literature relating to the experiences of nursing staff caring for disabled children during hospital admission. Chapter 3 will present the project methodology.

Chapter 3 : Project Methodology

3.1 Introduction

This study is part of a service evaluation aiming to gain an insight into the delivery of inpatient hospital care to children and young people with disabilities and those with complex health needs.

This project comprises three components:

1. Focus group activities using nominal group techniques (NGT) with registered children's nurses and HCSWs to identify the rewards and challenges of caring for disabled children and young people and those with complex health needs
2. An in-depth content analysis of three UK university curricula for undergraduate child health nursing pertinent to the care of disabled children and young people and those with complex health needs
3. An audit of compliance with child healthcare policy benchmarks pertinent to the care of disabled children and young people and those with complex health needs

3.2 Service Evaluation and Scholarship Activity

Evaluation is defined by the UK Evaluation Society (UKES 2011) as an in-depth study with a time scale, utilising a systematic approach and following analytical procedures. Additionally, it is a judgment or assessment of a service related to the needs of customers (Nolan & Grant 1993; Marsh & Glendenning 2005b; UKES 2011). The Institute of Medicine (2001) claimed that patients' needs and resources must be integral to any activities aimed at improving outcomes; therefore, a service evaluation can involve transfer of knowledge as well as monitoring and evaluation of the outcomes of the services provided (Graham & Tetroe 2007).

Marsh and Glendenning (2005a) noted that service evaluations are planned and conducted in order to develop a clearer understanding of the strengths and weaknesses of the service being offered

Chapter Three

A service evaluation provides evidence of the effectiveness of a service (NRES Ethics Consultation 2007) and can result in changes in practice (Wade 2005; Sampaio et al. 2008). Evaluation of services by using reliable ways to collect evidence may promote quality of care (Black 1992; Smith 1992; DiCenso et al. 1998; Estabrooks 2003; Le May & Holmes 2012); therefore, the benefits of service evaluation can be directed back at service providers (Nolan & Grant 1993; Marsh & Glendenning 2005b).

Promotion of health and provision of guidance for nursing care (Pearson 2004) are the ultimate aims of a service evaluation; this relates to the concept of application and its links to nursing scholarship. Application provides a bridge between theory and practice (Beattie 2000).

Clinical scholarship is a foundation for nursing professionals to make decisions to the best of their ability (Crookes & Bradshaw 2002). Schlotfeldt (1992) stated that clinical scholarship relates to improvement of nursing knowledge and ensuring that fundamental nursing services are delivered, with emphasis on standards for practice. Promotion of quality of care by service evaluations and implementing change was emphasised by Rycroft-Malone et al. (2002). Furthermore, Graham and Tetroe (2007) believed that findings generated from research studies and service evaluation should be translated from knowledge to action, which leads to a diminished gap between what we know and what we do. A good example of knowledge translation into action is the collaboration between the University of Sheffield and Sheffield Teaching Hospital NHS Foundation, led by Professor Kate Gerrish. The project aims to utilise findings from clinical audits and service evaluations in order to improve quality of care for patients (National Institute for Health Research 2000).

Palmer (1986) noted that clinical scholarship in the form of analytic observation of clients and patients might produce knowledge

NHS Direct (2012) contended that a service evaluation is a way of measuring current practice with the aim of generating internal recommendations for improvements. The aim of this current project is to create recommendations for enhancing service provision. Additionally, the results from this service evaluation can be used to redesign service provision with a focus on the needs of disabled children and their families. Some key benefits will be:

- More effective service provision
- Identification of drivers in terms of cost
- Planning and configuring services so as to inform policy-makers and decision-makers
- Improving clinical outcomes by utilising the findings (The Nuffield Trust 2007)

Service evaluations provide practical information relating to costs, benefits, strengths and weaknesses of service provision (Horan et al. 2004). Therefore, in order to meet the objective of this service evaluation, the project is utilising the seven domains of the Original Health Transition Fund as set out in the typology: the domains are presented in Table 3.1.

Type of Evaluation and Domains	Description
Appropriateness of the service for which it is designed	Is the designed service meeting the needs of disabled children and their families?
Efficiency and effectiveness of the service	Is this service implemented well or badly?
Competence of personnel	How competent are the managers and staff in meeting the needs of disabled children?
Quality of service	What is the quality of the service provided to families of disabled children?
Sustainability	Can optimum care be delivered to families with disabled children within the current configuration of the service?

Table 3.1 The domains utilised within the service evaluation. Source: (Hanucharunkul 2009)

Appendix 3.1 summarises the differences between research, clinical audits and service evaluation.

3.2.1 Dimensions of the Current Service Evaluation

This evaluation is formative, due to the on-going service delivered to disabled children and their families. The dimensions of an evaluated service are important factors to consider (Health Knowledge 2012). These dimensions include inputs, process, outputs and outcomes (Donabedian 1968) (see Table 3.2).

Chapter Three

	Structure/inputs	Process	Outputs	Outcomes
Definition	What makes service provision high quality, e.g. time, people?	How does it happen?	What does the service provide?	What are the actual benefits or disadvantages of the service provision?
Type of measure	<ul style="list-style-type: none"> • Costs • Resources: staff, equipment, buildings, beds 	<ul style="list-style-type: none"> • Patient care • Strategies, plans, policies • Patient pathway 	<ul style="list-style-type: none"> • Hospital activity • Number of complaints • Change in bed occupancy • Length of stay 	<ul style="list-style-type: none"> • Mortality • Impairment • Disability • Acceptability • Clinical and patient outcome measures • Discharge
Indicators	<ul style="list-style-type: none"> • Staff time • Expenditure 	<ul style="list-style-type: none"> • Patient records, treatment plans, information leaflets • Waiting times 	<ul style="list-style-type: none"> • Occupied bed days • Number of patients receiving treatment • Number of complaints 	<ul style="list-style-type: none"> • Mortality rate • Clinical and patient outcome measures • Emergency readmission rates

Table 3.2: Measures of each aspects of the evaluation (adapted from Health Knowledge 2012)

The current study focuses on the structure of the service evaluation in terms of the perspectives of nursing staff on care delivery to disabled children and their families.

3.2.2 Why Use Different Approaches for this Project?

Ingleton et al. (1997) highlighted that a service evaluation requires a comprehensive approach, due to the involvement of different interest groups and the complexities of service provision. Rossi and Wright (1984) believed that different methods are applicable to evaluation, especially when multiple views are required. In order to secure more comprehensive and complete data from different groups of participants, as well as in-depth information about the problem under study, different approaches were employed in this project. Gaining an understanding of individual perspectives requires not only the quantification of facts but also an in-depth understanding of the situation by the investigator.

In the nursing field, when a single method is insufficient, the investigator will use a comprehensive approach, which helps to explain the complexity and

variety of a healthcare situation (Morse 1991; Greene & Caracelli 1997; Morgan 1998; Foss & Ellefsen 2002; Sale et al. 2002b) such as caring for disabled children and their families.

Utilising different approaches in an evaluation study provides high quality evidence and additionally decreases bias (Smith et al. 2005). The qualitative component of an evaluation study tends to concern the individual rather than any clinical outcome, whereas the quantitative arm measures other aspects of service evaluation (Smith & Cantley 1988). Johnson et al. (2007) concluded that carrying out different methods provides broad strengths and creates inclusive knowledge and a deeper insight into the complexity of phenomena (Foss & Ellefsen 2002; Sale et al. 2002a). Table 3.3 illustrates the strengths of using different approaches.

<ol style="list-style-type: none"> 1. Ability to use numbers as well as words, pictures, insight, meaning and narrative (Johnson & Onwuegbuzie 2004) 2. Improves performance of one method by using the strength of the other method (Morgan 1998; Johnson & Onwuegbuzie 2004) 3. Overcomes the limitation of using a single technique (Brewer & Hunter 1989) 4. Provides stronger evidence for a conclusion (Morgan 1998; Johnson & Onwuegbuzie 2004) 5. Ability to increase the generalisability of the results (Johnson & Onwuegbuzie 2004) 6. Produces a more complete knowledge (Johnson & Onwuegbuzie 2004) 7. Improves the quality of study (Foss & Ellefsen 2002) 8. Develops the skills and knowledge of the investigator (Foss & Ellefsen 2002) 9. Produces a practical study (Morgan 1998) 10. Provides a validated, comprehensive and internally consistent explanation for findings (Burke et al. 2007; Polit & Beck 2008) 11. Provides a better and richer understanding of phenomena (Greene et al. 1989; Foss & Ellefsen 2002; Bryman 2006; Burke et al. 2007) 12. Provides deeper and more meaningful answers to a broader range of questions (Johnson & Onwuegbuzie 2004; 2007) 13. Provides a workable solution (Johnson & Onwuegbuzie 2004) 14. Provides more accurate information (Darbyshire et al. 2005; Parahoo 2006 ; Polit & Beck 2008)

Table 3.3: Strengths of using different approaches

3.2.3 Justification for Using Different Approaches for the Current Project

Understanding the complexity of the concept of care delivery to disabled children requires gathering data from different sources, as care is not a discrete activity but instead complex, with a wide range of professional

Chapter Three

settings (Parahoo 2006). In order to capture the most important aspects of care delivery to disabled children, and also in an attempt to eliminate the potential weaknesses of the single method, the investigator combined different approaches. Johnson et al. (2007) and Morgan (1998) suggested that different approaches might provide a greater range of findings and outcomes, as well as maximising the success of the study.

3.2.4 Steps for Conducting the Current Service Evaluation

Marsh and Glendenning (2005a) have developed a service evaluation toolkit on behalf of the University of Cambridgeshire. The Cambridgeshire model is a 10-step approach for conducting a service evaluation of any service within health and social care, with the objective of producing recommendations for improvements in the service under evaluation (Marsh & Glendenning 2005a). This study followed this service evaluation toolkit, as outlined by Marsh and Glendenning (2005a):

1. Identifying a requirement for conducting an evaluation
2. Selecting stakeholders
3. Identifying the key questions for the study
4. Planning study design in terms of timing and resources
5. Ethics and governance
6. Planning evaluation design
7. Planning how to collect the data
 - A. Nominal Group Technique (NGT)
 - B. Content analysis of child healthcare nursing curricula
 - C. Audit
8. Analysis of the data, including:
 - A. Analysis of each component of study
9. Writing and disseminating the results in a report format

10. Promoting the utilisation of the result

3.2.4.1 The Requirement for Conducting the Current Service Evaluation

Negative correspondence from parents of children with disabilities relating to the standards of inpatient care received by their children was the first trigger for this current service evaluation. Therefore, the Primary Care Trust referred this feedback to the matron of the women and children's division, who, in turn, requested an investigation into the issue. It was hoped that an approach for improving care delivery to disabled children would be established.

3.2.4.2 Stakeholders in the Current Project

The first step of a service evaluation is identifying stakeholders (Nolan & Grant 1993). Marsh and Glendenning (2005b) describe stakeholders as those involved or affected by an evaluation exercise. This project is an attempt to gather information relating to the unmet needs of hospitalised disabled children from the point of view of nursing staff. The potential stakeholders for this study are:

1. Disabled children and their parents who use this service
2. Staff responsible for delivering care to this population
3. Policy-makers and decision-makers responsible for services delivered to disabled children and their families

The limited time available for this study and the length of time required to obtain ethical approval from the NHS meant that the views of disabled children and their parents could not be obtained. However, there is a paucity of studies examining nursing staff's perspectives on the subject. Jennings (1991) states that nursing staff can make a substantial contribution to any evaluation exercise. Therefore, this service evaluation has focused on this group of professionals as primary stakeholders.

Managers and other professionals involved in service delivery to disabled children and their parents were contacted and spoken with while conducting the audit. This service evaluation has attempted to involve these key stakeholders actively. According to Swenson (1991), the aim of an evaluation is to give power to all of the involved stakeholders.

Chapter Three

3.2.4.3 Planning the Data Collection

In order to meet the aims and objectives of the current service evaluation, three discrete parts were designed: the NGT, a content analysis of child healthcare nursing curricula and an audit (see Figure 3.1).

The first component of the service evaluation was the NGT. The NGT has provided new insight into challenges and rewards for registered nurses and HCSWs working with disabled children. As such, this component will improve care delivery to disabled children by identifying ways to overcome challenges and use rewards as a motivator. The NGT revealed that the greatest concerns among nurses and HCSWs involved training in this field. Therefore, the second component of this service evaluation was designed as a content analysis of contemporary nursing curricula relating to care delivery to this population, which has provided a better understanding of how undergraduate children's nursing courses are conducted at three UK universities. The third component involved conducting an audit of children's wards at a general hospital. The first part of the audit was constructed with an audit tool, by using health policies relating to care of disabled patients. A pilot was then carried out in the children's outpatient department. The pilot audit provided some important insights into potential problems with conducting the factual audit. The main audit was conducted in children's hospital inpatient wards in order to provide practical recommendations for improving standards of care for disabled children and their families.

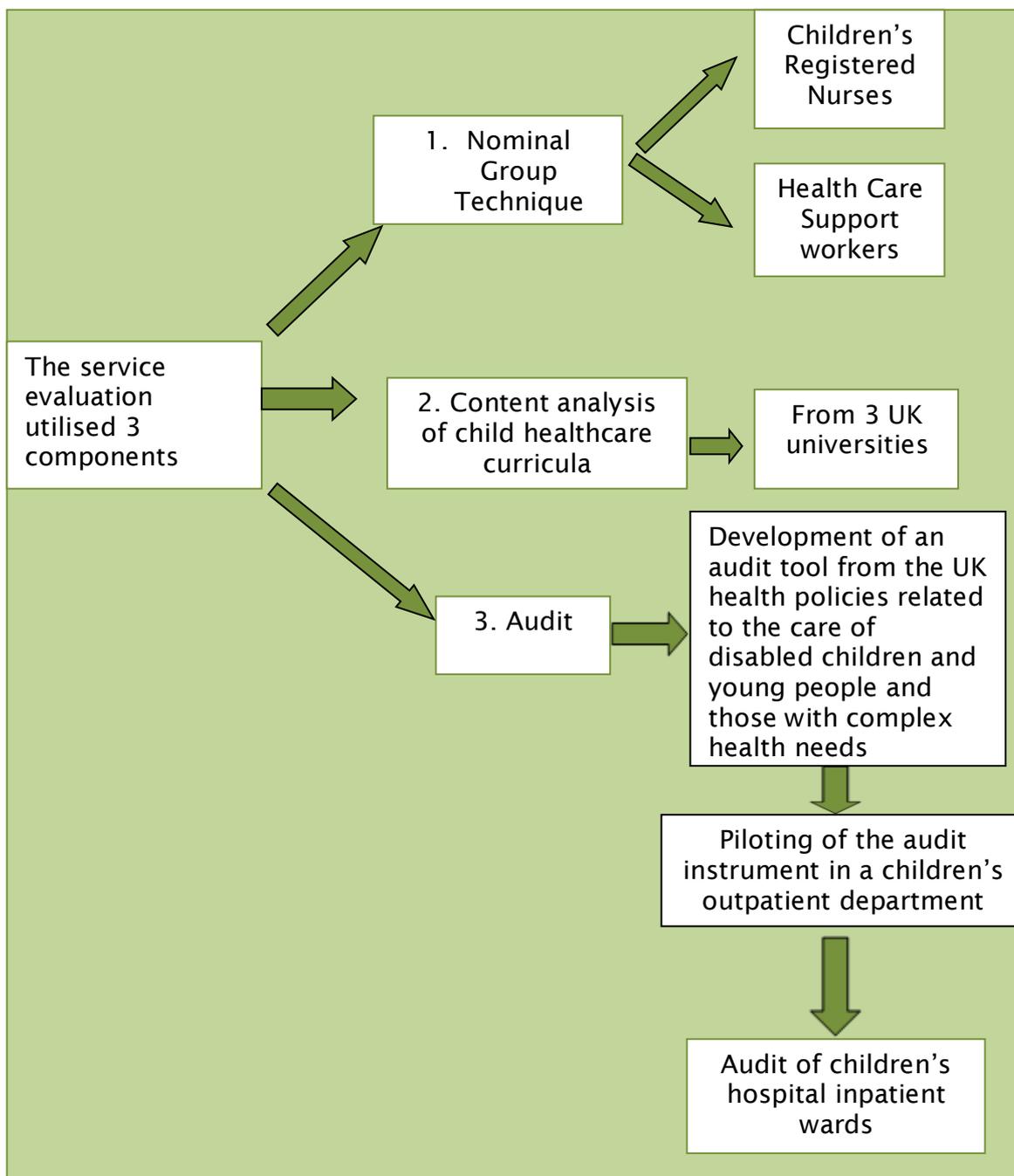


Figure 3.1: The service evaluation design

3.2.4.4. Stage one of the service evaluation

The project utilised the Nominal Group Technique (NGT), exploring the meaning and experiences of nursing staff working with disabled children in order to gain an understanding of their ways of thinking, experiences, priorities, motivation, beliefs and feelings. Additionally, nurses and HCSWs identified their areas of concern (see Figure 3.2). Detailed discussion and illustrations relating to this component are provided in section one.

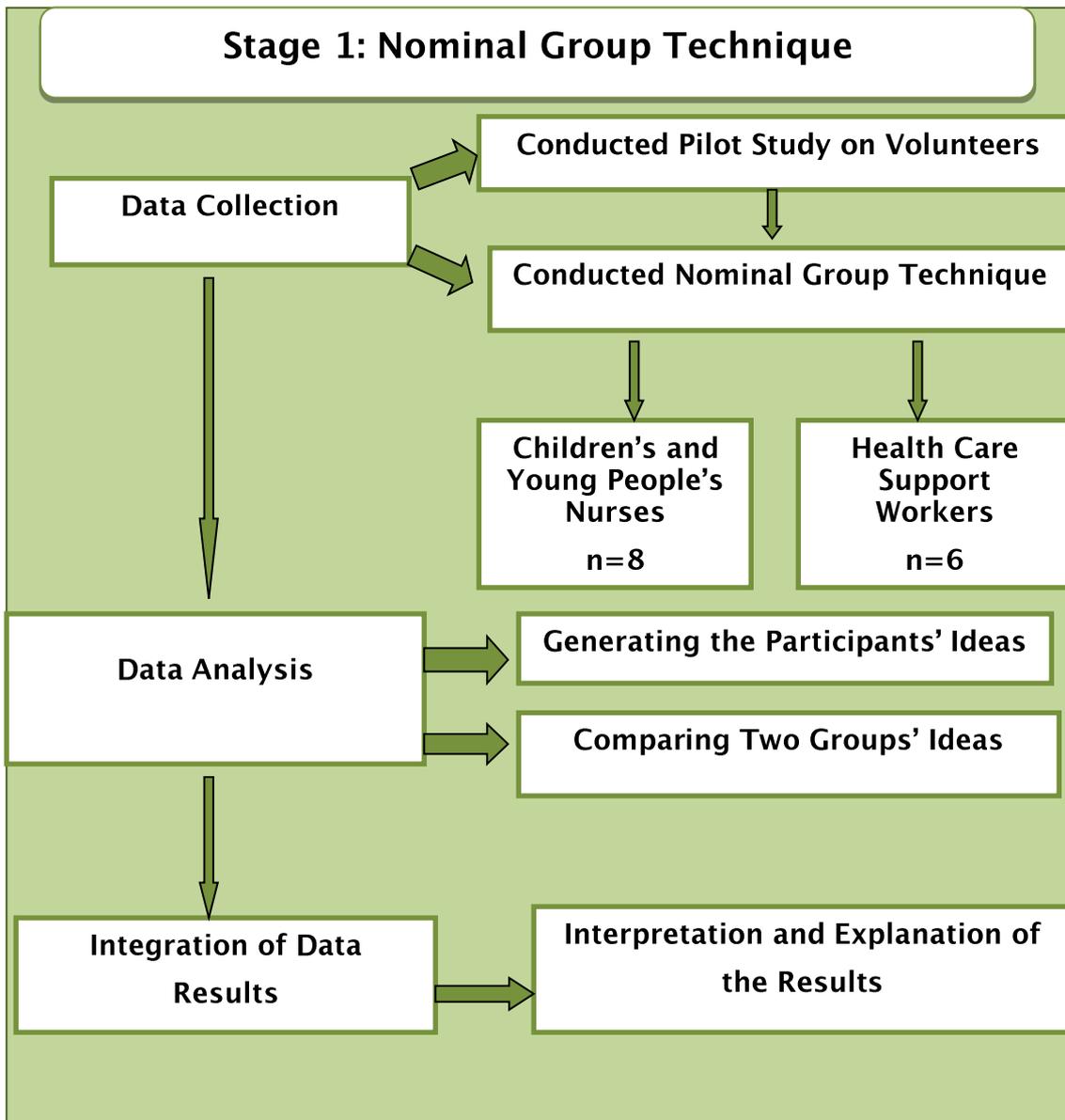


Figure 3.2: Stage 1 of the service evaluation

3.2.4.5 Stage 2 of the service evaluation

The results from the NGT revealed that children’s nurses and HCSWs were concerned about their training in the field of caring for disabled children. Therefore, in the second stage of the study, a content analysis of undergraduate childcare nursing curricula was conducted, in order to better clarify and attain a broader perspective on nursing staff training backgrounds (Figure 3.3). The deeper discussion and illustrative evidence for this component are delivered in section two.

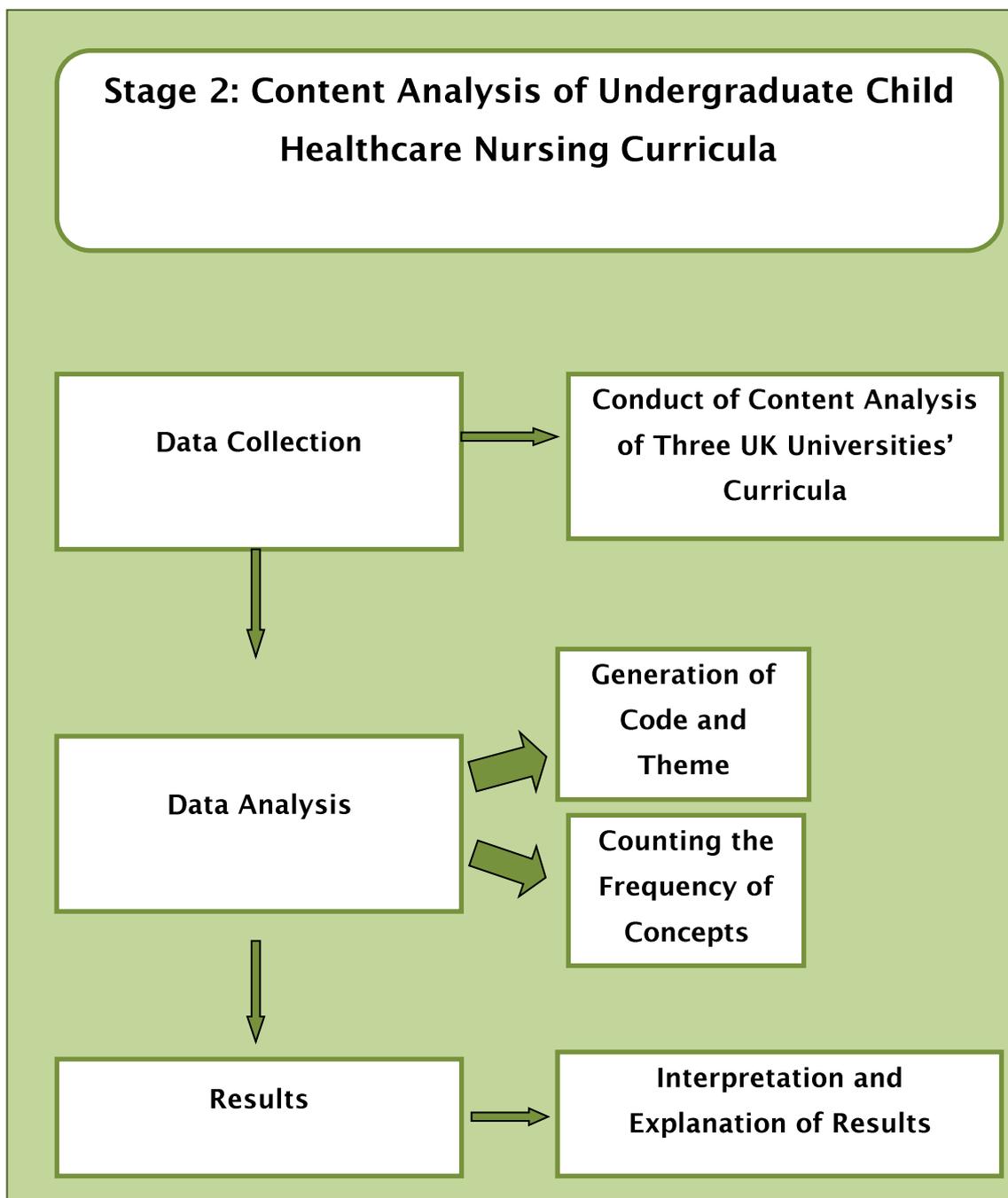


Figure 3.3: Stage 2 of the service evaluation

3.2.4.6 Stage three of the service evaluation

The third component of this project comprised an audit, carried out on the children's ward at an NHS Foundation Trust, as a means of discovering how the children's ward performance met the needs of children with disabilities. This part of the service evaluation identified which part of the compliance had not met the best practice criteria, via data which was obtained quantitatively as

Chapter Three

outlined in Figure 3.4). The deeper discussion and illustrative evidence for this component are delivered in Section 3.

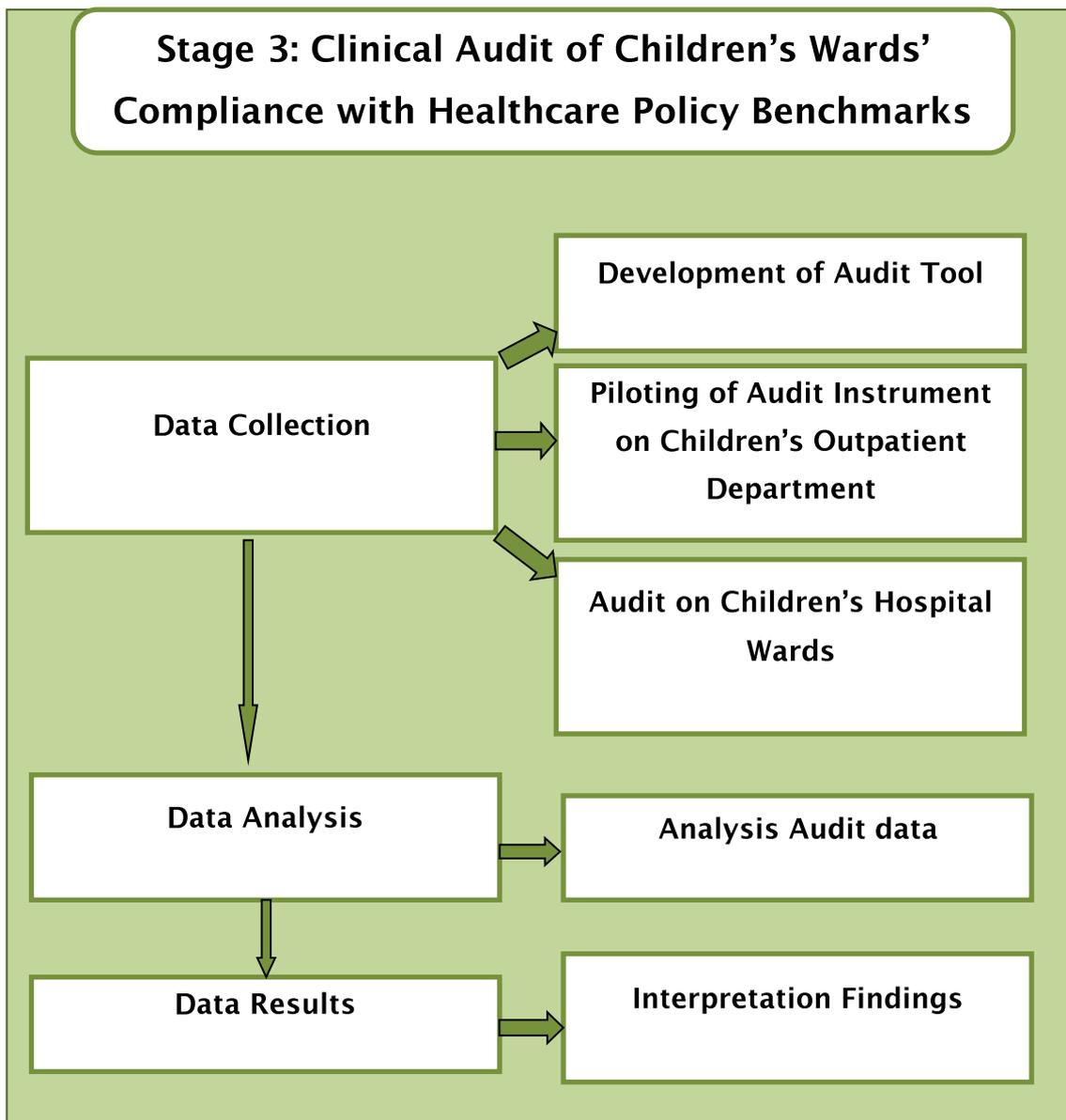


Figure 3.4: Stage 3 of the service evaluation

3.2.5 Validity of the Current Service Evaluation

Rossi et al. (2003) argued that one or more of the following criteria are required for establishing the validity of an evaluation study: consistency with usage, alternative measures and internal consequential predictability. In this project, validity was met by means of internal consistency, due to the use of three different approaches aiming to produce similar results.

3.2.6 Limitations of the Current Service Evaluation

The results that emerged from this service evaluation did not show the factual services received by disabled children and their families, as the project was not able to cover all the dimensions of a service evaluation or employ different indicators. Due to insufficient time and lack of budget, the main evaluation tools used were the Nominal Group Technique (NGT), a content analysis of nursing curricula relating to care of disabled children, and an audit.

The results obtained from this service evaluation cannot be generalised or extrapolated due to lack of external validity, which renders the data inapplicable to other settings or services.

Chapter Three

3.3 Section 1: The Nominal Group Technique

The first component of the current service evaluation involved a focus group activity, known as the Nominal Group Technique (NGT), with registered children's nurses and HCSWs. The aim of this first stage was to identify the rewards and challenges of caring for disabled children and young people and those with complex health needs.

3.3.1 The Nominal Group Technique

Patton (1990) noted that utilising a focus group can be a highly efficient data collection technique. Baker (1993) pointed out that a focus group can be used in a clinical audit. The NGT approach to focus groups is designed to gain meaningful information from key informants (Elliott & Shewchuk 2002). It is defined as a purposeful group process with the aim of finding a solution to a conflict situation (Scott & Deadrick 1982). Van de Ven and Delbecq (1972) point out that the NGT can generate a high quantity and quality of data from different aspects of a healthcare topic. Additionally, it provides broad and smooth coverage of the ideas emerging from the participants (Moore 1987). Carney et al. (1996) described the NGT as a useful and informative tool which can be applied to the areas of education, policy and research. It was used in this service evaluation in order to gain a deeper insight into the perceptions of challenges and rewards on the part of children's nurses and HCSWs who care for disabled children.

The NGT is described as a semi-quantitative/qualitative approach (Potter et al. 2004). The generation of items and group discussion are closer to the qualitative approach, but quantitative analysis of data contributes to the ranking process (Steward 2004). In addition, participants can actively help to check the results, which ensures the accuracy of judgments and prevents bias in the results (Denscombe 1995; Steward 2004). The NGT provides a qualitative understanding of problems and prioritises them by using a structured discussion group of participants who have the same interest, expertise or perceptions (Van de Ven & Delbecq 1972; Gallagher et al. 1993). Stewart and Shamdasani (1990) pointed out that the NGT provides inclusive data in a cost-effective manner (Stewart & Shamdasani 1990).

3.3.2 The Nominal Group Technique Background

Gibson and Soanes (2000) indicated that the NGT originated from group decision-making by Delbecq and Van de Ven (1971). The NGT can be employed to investigate aspects of healthcare and health policy (Van de Ven & Delbecq 1972), identify clinical competencies (Gibson & Soanes 2000; Steward 2001) and examine professional issues relating to the nursing of children and young people (Gibson & Soanes 2000; Glasper et al. 2007). It can also be used to identify the problems experienced by physically disabled persons (Elliott & Shewchuk 2002). Additionally, it can be utilised to evaluate curriculum tools or service needs (O'Neil & Jackson 1983; Lloyd-Jones et al. 1999; Keatinge et al. 2000; Glasper 2001; Dobbie et al. 2004; Perry & Linsley 2006). In this current service evaluation, the NGT was used to obtain the perspectives of the children's nurses and HCSWs relating to care delivery to disabled children.

3.3.3 The Advantages of the Nominal Group Technique

The NGT is a multi-phased decision-making process in which participants share their perspectives of a problem which needs to be solved. The NGT has several advantages, which are presented in Table 3.4.

1. Generates more ideas and information and prioritises them (William 1989; Stewart & Shamdassani 1990; Gallagher et al. 1993)
2. Provides equality for participants (William 1989; MacPhail 2001; Dobbie et al. 2004; Perry & Linsley 2006) and reduces the effects of negative attitudes amongst the group members (Beruvides 1995; MacPhail 2001)
3. Enjoyable exercise (Van de Ven & Delbecq 1974)
4. Provides valuable judgements in terms of effectiveness (Van de Ven & Delbecq 1974)
5. Appropriate for small group size (Lloyd-Jones et al. 1999; Glasper 2007)
6. Relieves the researchers' burden of later recall (William 1989; McMurray 1994; MacPhail 2001)
7. No need for further validation of the data (Van de Ven & Delbecq 1974; MacPhail 2001)
8. Increases accuracy by recording throughout the discussion (Rohrbaugh 1981)
9. Depersonalisation of generated ideas (Carney et al. 1996)
10. Appropriate time consumption for the framework of study (Carney et al. 1996) and ability to conduct one session only (McMurray 1994)
11. Cost-effective method (MacPhail 2001)
12. Provides quick results (Carney et al. 1996)
13. No requirement for any preliminary preparation (Gibson & Soanes 2000)
14. Increased productivity of group due to peer influence (McMurray 1994; Gibson & Soanes 2000)
15. Provides a solution within a complex situation (Stephenson et al. 1982; Frankel 1987)
16. Improves the decision-making process (Ho et al. 1999)
17. Self-closure among participants (Glasper et al. 2007)

Chapter Three

- | |
|---|
| 18. Maintains anonymity of participants during the meeting (MacPhail 2001)
19. Provides a chance to discuss the ideas further before final vote (William 1989) |
|---|

Table 3.4: The advantages of the NGT

3.3.4 NGT Difficulties

Van de Ven and Delbecq (1972) stated that there are three methodological difficulties often faced by investigators when employing the NGT:

- Arrangement of group members
- Selection of the question
- Analysis of the data

Van de Ven and Delbecq (1972) suggested that conducting several sessions with different target groups and selecting clear and understandable questions related to the aim of the study can limit the problems with conducting the NGT. Table 3.5 presents the limitations of the NGT.

- | |
|--|
| 1. Frustration of participants due to unfamiliarity with the technique (Steward 2001)
2. Inflexible timetable and methodology (Steward 2001)
3. Expeditious decision-making (Steward 2001)
4. Self-disclosure does not always happen (Steward 2001)
5. Not adequate for giving routine information or negotiating meetings (William 1989)
6. Need for special material, such as flipcharts (William 1989)
7. Less opportunity for qualitative explanation in comparison with other group discussion approaches (Keatinge et al. 2000)
8. Problems with generalisation of NGT results (Lloyd-Jones et al. 1999)
9. Low flexibility in terms of methodology (Van de Ven & Delbecq 1974)
10. Provides more positive than negative feedback and sometimes exuberantly optimistic (Dobbie et al. 2004)
11. Generated ideas not always financially practical or logical (Dobbie et al. 2004) |
|--|

Table 3.5: The limitations of the NGT

3.3.5 Rationale for Employing the NGT as a Service Evaluation Tool

The rationale for applying NGT to this particular study was the evaluator's need for a highly structured format (Carney et al. 1996), easy to understand and follow (Carney et al. 1996; Camiah 1997; Gibson & Soanes 2000); furthermore,

the NGT generates an inclusive, detailed with different range of ideas and can be conducted in one session (Gibson & Soanes 2000; MacPhail 2001; Elliott & Shewchuk 2002).

The NGT also follows a democratic style, providing more opportunity to balance the power between dominant and submissive participants and the facilitator and diminish factors such as fear related to failure and criticism which can limit the bias (Van de Ven & Delbecq 1972; McMurray 1994; Carney et al. 1996; Chapman 1998; Potter et al. 2004). Therefore, this approach may generate more ideas (O'Neil & Jackson 1983; McMurray 1994) by encouraging more participants to contribute (Delbecq & Van de Ven 1971).

In summary, the NGT was employed as it ensured the gathering of a comprehensive and high quality range of ideas raised by participants, in a democratic style and in a short time.

3.3.6 The Role of the Investigator in the NGT

Sim (1998) stated that personal and social identity and interpersonal skills are key factors in the success of a facilitator. Bland and Schmitz (1986) claim that having background knowledge and skills and academic values and attitudes derived from specific socialisation experiences are necessary for this role.

I am a 50-year-old, middle class, white female. I consider myself to have a supporting and caring personality, which has influenced my career development and professional socialisation. I have a nursing background with a focus on caring for patients with special health needs, which has driven me to conduct my study. Gibson and Soanes (2000) emphasise the facilitator's ability to identify and carry out the NGT steps; the current investigator has been trained in NGT by her supervisor, who has experience in this field.

This investigator acted as a non-judgmental facilitator during the NGT. The same facilitator was present for both of the NGT meetings. Litosseliti (2003) suggests that this can reduce problems with different styles when analysing the data, and decrease the potential for bias. A second facilitator acted as a note-taker, coordinating activities with the flipchart and documentation.

Chapter Three

3.3.7 Composition of Participants

As a large number of the staff who work with disabled children are nursing staff, this group of professionals was chosen in order to learn about their ideas about care delivery to this population.

Van de Ven and Delbecq (1972) and Gallagher et al. (1993) suggested that group members should be on a similar professional level in terms of their profession and expertise (Jones & Hunter 1995). As such, the investigator conducted two separate NGT groups, one with a group of registered children's nurses and the other with HCSWs - convenient samples for the NGT meetings. The literature suggested that group size can vary within a range of three to 12 group members (Delbecq et al. 1975; Bray et al. 1978; Moore 1987; Williams et al. 2006) and that NGT is most suitable for small group sizes (Glasper et al. 2007). Lomax and McLeman (1984) warned that a large group might impact on the validation of the results. Therefore, it was decided that eight registered children's nurses would comprise group I. The second group of participants contained six HCSWs from the same hospital, who were involved in the care of disabled children. (The meetings were held on 1 April 2011 for nurses and 17 May 2011 for HCSWs) (See Table 3.6.).

Characteristics	Registered children's nurses n=8	HCSWs n=6
Age (years)		
21-30	2	3
31-40	2	2
41-50	3	1
50+	1	0
Work experience (years)		
1-4	3	4
5-9	1	2
10-19	1	0
25-29	2	0
30+	1	0
Previous training in disability		
Yes	3	4
No	5	2
Gender		
Female	8	6
Male	0	0

Table 3.6: Characteristics of participants

3.3.8 Recruitment Process for NGT Meetings in this Study

Potential participants were identified by the matron of the children's wards. Participants were asked to read, complete and sign a consent form (Appendix 3.2). The investigator's telephone number was given out in case the participants had any further questions about the study. The investigator also checked participants' understanding of what was entailed by involvement in the study.

3.3.9 Location of the NGT Meetings

The venue was the child health seminar room at a general hospital. Detailed directions to the seminar room and accessible facilities at the location were provided and clarified. The meeting room was light, airy, free of distractions such as noise or traffic and away from patient areas, thus meeting the criteria suggested by MacPhail (2001). Participants were seated in an oval formation in order to ensure eye contact for all and visibility of the flipchart and to provide

Chapter Three

an atmosphere of impartiality and informality. Refreshments were provided throughout the meeting and between the two sessions of the NGT process.

3.3.10 The Questions Posed

Delbecq et al. (1975) commented that clear questions are a requirement, as the NGT is informed by a microscopic focus. The NGT question was generated from a number of sources, including academic and professional literature and experts' views, and was related to the aims and questions driving the study. Lomax and McLeman (1984) claimed that narrowing the question helps to limit the responses of the group members. However, this investigator considered that the evaluative nature of the study required a more open question.

The questions posed for each group were:

1. What do you find the most rewarding when caring for children with complex disabilities?
2. What do you find the most challenging when caring for children with complex disabilities?

3.3.11 Time Required

The time spent in collective activities was four hours and 50 minutes (two hours for Group I, two hours and 50 minutes for Group II).

3.3.12 Design of Voting Card

The 12x12 cm voting card was designed as shown in Figure 3.5. The left hand box is for recording a number which corresponds to the number of a flipchart statement. The space adjacent to the left hand box is for writing the actual statement. The right hand box is for recording a score of between one and five.

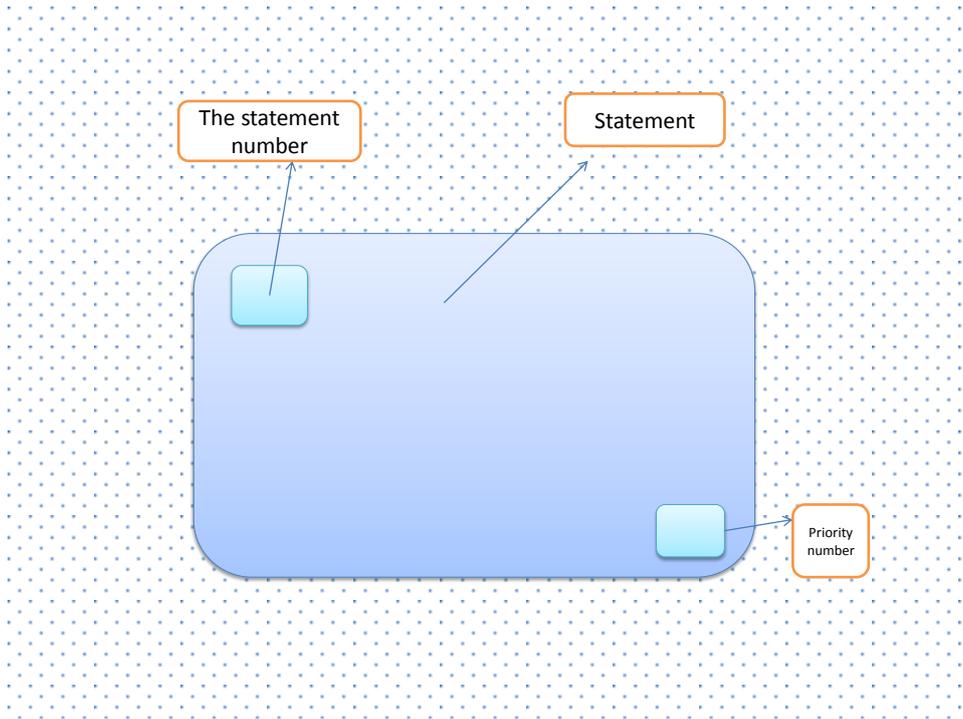


Figure 3.5: Voting card

3.3.13 NGT Process with the Groups

The number of steps used in the NGT can vary, for example five steps were set out by Lloyd-Jones et al. (1999) while eight steps were reported by Gibson and Soanes (2000) and Gallagher et al. (1993). For this study, the five-step process was followed (Figure 3.6).

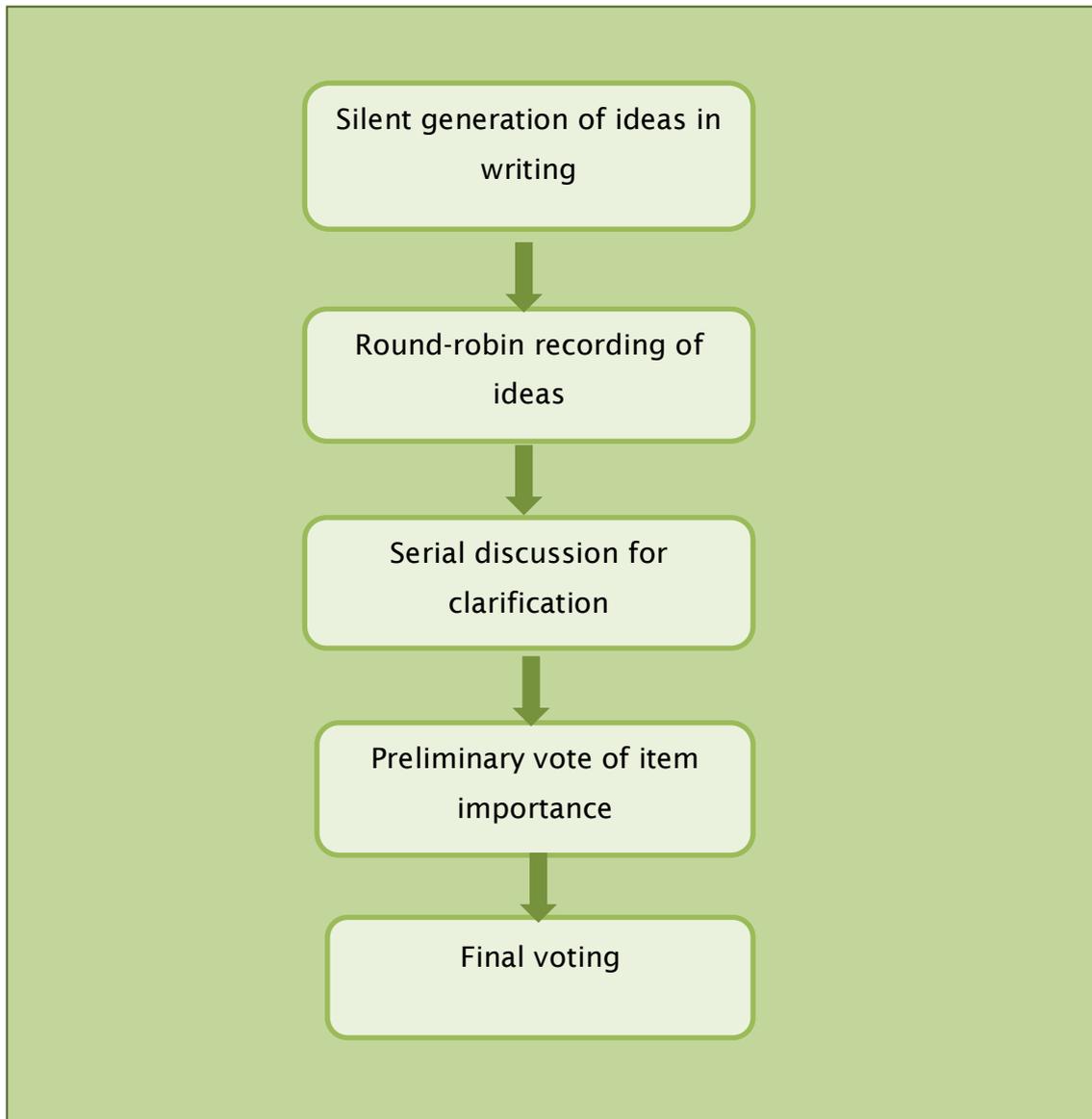


Figure 3.6: The five steps of the NGT

3.3.14 Process of the NGT

Introduction to the NGT Meeting

After welcoming the participants, the investigator explained her own interest in the subject. The investigator encouraged people to introduce themselves, giving a brief overview of their job. The participants were given full details of the process.

Step 1: Silent Generation of Ideas in Writing

The silent generation of ideas is designed to encourage independent creativity and capture different views of participants (Carney et al. 1996; Camiah 1997; McMurray & Beebee 2007). The question was printed on paper and given to each participant, written in large letters on a flipchart at the front of the room and verbally articulated to avoid misunderstanding. Participants were asked to take a moment to carefully consider their responses. All of the exercises were conducted in a quiet room. The participants were asked to silently write down their key thoughts related to the posed question, without conferring with the other group members. Group members were given paper and 10 minutes to write as many items about the question as possible. The process was the same for both groups.

Step 2: Round-Robin Recording of Ideas

For this part of the process, responses were elicited from the group (anti-clockwise for the first round and clockwise for the second). Participants' responses were recorded verbatim, numerically coded on the flipchart and attached to an adjacent wall with blu-tack for full visualisation. The fact that ideas were written down made it less personal and more objective than other focus group meetings (Delbecq et al. 1975). Group members were informed that they could miss a turn by saying 'pass', indicating that they had no further ideas to add. Members were invited to rejoin the round-robin if they had generated other independent ideas. No conferring or discussion was allowed at this point. These rules enabled participants to contribute equally, listing their thoughts while preventing certain members from dominating the group. Eventually, all items were generated from the participants, and this stage came to a natural conclusion when every member of the group offered a 'pass'.

Step 3: Serial Discussion for Clarification

Each of the recorded items identified in Step 2 were discussed within the group to arrive at a satisfactory level of clarification and understanding. Additionally, similar points were amalgamated to form one single statement. Furthermore, the process of member checking formed an integral part of the internal validity of the study.

Chapter Three

The pages were displayed around the classroom in numerical sequence, to make sure that each page was in full view of all participants.

Step 4: Preliminary Vote of Item Importance

The strength of the NGT depends on each group member making independent decisions, accomplished through a rigorous voting system (Glasper et al. 2007). Each participant was given a package of five of the prepared voting cards, designed as discussed earlier in Section 3.3.12. The investigator initially asked the individual participants to identify their own top five items from the flipcharts and to silently write them down without conferring. Each statement was written in the top of the voting card with the number of the statement in the top left hand square. Only those topics that were judged to be highly pertinent were selected by the subjects.

Step 5: Final Voting

Each participant was asked to study the five cards and to award five votes to the card-recorded item which, in their opinion, was the most important. This score was recorded in the right hand box of the card. Each participant was then asked to place the card face down. Following this, each participant was asked to examine the remaining four cards and then to award one vote for the item which they considered to be the least important. Next, each participant was asked to place the card face down. Each participant was then asked to study the remaining three cards and to allocate four votes to the one they considered to be the most important. They were then asked to place the card face down.

Participants were then asked to study the remaining two cards. The card which was considered to be the least important would be allocated a vote of two. The remaining card was given a score of three. This rank-ordering would indicate the accuracy of judgements (Delbecq et al. 1975) in a democratic style (Glasper 2007). This process provides transparency and facilitates interaction among members of the group in a structured meeting.

The facilitator collected the cards and a general discussion ensued. It was aimed that this discussion should be short and orderly, and not misrepresent or affect judgements in the final vote (Glasper 2007). After a short break, the

second task statement was given to both groups and the process for the NGT was repeated. At the end of the NGT meeting, the facilitator asked the participants to raise any further points for discussion or issues as feedback from the meetings.

3.3.15 Approval to conduct the Service Evaluation

Approval to conduct the service evaluation was granted by the clinical governance committee of the children's unit at the district general hospital being evaluated.

3.3.16 Data Analysis of the NGT

NGT data can be analysed quantitatively or qualitatively (Keatinge et al. 2000). The quantitative data (ranking) that emerges from the NGT process provides an opportunity to evaluate the strength of the statement (Lloyd-Jones et al. 1999; MacPhail 2001).

This service evaluation utilised the quantitative results generated by the NGT to provide a baseline for an inclusive qualitative analysis, as described by Gallagher et al. (1993). The priorities of the participants in each NGT meeting were determined by selecting the most common statements from one to five. In addition, responses which participants offered, but did not prioritise, were identified. Comparisons were made at two levels of analysis: within groups and between groups. Areas of agreement at the group level were also recognised.

3.3.17 Validity of the Current Nominal Group Technique

The most frequent validities reported in research articles are face and content validity (Parahoo 2006). In order to assess the content validity for this project, the questions for the NGT meeting were submitted to the team of supervisors, who are experienced and knowledgeable about care for children with disabilities. Internal validity was addressed by involving participants in all phases of the NGT and by the process of member checking during Step 3 of the study. External validity, which is concerned with the generalisation of the findings, was provided and ensured as both the children's nurses and HCSWs represented their own profession.

Chapter Three

3.4 Section 2: Content Analysis of Nursing Curricula Relating to the Care of Disabled Children

This project utilised content analysis in order to investigate whether the current nursing curricula for children's nurses contains adequate content relating to the care of children with disabilities. This section will commence with a presentation of nursing education in this area and then discuss content analysis and its history, process, objectives, sampling strategy and trustworthiness.

3.4.1 What is Content Analysis?

Content analysis is a research method employed to analyse the content of various data by summarising it into defined categories with the aim of generating meaningful information (Bates et al. 2004). The paramount definition of content analysis is: a scientific, objective, systematic, replicable and generalisable method which describes the content of phenomena or events (Kassarjian 1977; Webber 1990; Krippendorff 2004; Bryman 2008; Elo & Kyngäs 2008). See Table 3.7 for the benefits of content analysis.

- | |
|--|
| <ol style="list-style-type: none">1. Content-sensitive method (Krippendorff 2004)2. Provides flexibility in terms of study design and analytical approach (Harwood & Garry 2003; Duriau et al. 2007)3. Applicable to a broad range of phenomena (Duriau et al. 2007)4. Discovers and in-depth explains of structures such as values, attitudes, consequence and meaning within the text (Webber 1990; Carley 1993)5. No intrusiveness, collaborative approach (Kabanoff & Holt 1996; Duriau et al. 2007)6. Cost-effective (Duriau et al. 2007)7. Ability to scale (Duriau et al. 2007) |
|--|

Table 3.7: Content analysis benefits

Content analysis, as a methodology, can be conducted both qualitatively and quantitatively. The qualitative approach includes developing stages or a hypothesis for study, identifying prominent themes, exploring patterns among themes that may be manifest or latent within the text, downsizing themes into smaller units and categorising coded text based on common concepts (Kassarjian 1977; Polit & Beck 2008; Zhang & Wildemuth 2009). The quantitative approach involves recording frequency of phenomena in order to gain a better understanding of the data and provide insight into the similarities and differences within the context (Kassarjian 1977; Harwood & Garry 2003;

Bates et al. 2004). As such, the current investigator utilised content analysis in order to study how disability and special health needs issues relating to disabled children were covered within contemporary nursing curricula, combining quantitative and qualitative approaches. According to Kabanoff (1996), content analysis can be utilised in conjunction with other methods via triangulation; this investigator thus utilised content analysis as one of the three components of the study.

3.4.2 History of Content Analysis

Content analysis is broadly used in communication, journalism, sociology, psychology and business (Neuendorf 2002). In the USA, at the beginning of the 20th century, content analysis was used as an analytical approach (Barcus 1959). Until the mid-1950s, it was utilised mainly as a quantitative method for coding text into explicit categories via the use of statistics (Neuendorf 2002). Content analysis as a quantitative approach has been widely used in health studies and particularly nursing over the past 20 years (Neuendorf 2002; Hsieh & Shannon 2005).

3.4.3 The Process of the Current Content Analysis

According to Hsieh and Shannon (2005), content analysis has three different approaches: conventional, directed and summative. All three approaches are utilised in order to explain the meaning of the content of text (see Table 3.8).

The major differences between the methods are coding pattern, origin of codes and trustworthiness bias. Zhang and Wildemuth (2009) stated that summative content analysis means counting words or explaining content, and making comparisons, followed by an analysis of the latent meaning and themes. For this study, summative content analysis was conducted on all the selected modules in order to explore the utilisation of the keywords in an inductive manner (Zhang & Wildemuth 2009).

Chapter Three

Type of Content Analysis	Study Starts With	Time of Defining Codes or Keywords	Sources of Codes or Keywords
Conventional content analysis	Observation	Codes are defined during data analysis	Codes are derived from data
Directed content analysis	Theory	Codes are defined before and during data analysis	Codes are derived from theory or relevant research findings
Summative content analysis	Keywords	Keywords are identified before and during data analysis	Keywords are derived from researchers' interests or literature review

Table 3.8: Differences between the three content analysis approaches.

Adapted from Hsieh and Shannon (2005).

3.4.4 Nursing Education for Delivery of Care to Disabled Children and Young People and Those with Complex Health Needs

There are many obstacles to achieving an adequate provision of healthcare for people with disabilities. One of the most well-known strategies for overcoming low standards of care (Lennox et al. 1997; Scullion 2000; Walsh et al. 2000; Kirschner & Curry 2009) and improving quality of life among disabled people (Hahn 2003; Werner & Grayzman 2011a) is improving the quantity and quality of education among health professional teams (Lennox & Diggins 1999b; Duff 2000). Additionally, this improvement can lead to increased satisfaction among nursing staff (Scullion 2000) and enhance their competence (Duff 2000).

The lack of education in this area is a worldwide problem. Scullion (1999a) and Walsh et al. (2000) mentioned that there was a paucity of evidence for the way disability is presented in nursing curricula in the UK. Walsh et al. (2000) conducted a mailed survey of over 500 nurses in New Jersey. Nearly 60% of the participants had little or no training in this field; in addition, approximately 50% reported not having any type of experience with this population. The researchers claimed that enhancing knowledge and training would result in an improvement in the quality of care provided by nurses. In the UK, this concern has been echoed by Gibbs and Pries (1999) and Bates et al. (2004). In addition, Bates et al. (2004) carried out a survey across the UK using a self-completed questionnaire, involving 365 nurses. Nearly 50% of staff had not received any

training related to the mental health needs of their patients; surprisingly, only 20% felt confident about their level of knowledge and skills.

3.4.5 Nursing Curriculum Relating to Care for Disabled Patients

A curriculum is defined as a plan, design (Quinn & Hughes 2007) or sequence of potential experience based on education provision (Kliebard 1989). Hahn (2003) noted that the content and processes of curricula help students to improve their knowledge, skills, competencies and positive attitudes.

In the UK, Nolan and Nolan (1999) revealed an absence of in-depth focus on disability within nursing education. Additionally, the concept of disability does not appear to be well-incorporated into the curricula (Nolan & Nolan 1999; Smeltzer et al. 2005), is too broad (Piachaud 2002) and is incoherent, constituting a gap within medical education curricula (Kahtan et al. 1994).

Furthermore, the major barriers towards teaching on disability were noted thus: lack of adequate time, an overloaded curriculum (Banks & Kane 2004; Smeltzer et al. 2005) and lack of sufficient content and resources about learning disability (Shanley & Guest 1995; Banks & Kane 2004). Additionally, this population is not paid sufficient attention in nursing curricula in terms of their unique needs and concerns (Wilson & Merrill 2002). Ideally, the 'nursing children' curriculum should cover all themes relating to care for children with disabilities.

There were very few papers investigating course content (Roxburgh et al. 2008). Therefore a content analysis was conducted on seven modules for disabled children and those with special health needs, from three UK (undergraduate children's nursing) university courses, to provide a scope for contemporary nursing training in this field. According to Scullion (1999b), analysis of curricula can provide useful insights into the disability theme. The literature review of content analyses of disability within nursing curricula is presented in Appendix 3.3 and 3.4.

Chapter Three

3.4.6 Questions for the Current Content Analysis

Zhang and Wildemuth (2009) noted that content analysis begins with identifying questions. Therefore, the investigator set out the following questions for this part of the study:

1. Which primary module topics related to care for children with disabilities exist in these curricula?
2. Which elements relating to care for children with disabilities are deficient in these curricula?
3. What is the frequency of terms and keywords relating to care for children with disabilities in these curricula?
4. What is the common nomenclature within the modules under examination?
5. Which learning resources were used for teaching (textbooks, articles, films, internet resources, software, speakers, games, artwork or popular books)?
6. Which type of textbook is suggested in the reading list?
7. What percentages of modules were taught using didactic methods?
8. Which group of disabilities are addressed in the nursing curricula?

3.4.7 Objective of the Current Content Analysis

This study has sought to gain insight into the provision of contemporary curricula in three UK universities and how disability and special health needs relating to disabled children and young people and those with special health needs are covered within them.

3.4.8 Sampling Strategy

All UK curricula are predicated on the pre 2010 UK, Nursing and Midwifery Council (NMC) standards. All education institutions offering children's nursing have been assessed for compliance with these standards by the NMC which is responsible for ensuring that standards for practice are central to the nursing curriculum (Roxburgh et al. 2008).

A convenience sample of two universities from England and one university from Northern Ireland were selected for analysis. It was envisaged that a

content analysis of these three universities curricula would provide a picture of how disability was represented in children's nurses' training. Therefore, all modules related to the study objectives are presented in Table 3.9. Four modules from University 3, two modules from University 2 and one module from University 1 all related to care delivery for disabled children and complex health needs. A comparison between the teaching characteristics used in the modules is presented in Appendix 3.5.

University 1	University 2	University 3
Module 1: Caring for children with long term needs	<ul style="list-style-type: none"> • Module 1: Therapeutic skills for children's nursing • Module 2: Role of children's nurse: professional, ethical and legal context 	<ul style="list-style-type: none"> • Module 1: Long term conditions and care • Module 2: complex care • Module 3: End of life and palliative care • Module 4: Principles of nursing practice

Table 3.9: Selected modules from three UK universities relating to the study

3.4.9 Content Analysis of the Nursing Curricula

The selected curricula were read carefully through several times to obtain a sense of the whole, then words and content in the modules were identified and quantified without changing the meaning, using them as units of analysis. This study followed the eight category coding steps set out by Carley (1993). (See Figure 3.7).

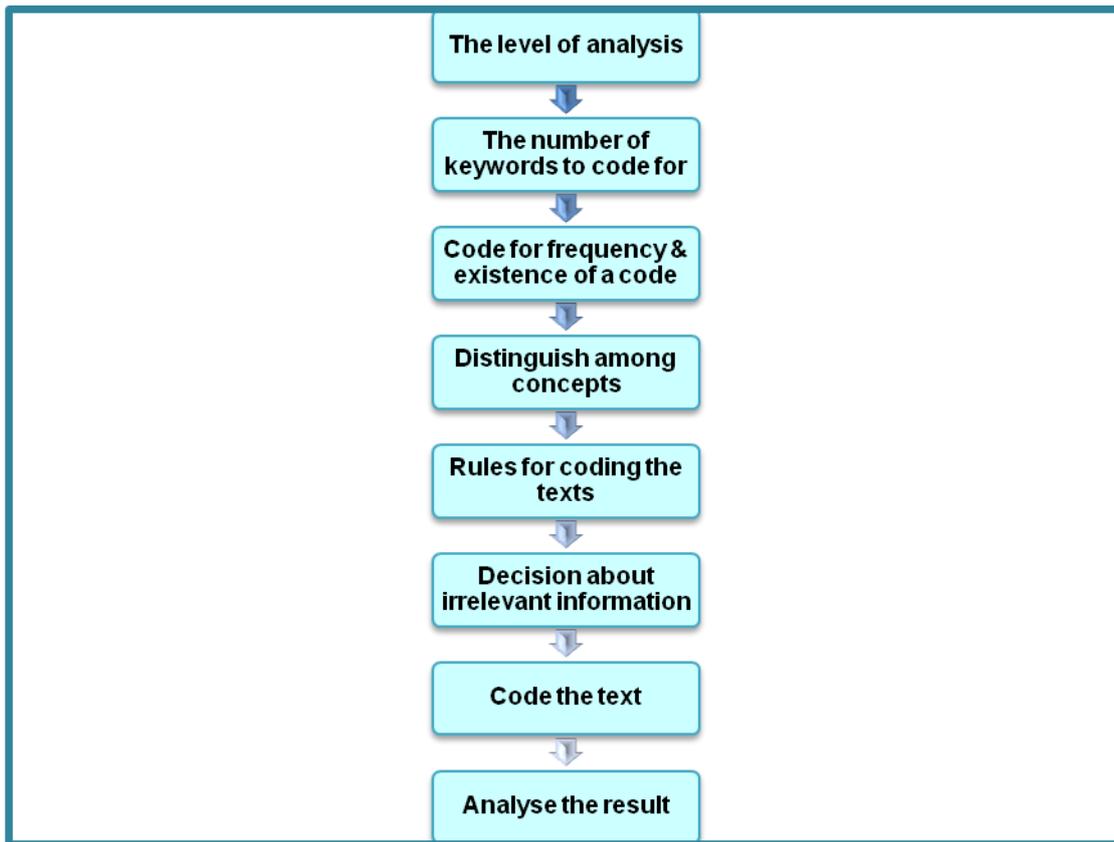


Figure 3.7: Coding steps (adapted from (Carley 1993))

The current study has established the existence and frequency of keywords in the text (Zhang & Wildemuth 2009). The process of coding started with an examination of the entire text for each keyword, as a unit. According to Zhang and Wildemuth (2009), the unit of analysis is a symbol which may include single words or word compounds. Krippendorff (2004) provides five definitions for the unit: physical, syntactical, categorical, propositional and thematic distinctions. This content analysis utilises thematic units. The unit of analysis in this study was care for children with disabilities: the number of times each keyword occurred was counted. This approach might be more effective when grammatical variations of the keywords are used, rather than only one form (Carley 1993).

A set of rules were developed to aid consistent and coherent coding throughout the text (Carley 1993). The next step was to record the concept's existence manually. Following the coding steps, the different codes were compared based on differences and similarities and sorted into *sub-categories* and *categories* (Carley 1993). Krippendorff (2004) explains that a category is a group of codes with a commonality. The categories were exhaustive and

mutually exclusive. This means that no data were excluded due to an absence of appropriate categories; in addition, no data fell between two categories or could be located in more than one category (Carley 1993). The next step was to employ Krippendorff's analytical technique of clustering in order to identify data that could be grouped together by sharing some commonality. Then dendrograms were drawn up, i.e. treelike diagrams to illustrate how the data clustered (Polit & Beck 2008). Figure 3.8 presents the dendrograms for one of the modules. The underlying meaning, the latent content of the categories, was formulated into a *theme*. Graneheim and Lundman (2004) consider a theme to be a latent meaning gleaned through condensed units, codes and categories. Kassirjian (1977) notes that themes are the most useful units of content analysis due to the fact that issues, values, beliefs and attitudes are usually discussed within them. The codes, sub-categories, categories and a theme are given in Appendix 3.6, sorted by the different modules. The final step was to scrutinise the data, providing conclusions and generalisations (Carley 1993).

Chapter Three

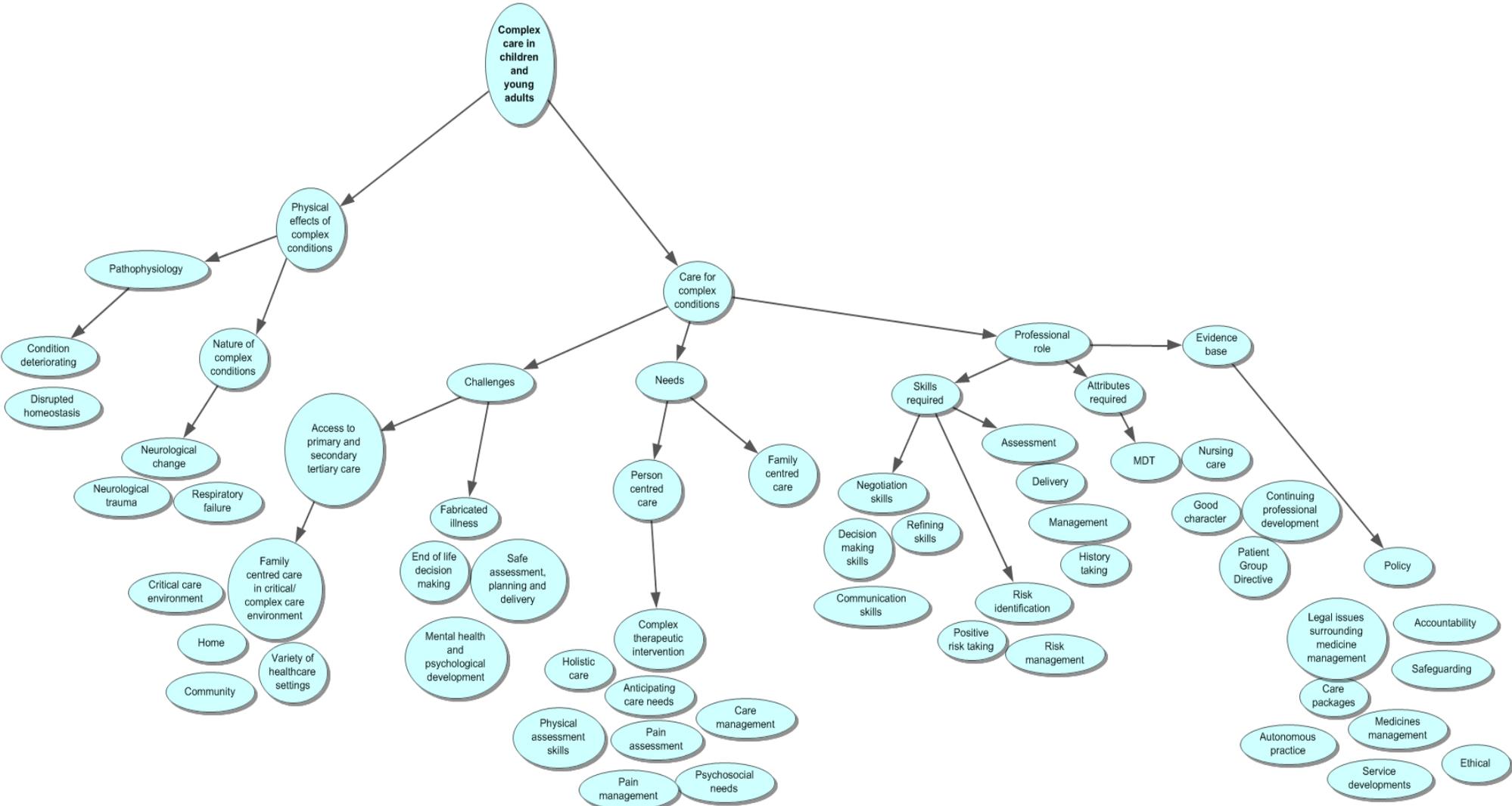


Figure 3.8: The dendrogram for Module 2, University 2

3.4.10 Trustworthiness of the Current Content Analysis

3.4.10.1 Reliability

Graneheim and Lundman (2004) point out that research findings should be as trustworthy as possible and that every study must be examined in terms of the procedures utilised to generate the results. Reliability, or reproducibility, is one of the unique characteristics of content analysis, which depends upon the analyst's ability to formulate, present and judge the definitions of the categories (Kassarjian 1977)

The current content analysis process was repeated three times in order to enhance the data's stability or intra-rater reliability, which means that the same results were generated by the investigator at different times (Stemler 2001). Following this, a different coder was employed for reproducibility or inter-rater reliability, which means that the coding process leads to the same text being coded by different people (Stemler 2001). Inter-judge reliability is the degree of agreement between multiple coders about the same text (Kassarjian 1977). The percentage of agreement between this investigator and the coder mainly appeared on the level of sub-category (41%), code (37.6%) and sub-code (42.8%).

3.4.10.2 Validity

Validity is defined as the extent to which an instrument measures what it is designed to measure (Kassarjian 1977). The current study used a form of content validation; in this case, the content validity took the form of feedback on the content of the curricula from two senior lecturers in the field (one internal senior lecturer and one external senior lecturer).

3.4.11 Limitations of the Current Content Analysis

This study has limitations within the methodology. The sampling technique was non-probability, focusing on only seven modules from three selected universities. Any claim to generalise these results cannot be substantiated. Validity is probably high due to the range of data sources chosen for the current study.

Chapter Three

3.5 Section 3: The Audit

In the NHS, providers of services and those who deliver care to disabled children are required to measure and demonstrate the effectiveness of the services they are providing (Milner et al. 1996; The Children's Trust Tadworth & Every Disabled Child Matters 2011). One approach to improving the quality of care is to conduct a clinical audit (Johnston et al. 2000). An audit was carried out as part of a service evaluation of the care and welfare of disabled children and young people and those with complex health needs, as well as their families, who use the children's wards at an NHS Foundation Trust. The scope of the audit was to identify potential improvements that could be made in care delivery to children with disabilities.

3.5.1 Definition of an Audit

An audit is a systematic measurement of care standards against benchmarks (Jamtvedt et al. 2007). Conducting an audit can highlight any potential deficiencies (Johnston et al. 2000) or confirm that the current practice is at the expected level (Burgess 2002). In addition, audits can help to implement changes to the system of care and service provision, ensuring that health professionals are providing the highest standard of patient care (Shaw 1992; Olwen 1996; Johnston et al. 2000; Rawlins & Hine 2002). Nurses utilise the audit to measure the quality of nursing care (Björvell et al. 2000).

3.5.2 Advantages and Disadvantages of Conducting an Audit

The current clinical audit will be a valuable tool for evaluating the inpatient services provided by an NHS Foundation Trust for disabled children: the aim is to improve the quality of healthcare, as noted by Johnston et al. (2000) and Jamtvedt et al. (2007). Further advantages of carrying out an audit are demonstrated in Table 3.10.

- | |
|---|
| <ol style="list-style-type: none"> 1. Measuring the level and effectiveness of current practice (Shaw 1992; John et al. 2004; Jamtvedt et al. 2007) 2. Measuring the outcome of care (Lord & Littlejohns 1996; John et al. 2004) 3. Setting standards of care (John et al. 2004) 4. Identifying problems in care provision (Rawlins & Hine 2002) 5. Implementing changes in the care system (Shaw 1992; Rawlins & Hine 2002; John et al. 2004; Jamtvedt et al. 2007) 6. Providing better administrative systems (Gould 2008) 7. Improving the quality of care (Shaw 1992; Bull 1993; Olwen 1996; Burgess 2002; Rawlins & Hine 2002; Gould 2008) 8. Enhancing patient feedback and satisfaction (Johnston et al. 2000) 9. Enhancing professional development, knowledge, practice and satisfaction (Lord & Littlejohns 1996; Sealey 1999; Johnston et al. 2000; Jamtvedt et al. 2007) 10. Improving professional attitude, morale, motivation, and enthusiasm (Johnston et al. 2000; Bailey et al. 2002; Gould 2008) 11. Enhancing inter and intra-professional communication (Lord & Littlejohns 1996; Johnston et al. 2000; Gould 2008) 12. Providing equality in clinical decision-making (Johnston et al. 2000) 13. Encouraging the auditor to improve accountability and the effectiveness of an audit (Lord & Littlejohns 1996) 14. Flexible tool (Sealey 1999) 15. Enhancing the efficient use of resources (Bailey et al. 2002) |
|---|

Table 3.10: Advantages of conducting an audit

3.5.3 Difficulties with Conducting an Audit

The College of Occupational Therapists (1998) and Johnston et al. (2000) highlighted the main difficulties in auditing: lack of time, insufficient skills and lack of knowledge or training related to the audit process. Further disadvantages and barriers to conducting an audit are presented in Table 3.11. The current auditor was trained by her own supervisor, and prior to this study, had already participated in an audit for children's wards related to the Welcoming Programme (2 August 2011) at one of the other NHS Foundation Trusts. Additionally, this auditor carried out the audit alongside one of her supervisors, due to English being her second language.

Chapter Three

Barriers
1. Lack of resources and time (Johnston et al. 2000; John et al. 2004)
2. Lack of expertise (Johnston et al. 2000; John et al. 2004)
3. Intra-professional problems (Johnston et al. 2000)
4. Organisation barriers (Johnston et al. 2000)
5. Lack of an organised plan (Johnston et al. 2000)

Disadvantages
1. Increasing workload (Johnston et al. 2000)
2. Professional threats (Johnston et al. 2000)
3. Limited clinical autonomy (Johnston et al. 2000)
4. Fear of litigation (Johnston et al. 2000)
5. Producing a territorial attitude (Johnston et al. 2000; Gould 2008)

Table 3.11: Barriers and disadvantages of conducting an audit

3.5.4 Differentiating Between Audit and Research

An audit may be considered a form of research with different purposes (Black 1992; Russell & Wilson 1992). Wade (2005) noted that an audit usually provides more and greater changes than research. Furthermore, Lord and Littlejohns (1997) stated that in most cases research cannot resolve major problems. Improving the quality of patient care and health provision as a result of strong relationships between the research and audit was highlighted by Harvey (1996). Furthermore, research tends to focus on what staff actually do, whereas an audit is instead aimed at uncovering the best way of doing things (Smith 1992; Wilson et al. 1999; John et al. 2004). Figure 3.9 demonstrates the interaction between audits and research.

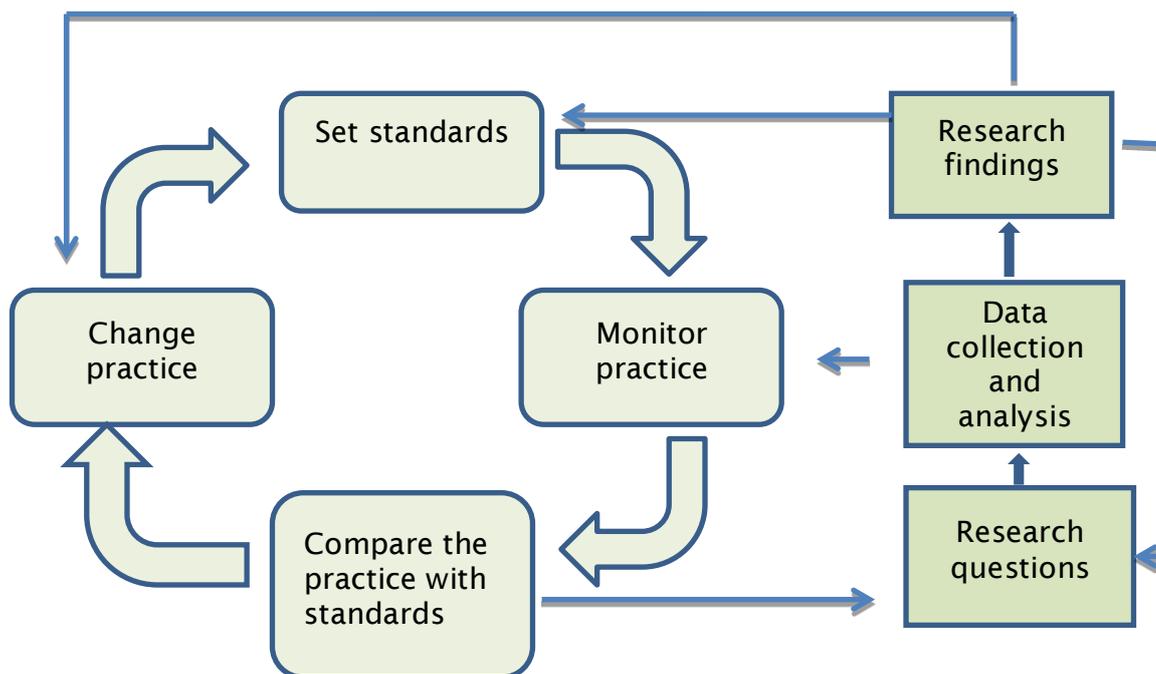


Figure 3.9: Interaction between audits and research (adapted from Closs and Cheater (1996))

Audits and research have some common characteristics and differences; their aims, implementation and findings overlap (Smith 1992; Closs & Cheater 1996) as demonstrated in Appendix 3.7.

In order to establish best practice, the present audit was conducted with the aim of gleaning information on the current quality of care received by disabled children and their families. Rawlins and Hine (2002) highlighted that data collection through both an audit and research provides fast feedback and a large amount of data on current service activities: it can also be a positive driver for enhancing service provision (Black 1992; Smith 1992).

3.5.5 Aims and Objectives of the Current Audit

The final component of this study was a clinical audit of children's wards within an NHS Foundation Trust. This audit constituted a systematic examination at the quality of care delivery to disabled children.

3.5.5.1 Aims

The main aims of this clinical audit were (I) to identify areas of optimum and less than optimum compliance with best practice benchmarks relating to care

Chapter Three

delivery to disabled children and those with complex health needs and their families, and (II) inform the system of the quality of current care delivery with a view to implementing improvements.

3.5.5.2 Objectives

- To assess the care and welfare of children with disabilities and their families at the children's wards of an NHS Foundation Trust
- To evaluate whether the current care delivered to disabled children and young people and those with complex needs meets the optimal standard of care at the children's wards of an NHS Foundation Trust
- To identify improvements that could be made in care delivery to disabled children and their families at the children's wards of an NHS Foundation Trust
- To provide recommendations for improving the quality of care delivery to children with disabilities at the children's wards of an NHS Foundation Trust

3.5.5.3 Question

To what extent do children with complex disabilities and their families receive optimal care during hospital admission?

3.5.6 The Process of this Audit

The four stages of clinical audit suggested by Rawlins and Hine (2002) were followed for this audit (see Figure 3.10).

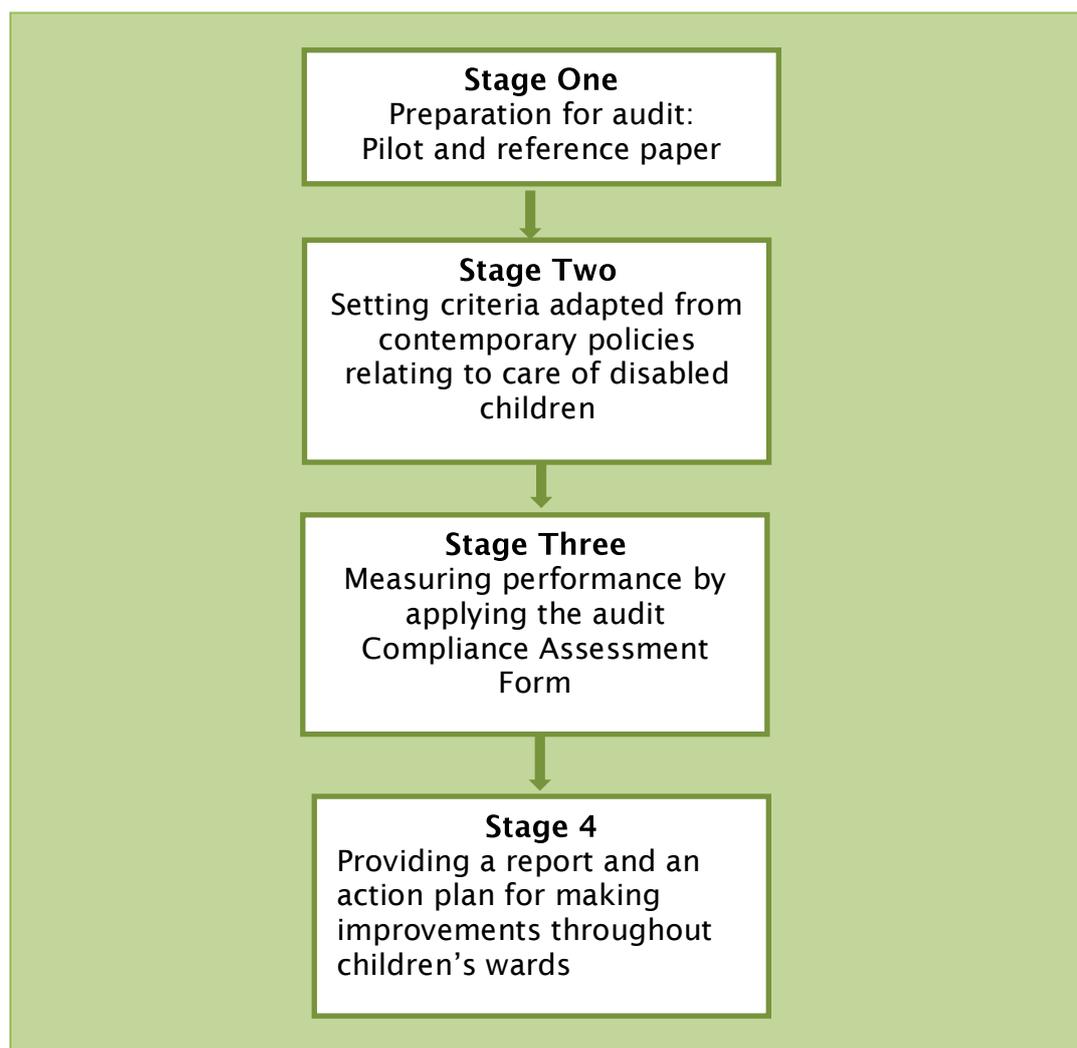


Figure 3.10: Stages of this audit

Stage 1: Preparation for Audit

The aim of the audit was to identify the strongest and weakest points of the care delivered to this group of patients throughout a single Trust. A pilot audit was conducted within a children's outpatient department at the same NHS Foundation Trust as a preparation stage. The result of this pilot audit was published (Appendix 3.8).

Stage 2: Setting Criteria

This stage involved selecting the appropriate methods for collecting data relevant to identified issues (NICE 2002). Bailey et al. (2002) and Justham (2005) stated that essential part of an audit is choosing the clinical standards against which to measure. John et al. (2004) defined standards as an expected quality of service. Bailey et al. (2002) and Closs and Cheater (1996) noted that

Chapter Three

the criteria for an audit should be based on scientific evidence, measurable and realistic. The Compliance Assessment Instrument was used as the audit tool (Appendix 3.9). This audit tool was developed as part of the Association of Chief Children's Nurses' (ACCN)¹ generic healthcare audit tool. The Compliance Assessment Instrument for this discrete audit tool was configured from a comprehensive range of policy documents:

- Aiming High for Disabled Children: Best Practice to Common Practice (DCSF & DH 2009)
- Aiming High for Disabled Children: Better Support for Families (DfES & DH 2007)
- Better Care: Better Lives (DH 2008)
- Disabled Child Standard, National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and Those with Complex Health Needs (DH 2004)
- Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs (DH 2007)
- Together from the Start - Practical Guidance for Professionals Working with Disabled Children (Birth to Third Birthday) and Their Families (DfES & DH 2003)
- Valuing People: a New Strategy for Learning Disability for the 21st Century (DfES & DH 2001b)
- Valuing People Now: a New Three-Year Strategy for People with Learning Disabilities (DH 2009)

The audit Compliance Assessment Instrument comprised 11 individual segments, reflecting all aspects of policies relating to care delivery to disabled children and their families (see Table 3.12). These 11 criteria related to important and measurable aspects of care derived from contemporary policies, with the role of health policy described as supporting or enhancing the care of patients (Coles et al. 2010).

¹ The Association of Chief Children's Nurses is a group of senior nurses representing children and young people's services (<http://www.accnuk.org/>).

1.	Communication
2.	Training
3.	Multi-agency teamwork
4.	Information
5.	Support services
6.	Decision-making
7.	Key workers
8.	Assessments
9.	Equipment
10.	Palliative care
11.	Bereavement

Table 3.12: Segments of the Compliance Assessment Form

The Audit Compliance Assessment Instrument utilised non-parametric grading from 0-10, with 10 representing full compliance with policy standards and benchmarks. The utilisation of scored benchmarks allowed a quick and easy way of metricising compliance with best practice (Ilkhani et al. 2012). Each segments of the audit tool was subdivided into section discrete which related to the key concept being audited (e.g. using a variety of methods for non-verbal communication with disabled children). Individual section of the instrument were made up of benchmarks which, when identified, contributed to the overall score. The benchmarks themselves consisted of evidence criteria which varied in score, ranging from 0-2 or 0-4. A full copy of the audit tool, which is part of a larger ACCN full audit tool, can be found in Appendix 3.9.

Stage 3: Data Collection and Methodology

This stage involved data collection, which provides good information about performance (Rawlins & Hine 2002). According to Burgess (2002), a clinical audit requires the involvement of all stakeholders, which encourages a sense of ownership among data providers (Johnston et al. 2000). The audit was arranged by approaching the senior children's nurse and members of the inter-professional team involved with care delivery to disabled children throughout the children's wards within the NHS Foundation Trust under study (see Table 3.13). The baseline benchmarking exercise was completed over two days (3-4 July 2012). The evidence for the audit was documented and verbally checked in terms of the range of areas scored against the best practice

Chapter Three

benchmarks. According to Rawlins and Hine (2002), benchmarking approach can assist to judge performance on a realistic basis.

Profession	Number of participants
Senior children's nurse	9
Matron	1
Play specialist	1
Transition leader	1
Training, development and practice leader	1
Teacher	1
Total	14

Table 3.13: Key informants who participated in the audit

Stage 4: Data Analysis and Implementation of an Action Plan

This stage included data analysis (see Chapter 4), identifying areas that needed attention and providing suggestions for improving care provision (Burgess 2002). The detailed analysis of the data will be presented by the auditor to key stakeholders and the Trust, as a report, to ensure that the required changes take place.

Stage 5: Re-audit

This stage will require conducting a re-audit, using the same methods as those employed in the initial audit exercise, in order to ascertain that the Trust has responded to the findings from the first audit (Burgess 2002).

This auditor could not carry out Stage 5 of the current audit as it is beyond the time frame for her study; the re-audit will be carried out by the Trust.

3.5.7 Ethical Considerations

Ethical audit issues include consent, confidentiality, effectiveness of the audit and accountability (Morrell & Harvey 1999). Ethical approval for the audit exercise was given by the clinical governance department of the children's division of the hospital.

3.5.7.1 Confidentiality

Staff concerns that attention would be drawn to deficiencies in care by the audit (Lord & Littlejohns 1996) were addressed by assuring respondents of confidentiality and anonymity. In addition, the data would represent the entire children's wards, not the individual performance of any particular staff member.

3.5.7.2 Consent

Verbal consent was attained from each key informant at the time of the audit, without any pressure on the individual data provider.

3.5.7.3 The Effectiveness of the Audit

To ensure the appropriate use of resources in terms of professional time, the audit tool was given to all key informants prior to the audit itself, via the matron of the women and children's division. Additionally, a predetermined timetable was utilised in order to maintain momentum during the conduct of the audit.

3.5.7.4 Accountability

The audit's results suggested that the practice needed improvement in some areas; therefore, an action plan was submitted to the managers of the Trust with the hope that the appropriate recommended changes would be implemented.

3.5.8 Data Analysis

This audit was an assessment of inpatient care delivery to disabled children. Closs and Cheater (1996) noted that an audit is predominantly a quantitative process. The findings should be presented simply and clearly (Rawlins & Hine 2002). Therefore, the data was presented in a numerical, continuous form (Petrie & Sabin 2009). Rawlins and Hine (2002) noted that bar charts are the most common format. Additionally, the numerical data should be available in separate tables together with the charts. The findings of this audit are presented in bar chart format created in Excel 2010; a numerical table for each

Chapter Three

criterion with its presenting mean, created with the Statistical Analysis in Social Science (SPSS) 19 programme, is also provided.

3.5.9 External Validity

The current audit had a lack of external validity due to being conducted on only one local NHS Foundation Trust; therefore, wider generalisability is questionable.

3.5.10 Pilot

According to Leon et al. (2011) the feasibility of an approach can be examined by conducting a pilot study. The current audit benefited from the conduct of a pilot audit at the children's outpatient department within the same NHS Foundation Trust (22 March 2012), which allowed the auditor to develop audit skills. The result of the pilot audit has been published (Ilkhani et al. 2012). The pilot audit process provided some important insights into potential problems which could be avoided in the main audit by careful planning, coordinating and systematic monitoring. For example:

- Provided better understanding of conducting an actual audit
- Improved the skills and knowledge of the auditor
- Identified the potential obstacles of the audit
- Developed material such as a timetable sheet
- Gained exercise on data analysis

In addition, the pilot audit showed that the audit tool was sensitive enough to gather data on disabled care provision in children's wards.

3.5.11 Limitations

According to Crossan et al. (2004) and Irvine and Irvine (1991) the main point of an audit is to identify the need for changes. It cannot be claimed that the results of the current audit will lead directly to improvements in care delivery to disabled children and their families; furthermore, the audit cycle emphasised by Sealey (1999) and Crombie and Davies (1993) has not been completed. However, a report and a detailed data analysis will be prepared and submitted to the Trust, in order to ensure that the findings are communicated

to policy-makers; it is hoped that this will enable them to address the identified problems by means of a long term plan.

3.6 Summary of the Chapter

This chapter has discussed how the present study was conducted with a detailed explanation. Additionally, the three components of the service evaluation have been discussed and illustrated in detail within three discrete sections.

Chapter 4 will concentrate on the results and discussion from the three components of the service evaluation.

Chapter 4 : Results and Discussion

4.1 Introduction

This chapter is organised into four sections based on the results and findings of the three components of the service evaluation, namely the NGT, the content analysis of contemporary nursing curricula, and the clinical audit. The fourth section will present the integrated results from the three components of the service evaluation.

4.2 Section 1: Nominal Technique Results

4.2.1 NGT Results for Question One

What do you find the most rewarding when caring for children with complex disabilities?

Delbecq et al. (1975) indicated that discussion statements normally generated a range of between 18 and 25 items. The registered children's nurses group generated 24 items. Group HCSWs generated 34 items. All items are presented using the participants' own words. The responses from registered children's nurses to the first question are presented in Table 4.1.

Chapter Four

No	Items	Scores	Collective total	Total number of votes
1	Building up trust with child and family	5+5+1+5	16	4
2	Like interacting with each individual child	0	0	0
3	Building a rapport or relationship	5+5+4	14	3
4	Helping them achieve something new	3+2	5	2
5	Familiarity with returning patients	3	3	1
6	A smile	4+3	7	2
7	Teaching skills and improving independence	1+2+5	8	3
8	Finding out more about day to day living	4	4	1
9	I learn something new	1+1	2	2
10	Pride in seeing the family being able to leave the child in our care	1+2	3	2
11	Reassuring parents	3	3	1
12	Improving health	2+4+3+3+3	15	5
13	Being an advocate for the child	4+4+2	10	3
14	Delivering human touches	4	4	1
15	Promoting communication	3	3	1
16	Improving the quality of life	5+4+5	14	3
17	Helping them to adapt to new environment	0	0	0
18	Exceeding medical expectations	1	1	1
19	Sense of amazement at how families have a life and are happy	2+1	3	2
20	Providing holistic care planning with psychosocial needs identification	2	2	1
21	Nice to have a challenge	0	0	0
22	Privilege to learn from families	1+2	3	2
23	Grateful for your own able-bodied life	0	0	0
24	Creativity and thinking outside the box	0	0	0

Table 4.1: Statement responses to Question one from registered children's nurses

Responses from HCSWs to the first question are presented in Table 4.2.

No	Items	Scores	Collective total	Total number of votes
1	Good communication	4+5	9	2
2	Being able to meet their particular needs	4+5	9	2
3	When they achieve little steps	5+1	6	2
4	Seeing them smile and laugh	4	4	1
5	Being there to listen	3	3	1
6	Seeing the whole family happy	4+3	7	2
7	Be able to play together	0	0	0
8	Knowing that I have contributed to the care required by the child that day	0	0	0
9	Supporting and working with the family	5	5	1
10	Using special communication skills such as Makaton	0	0	0
11	Giving a hug to the child	2+2	4	2
12	Bringing normality to their lives	0	0	0
13	Providing general hygiene	0	0	0
14	Being able to talk about the personal interests and their individual lives	0	0	0
15	Giving them life skill opportunities	0	0	0
16	Enjoying their individual personality	3+2+2	7	3
17	Bottle feeding the babies	0	0	0
18	Exceeding the expectations of the family	1	1	1
19	Enjoying translating for the families	0	0	0
20	Introducing the child to other patients and seeing them enjoy their company	0	0	0
21	Supporting their progress	0	0	0
22	Going the extra mile for the patients	3+1+3	7	3
23	Improving their lives	5+5	10	2
24	Enjoying being thanked for the care you have given	1+1	2	2
25	Transferring the patient to another client area	0	0	0
26	Uplifting their mood	3	3	1
27	Getting them comfortable and looking nice	2+4+2	8	3
28	Being recognised and called by your name	0	0	0
29	Rewarding when they go home	1	1	1
30	Forming relationships with the families	0	0	0
31	Spending time with the family	0	0	0
32	Ensuring that there is no discrimination in my practice	4	4	1
33	Being thanked and given an individual card or present	0	0	0
34	Being able to document progression in their progress diaries	0	0	0

Table 4.2: Statement responses to Question one from HCSWs

All participants prioritised their votes towards Stages 4 and 5 of the NGT process. The top five priority statements for both groups are presented and compared in Table 4.3.

Chapter Four

Priority	Registered children's nurses	Collective total	HCSWs	Collective total
1 st	Building up trust with child and family	16	Improving their lives	10
2 nd	Improving health	15	A) Good communication B) Being able to meet their particular needs	9
3 rd	A) Building a rapport or relationship B) Improving the quality of life	14	Getting them comfortable and looking nice	8
4 th	Being an advocate for the child	10	A) Seeing the whole family happy B) Enjoying their individual personality C) Going the extra mile for the patients	7
5 th	Teaching skills and improving independence	8	When they achieve little steps	6

Table 4.3: Comparison between the two groups' responses to Question one

4.2.1.1 Discussion of the Rewards of Caring for Children with Disabilities

This study shows that all the rewards that nurses receive from delivering care to disabled children, except for one item highlighted by HCSWs (statement 33), are psychological rewards. This finding is supported by Gieter et al. (2006), who state that nurses usually value non-financial and psychological rewards as they encourage them to use their maximum capabilities. According to Herzberg's two-factor theory of motivation (1959), personal feelings about the job are internal motivators. Maslow (1954) suggested that psychological rewards (self-actualisation) create more of a sense of completion for an individual than external or financial rewards. Similarly, Demerouti et al. (2000) found that a lack of rewards creates a psychological distancing between nurses and their tasks. The study of Newton et al. (2009) showed that a key motivator for nurses is the desire to help others; this can drive nurses' commitment to their duties, a conclusion confirmed by the current NGT. Benz (2005) showed that non-profit workers such as nurses were more satisfied with their jobs than 'profit' workers. A survey conducted by Hampton and Hampton (2004) indicated that rewards have a positive impact on job satisfaction; in the case of

nurses, this will in turn exert a positive effect on the quality of care they provide (Atkins et al. 1996). This NGT process has revealed that nursing staff essentially focus on the psychological rewards of delivering care to patients. Coyle-Rogers and Cramer (2005) found that the caring concept produced a feeling of self-satisfaction for caregivers.

The importance of communication with disabled children and their families was emphasised by both of the NGT groups as the greatest reward for nursing staff. A number of studies have emphasised nurse-patient communication (Ford & Turner 2001; Sowney & Barr 2007; Lunskey et al. 2008; Bellin et al. 2011). The cross-sectional research conducted by Bellin et al. (2011) suggested that healthcare teams do mostly meet families' needs relating to communication.

Both groups were enthusiastic about good communication with disabled children. The theme of 'building up a relationship' was among the top five priorities for both groups within the current NGT; this indicates that working with the families of disabled children is a valuable event for nurses. This finding was confirmed by Ford and Turner (2001), who raised the theme of 'development of trust between nurses and families'. The parents of disabled children who contributed to this study expressed that trust developed when they observed the care delivered to their patients by nurses. Additionally, Neill (1996) found that parents are more likely to trust staff after having stayed for longer, or when their children are readmitted to the hospital.

Iacono and Davis (2003) reported that many patients with disabilities expressed concern about their basic needs, such as getting enough to eat or drink, not being met by nursing staff. Furthermore, carers of disabled patients who participated in the study conducted by Cumella and Martin (2000) reported that only a few nurses were providing the care that disabled patients needed. This finding relating to patients' unhappiness with care was confirmed by Brown and Guvenir (2009). Additionally, the study carried out by Hemsley et al. (2008c) showed that families of disabled patients believed that nurses were failing in their responsibilities relating to direct care. On the other hand, the current NGT shows that nursing staff feel rewarded by high quality care delivery to disabled patients; this is supported by statements such as 'meeting patients' particular needs' and 'getting them comfortable and looking nice'.

Chapter Four

Both groups identified issues that were specific to their role. This finding was confirmed by Newton et al. (2009), whose study highlighted that a key motivator for nurses is the desire to help others. Similarly, the study conducted by McCabe et al. (2005) emphasised that working closely with people is an intrinsic motivator for nurses. The findings from Ford and Turner's study (2001) emphasised that nurses feel enriched when working with families with special needs children, and that this privilege leads them to feel close to the children and their families during special moments.

Patients' vulnerability motivates nurses to take an advocacy response towards them; the nurses also use their advocacy role to prevent inappropriate practice and establish interaction with patients (Mallik 1997). Cooper (1988) and Winslow (1984) both noted that nurses are well placed to act as patients' advocates due to their unique relationship with them. Graham (1992) argued that nurses can fill this advocate's role due to their awareness of systems and technical knowledge. Furthermore, nurses, it is suggested, could take on the role of 'advocates for better care' in addition to their other tasks and duties (Hemsley et al. 2007). In this NGT, the registered children's nurses group placed an emphasis on being an advocate for the child.

Wang and Barnard (2004) stated that technology-dependent children struggle for independence. Children with assistive technology need somehow to experience independence and autonomy in life, a view confirmed by surveys conducted by Parette and Vanbiervliet (1990) and Simon (1994). The theme of 'greater independence' was raised by the study of McConkey et al. (2004) who stressed that people with learning disabilities value their independence as well as their access to support staff. Helping disabled children to improve their independence was also recognised by the current NGT.

Sufficient support can help disabled children to cope and sustain a good quality of life (Kirk 1999; Glendinning & Kirk 2000). Wang and Barnard (2004) concluded that there are difficulties with improving the quality of life for disabled children and their families in terms of clinical policies. The issue of 'quality of life for disabled children' was also highlighted by the NSF. Nurses caring for disabled children have a substantial role to play in improving the quality of those patients' lives; a point addressed by both of the groups that contributed to this NGT. It appears that any progression in the disabled child's

life is a reward for nursing staff, a sentiment echoed in the statement given in the NGT meeting: ‘when they achieve little steps’.

4.2.2 NGT Results for Question Two

The NGT process was repeated with the following question:

What do you find the most challenging when caring for children with complex disabilities?

For the second question, the registered children’s nurses produced 35 items, which were recorded on four pages of the flipchart. The responses from registered children’s nurses are shown in Table 4.4.

No	Items	Scores	Collective total	Total number of votes
1	Lack of privacy and space	5+3	8	2
2	Colleagues not understanding the child’s individual needs	2+3	5	2
3	Getting to grips with what needs to happen for them to have their basic needs met i.e. time	1+1	2	2
4	Communication barriers with the child	3+5	8	2
5	Time + time	3+4+5+5+4+5+5+2	33	8
6	No disabled changing areas	5	5	1
7	Discharging complex patients too quickly	0	0	0
8	Availability of appropriate equipment	2+2+4+4	12	4
9	Personal lack of knowledge relating to disability	1	1	1
10	Parents not amenable to change	0	0	0
11	Learning to use their own special equipment	0	0	0
12	Concern about their safety, even basic needs	3+4+4+2	13	4
13	Fear of loss of inpatient services	0	0	0
14	Family expense in having a child in hospital e.g. car parking	0	0	0
15	Seeing the child as an individual not a £ sign	2	2	1
16	Communication to inter-professional (I.P.) team	0	0	0

Chapter Four

No	Items	Scores	Collective total	Total number of votes
17	Inadequate support in dealing with children with severe behavioural problems	4	4	1
18	Complexity of drugs regimes	0	0	0
19	Relying too much on parental care (having to)	2+1	3	2
20	Children are treated differently (not as age appropriate, etc.)	5	5	1
21	Non-wheelchair friendly care environments	3+4	7	2
22	Lack of respect for the individual child	0	0	0
23	Being concerned about not fully understanding the child's individual needs as the parent as the expert [does]	0	0	0
24	Need more play and family therapy	0	0	0
25	Dealing with unexpected care situation (e.g. tube falling out)	1	1	1
26	Talked over those related to the child while on medical rounds	0	0	0
27	No specific assessment document	1+2	3	2
28	Promises from management for facilities which are not fulfilled	0	0	0
29	Making the hospital experience positive	0	0	0
30	Need more sensory apparatus	0	0	0
31	Need time for nurses to visit child in their home and school environment prior to admission	0	0	0
32	Lack of space!	3+1	4	2
33	Issues around consent	0	0	0
34	More teaching on Makaton and signing	3+1	4	2
35	Lack of specific pain assessment	0	0	0

Table 4.4: Registered children's nurses' responses to Question two

For the second round of voting, the HCSWs produced 47 items which were recorded on seven pages of the flipchart. Responses to the second question are shown in Table 4.5.

No	Items	Scores	Collective total	Total number of votes
1	Lack of equipment and resources	2+5+1	8	3
2	Not being listened to by doctors (sometimes)	0	0	0
3	When they achieve little steps	0	0	0
4	Not enough time to spend with patients	4	4	1
5	Short-staffed so cannot dress and wash them yourself	4+5	9	2
6	Difficult aggressive parents	0	0	0
7	Not English speaking/translation problems	3	3	1
8	Ignorance of the follow-up post-discharge (lack of feedback)	0	0	0
9	Lack of communication with the inter-professional team	2	2	1
10	Forgetting that the child is a person, so some team members ignore them	0	0	0
11	Inappropriate use of the admission by the family	0	0	0
12	Waiting time to see a doctor	1+1	2	2
13	Messy medical notes!	0	0	0
14	Lack of privacy for the child	2	2	1
15	Parental dispute with care management	0	0	0
16	Rapid potential deterioration of the child	0	0	0
17	Communication barriers or lack of knowledge about the special communication needs of a particular child	5	5	1
18	Lonely child with no visitors	4	4	1
19	Complexities of community care team	0	0	0
20	Slow unnecessary discharge proceeding e.g. getting funding for wheelchair	0	0	0
21	Doctors' expectations for the child not always possible to achieve	0	0	0
22	Not having a multi-sensory room	3	3	1
23	Too heavy a workload to provide optimum care	3	3	1
24	Being involved with safeguarding cases	3	3	1
25	Slow or no medical progress	0	0	0
26	Emotionally challenging	0	0	0
27	Too little space	1	1	1
28	Not fully understanding their individual needs	0	0	0
29	Being the bearer of bad news	0	0	0
30	Lack of play support	3+2+4	9	3
31	Child restricted by professional advice	0	0	0
32	No outdoor play area	2	2	1
33	Disrespect shown to the child by others	0	0	0
34	No training to use special equipment e.g. hoists	0	0	0
35	Difficulty challenging rude visitors	0	0	0

Chapter Four

No	Items	Scores	Collective total	Total number of votes
36	Evidence of neglect on admission	4+5+4	13	3
37	Lack of family support for the child and staff	5+2+4	11	3
38	Discrimination towards staff	0	0	0
39	Mums ganging together	0	0	0
40	Care restrictions applied to the HCAs	1+3	4	2
41	Apportionment of blame for tasks not completed	0	0	0
42	Repeating information to family members – duplication of effort	0	0	0
43	Lack of personal food choice	0	0	0
44	Difficulties in building rapport	0	0	0
45	Doctors not being on time	0	0	0
46	Patient e.g. teenager not wanting to speak to parent	0	0	0
47	Conflict among doctors and blame put on HCSWs	1	1	1

Table 4.5: HCSWs' responses to Question two

The next step was to compare the data and search for commonalities between both nominal groups' answers to Question two (Table 4.6).

Priority	Registered children's nurses	Collective total	HCSWs	Collective total
1 st	Time + time	33	Evidence of neglect on admission	13
2 nd	Concern about their safety, even basic needs	13	Lack of family support for the child and staff	11
3 rd	Availability of appropriate equipment	12	A) Short-staffed so cannot dress and wash the patients B) Lack of play area	9
4 th	A) Lack of privacy and space B) Communication barriers with the child	8	Lack of equipment and resources	8
5 th	Non-wheelchair friendly care environment	7	Communication barriers/lack of knowledge about the special communication needs of a particular child	5

Table 4.6: Comparison of the responses of the two groups to Question two

4.2.2.1 Discussion of the Challenges of Caring for Children with Disabilities

There is a paucity of literature exploring the challenges facing nursing staff when delivering care to children with disabilities.

The biggest concern among nurses who contributed to this NGT related to the amount of time required to deliver care to disabled children. Lunskey et al. (2008) pointed out that care for this group of patients is time-consuming, which is a challenge for nurses. Parents of children with chronic diseases agree about this time-consuming nature of care for their children (Gravelle 1997). Inadequate time for nursing staff to meet disabled patients' needs was a concern raised by parents who participated in the study carried out by Hemsley et al. (2008a); one parent stated that 'they need so much care which nurses have not got time to give to them' (p.266). A number of studies show that lack of time affects many aspects of quality of care (Bridges & Meyer 2000; Balandin et al. 2001; Weiss et al. 2009). Furthermore, Bowers et al. (2001) highlighted that nurses are often working against the clock due to a 'pyramid of necessity'. Nurses who participated in this study reported that time pressure created feelings of frustration for them, due to failure to provide high quality care and being forced to tackle 'should do' work. Ford and Turner (2001) found that lack of time affects nurses' capabilities to deliver care to patients with special needs and thus impacts on their other duties. The inability to provide high standards of care can lead to guilty and frustrated feelings among nurses (Ford & Turner 2001). These findings are supported by Sowney and Barr (2007), who indicated that time is an obstacle to interaction between nurses and parents. One of the participants in their study was quoted as saying that 'sometimes you do not have the time to put in there to get the information or spend time with them' (Sowney & Barr 2007, p.1682) .

Robillard (1994) claimed that the lack of 'real time' for nurses for communicate is a source of discomfort, frustration and resentment for patients and therefore impacts negatively on rates of recovery and length of patients' stay in the hospital.

A shortage of nursing staff may impede the optimum delivery of care to disabled children (Cumella & Martin 2000). This NGT revealed that the limited

Chapter Four

numbers of nursing staff available to provide care for this population is a big challenge. Aiken et al. (2002a) reported that only 30-40% of nurses believed that the patient-to-nurse ratio was adequate for getting the work done. Aiken et al. (2001) had also previously reported that over 70% of nurses were providing direct patient care within the NHS, but that even this proportion of the workforce was not enough to provide a high quality of care.

Needleman et al. (2002) reported that a higher number of hours of care provided by nurses was associated with better care for patients. However, disabled patients indicated that their needs took up more of healthcare staff's time than those of patients without disabilities; the result may be that healthcare teams are reluctant to work with them (Drainoni et al. 2006b).

The evidence shows that no guidance exists for setting specific nurse-patient ratios for care to disabled children. The following is the nursing staff ratio per child/young person within specialist areas categorised by the Royal College of Nursing (2013):

Special care	1:4
High dependency	1:2
Intensive care	1:1

This is the minimum level of staffing, set out at a national level according to the guidance (2013b). In reality, the ratio of care for disabled children not categorised as high dependency within the NHS Foundation Trust is under evaluation. The needs of children in the unit should be considered during the establishment of a nursing team. The Royal College of Nursing (2003) claimed that falling standards of care and lack of staff time for enhancing or developing practice are factors that should be revised for nursing staff. Recently, the Francis report into failings at Mid Staffordshire NHS Foundation Trust (2013) identified that the shortage of skilled nursing staff was a barrier to patient needs.

A survey conducted by Rafferty et al. (2007) in the UK showed that adequate staffing levels provide better patient outcomes, which was in agreement with a large number of earlier studies (Aiken et al. 2002a; Aiken et al. 2002b;

Kazanjian et al. 2005). It was also found that in hospitals with an inadequate number of nurses, patients receive a lower quality of care. Sovie and Jawad (2001) found that increased registered nurse hours per patient lead to lower patient fall rates, better pain control and fewer nosocomial infections.

Karasek (1979) identified that workload and lack of time are the most important stressors relating to work. Allan et al. (1999) highlighted that job intensity leads employees to experience higher stress levels and job insecurity. Additionally, patient dissatisfaction and higher levels of burnout among nursing staff were reported by Vahey et al. (2004). Job insecurity can produce physical exhaustion and dissatisfaction with life (Demerouti et al. 2000). Aiken et al. (2002b) found that shortages of nursing staff lead to increased burnout and job dissatisfaction among nurses, and may produce emotional exhaustion (Janssen et al. 1999). Additionally, job demands can change moods, energy levels and interests due to their impact on the individual's perceived level of life satisfaction.

'Enough staff to get the work done' was considered by the HCSWs as a challenge to the delivery of care to disabled children, as illustrated by the following:

'Short-staffed and cannot dress and wash them yourself'.

Recently, the Royal College of Nursing published the Frontline First Nursing on red alert report (2013a). The report showed that a significant number of nursing posts and student training places had been cut during 2010-2013 across the UK. The report concluded that high quality nursing care can be made possible by improving the nurse-to-patient ratio and decreasing the skill mix.

Shortages of nurses are a significant challenge to the delivery of safe and effective care for patients in hospital (Aiken et al. 1996). Rogers et al. (2004) reported that longer work hours lead to increased errors by nursing staff and enhance accident rates (Mills et al. 1983). The National Patient Safety Agency (NPSA) (2004) reported that people with learning disability are potentially at risk of physical and emotional harm during the process of hospital admission. Kirschner et al. (2007) highlighted that disabled patients are at risk of injuries due to neglect or malpractice by unskilled members of a healthcare team. Being short-staffed, even for basic care, was another issue raised by this

Chapter Four

study's NGT meetings. The findings of the study by Johnson-Pawlson and Infeld (1996) indicated that an increasing ratio of nursing staff directly corresponded with a lower deficiency index and higher quality of care scores in the UK. Griffiths et al. (2010) found that high levels of nursing numbers substantially improved performance, resulting in benefits for patients.

Lunsky et al. (2008) found that nurses complained about not having enough time to prepare themselves for the admission of patients with learning disabilities. Additionally, Phua et al. (2005) reported that parents of disabled children were not happy with the admission process. The rate of satisfaction with admission was 45% among parents of disabled children, compared to 77% of the control group; this data was echoed by the current NGT, where HCSWs raised their concerns about neglect during admission. Similarly, staff's unpreparedness for admission was identified by Sowney and Barr (2004) as a barrier to health services for disabled patients.

Both groups identified 'unfavourable environment' as a challenge to delivering care to disabled children; this was among the top five priorities for participants and is exemplified by the statements of 'lack of privacy and space' (RNs/ statement1) and 'lack of equipment and resources' (HCSWs/ statement1). Unfavourable environments may contribute to a failure to deliver a high standard of care to disabled children. The 'low technology' structure of health services, with its barriers to health services for disabled patients, was highlighted by Kirschner et al. (2007). Additionally, structural barriers were identified as difficulties by the disabled people who contributed to the study undertaken by Drainoni et al. (2006b).

The study by Iacono and Davis (2003) concluded that a lack of special equipment such as wheelchairs, communication aids and special food utensils tends to affect the quality of care. Access to equipment and assistive technology tailored to the needs of disabled children was emphasised by the NSF under Standard 8. Difficulties in obtaining and accessing equipment were confirmed by the study of Drainoni et al. (2006b); such equipment is vital for the health and basic functions of disabled people. Happ et al. (2004a) found that staff's unfamiliarity with devices is one of the obstacles to communicating with non-speaking patients. Both groups within this NGT stated that the lack of appropriate equipment and resources was an impediment to doing their job.

From the viewpoint of nursing staff in this service evaluation, interaction is both a reward and a challenge. Statements such as ‘promoting communication’ (RNs/ statement 15) and ‘good communication’ (HCSWs/ statement 1) highlighted that communication is a reward. On the other hand, ‘communication barriers with the child’ was one of the five most prioritised challenges for both groups. Participants who contributed to the study by Balandin et al. (2001) reported concerns about the lack of an effective communication system offered by nurses. Ineffective communication can be distressing for both patients and nurses; its potential for causing negative health consequences has been a finding of several studies (Barr et al. 1999; Hemsley et al. 2001; Buzio et al. 2002a; Chant et al. 2002). Sowney and Barr (2007) identified effective communication as the most challenging aspect of caring for patients with learning disabilities. Difficulties with communication are likely to have a negative effect on the assessment of children’s needs and the delivery of relevant information, and decrease the autonomy and cooperation of patients (Mitchell & Sloper 2001; Sowney & Barr 2007). Insufficient understanding by nursing staff directly affects patients’ needs (Kirk 1999). Happ (2000) conducted an interview with critically ill patients (n=16) and their nurses (n=9) in the USA. The patients reported that their voiceless condition was having a devastating effect and causing increasing levels of anxiety during hospitalisation; additionally, nurses depended more on family members for interpretation.

Effective communication is an important aspect of successful nursing practice (Balandin et al. 2001). A lack of augmentative and alternative communication (AAC) resources, a lack of knowledge of AAC among nurses and a lack of time or skills for effectively communicating were all identified by Balandin et al. (2001) as impediments to satisfactory communication. This finding is confirmed by the current NGT, echoed by the HCSWs’ statement about ‘lack of knowledge about the special communication needs of a particular child’ (statement 17). Meanwhile, Walsh (1999) suggested that it was important that nursing staff become familiar with the skills, tools and knowledge needed for communication with voiceless patients.

Walsh and Dolan (1999) and Avis and Reardon (2008) pointed out that producing a meaningful relationship is ‘the essence of good quality care’. The research by Hewitt-Taylor (2008) highlighted parents’ concerns about

Chapter Four

communication efforts by their child not being valued by nursing staff. In addition, Cumella and Martin (2000) suggested that limited communication skills among nursing staff may cause insufficient transition of information relating to such issues as admission, hospital procedures, discharge and menu choices. One result of communication problems with patients can be a dependence on parents or carers to deliver care (Iacono & Davis 2003); this point is confirmed by the RN group within this current study. The concern relating to dependence on parents was reflected by the following item raised by the RN group: 'relying too much on parental care (having to)' (statement 19). Furthermore, patients with learning disabilities have difficulties trying to describe their personal feelings (Sovner 1986), which impacts on their receiving sufficient care and services (Bates et al. 2004).

4.2.3 Evaluation of the Nominal Group Technique

The entire NGT process generated a significant response from the nurses and HCSWs, which signifies how seriously they view their role in dealing with this group of vulnerable children. O'Neil and Jackson (1983) noted that the influence of participants in the discussion phase of the NGT provides a sense of individual and group productivity in a short period of time, which leads to a fruitful group discussion (Hall 1983).

The number of items generated by the HCSWs, for both questions, was higher than nurses, which indicates that the HCSWs may be more involved in the day-to-day care delivery to this group of patients than previously thought, Spilsbury and Meyer (2005) claimed that HCSWs may have closer relationships with patients than nurses, due to their direct bedside care roles. Daykin and Clarke (2000) believed that HCSWs make a significant contribution to the delivery of care but were recognised as less privileged carers and the investigator suggests that HCSWs should be recognised by valuing their delivered care.

Another reason for this significant response from HCSWs may be that the NGT process provided a platform for the HCSWs to voice their concerns about caring for these vulnerable children. Daykin and Clarke (2000) confirmed that health care assistants seem to be devalued within the health services.

4.2.3.1 Evaluation: Qualitative Feedback (Children's Nurses)

The registered children's nurse group gave the following feedback on the NGT:

- It is a good exercise to capture ideas
- It provided an opportunity to share ideas
- It was helpful
- Frightening that so much proper care is challenging
- Good to know how this exercise reflects on the ward work
- Found out that there is not enough training to care for children with complex disabilities

4.2.3.2 Evaluation: Qualitative Feedback (HCSWs)

The HCSW group gave the following feedback on the NGT:

- Enjoyed it
- Pretty good experience
- Good to know we have more children with complex disabilities now than before
- Good to know we have more challenges in future
- Good to think now about which kind of training is necessary for healthcare professionals to deliver care to this group of patients
- Good to know how this meeting can be reflected in care of disabled children
- Good to know challenges when delivering care are more than rewards

4.2.4 Limitations of the NGT

As the results gathered from the two NGT meetings reflect the sum of the individuals' views, the results cannot be generalised or extrapolated. Ginsburg et al. (1997) suggested that NGT cannot provide in-depth qualitative description compared with other focus group models. More NGT groups would have been helpful in enhancing the validity of the data yielded from the two groups in this study.

Chapter Four

4.2.5 Summary of the Section

This section has presented the findings from the two NGT meetings, from the perspective of registered children's nurses and HCSWs. This part of the study demonstrated that nurses and HCSWs share common concerns about the care of children with disabilities during hospitalisation. This section may throw light on the nature of these concerns and the logic that underlies them. Some of the findings generated from the NGT meetings have been elucidated with reference to current studies.

4.3 Section 2: Results of the Content Analysis

4.3.1 Primary Module Topics Related to Caring for Disabled Children within the Curricula in Three Universities

Table 4.7 presents the first part of the content analysis, which is to determine the topics related to caring for disabled children provided in the curricula with the number and percentage weighting for all seven modules.

Chapter Four

Topics	University 1	University 2		University 3				No. of module citations (n=7)	Percentage of module citations (100%)
		Module 1	Module 2	Module 1	Module 2	Module 3	Module 4		
Evidence-based care	√	√	×	×	√	√	√	5	71.4
Professional and ethical issues	√	×	√	×	×	√	√	4	57.1
Multi-professional/multi-disciplinary care	√	√	√	√	√	√	×	6	85.7
Needs assessment of children/young people with complex health needs and their families	√	√	√	×	×	×	×	3	42.8
Different care setting: hospital, community, hospice	√	×	√	√	√	√	×	5	71.4
Communication skills/effective communication	×	√	√	√	√	√	√	6	85.7
Government inquiries, policies and guidelines, clinical governance	×	×	√	√	×	×	√	3	42.8
End of life issues	×	×	√	√	√	√	×	4	57.1
Person-centred care	×	×	√	√	√	×	×	3	42.8
Health needs and care across the age continuum	×	√	√	√	√	×	√	5	71.4
Self-help/self-care and pressure groups	√	×	×	√	×	×	√	3	42.8
Clinical care for persons with disabilities, including modifications required for nursing care and teaching	√	×	√	×	×	√	×	3	42.8
Family-centred care	√	√	√	√	√	×	√	6	85.7
Common psychological and behavioural problems in children with disabilities	×	√	×	√	√	√	√	5	71.4

Table 4.7: Primary module topics related to caring for disabled children and young people and those with complex health needs

4.3.1.1 Discussion of Findings

Watson et al. (2002b) claimed that children with special health needs should be supported effectively by a multi-professional team, with a holistic approach and improved patient care (Bates et al. 2004); this was stressed by the White Papers 'Valuing People' (DH 2009) and 'Every Child Matters' (DfES 2004a).

Crotty et al. (2000) found that effective communication within multi-disciplinary team members was highly scored by the medical students as an aim and object for the disability content of teaching. Tommet et al. (1993) recommended that the curriculum should be taught by inter-disciplinary members of faculty, leading to more clarity on issues such as role sharing, role ambiguity and discipline boundaries. The current content analysis shows that multi-professional and multi-disciplinary care gains a high attribution in seven modules.

Tommet et al. (1993) found that the participants in their study believed that nurses play a significant role in developing and coordinating healthcare service plans and reducing gaps within the health services, as they support and care for disabled patients and their families (Hewitt-Taylor 2005c). Care delivery in different settings is a major issue emphasised by this content analysis.

Melnyk et al. (2004) and Estabrooks (1998) mentioned that evidence-based practice might lead to improved patient care, increased good practice, a higher level of motivation for learning among nurses, a reduction in stress and resistance to change, and increased cooperation among staff (Prochaska et al. 2001). Evidence-based practice was prominent within the content analysis of the curriculum.

Effective communication was identified by the current study as the most significant challenge relating to care for children with learning disabilities. Difficulties in communication have been recognised by a significant number of studies (Iacono & Davis 2003; Cumella & Martin 2004b; Phua et al. 2005; Sowney & Barr 2007; Avis & Reardon 2008; Hewitt-Taylor 2008a; Lunskey et al. 2008). Although communication is a significant aspect of the nurse's role, it is considered to be highly challenging. Walsh and Dolan (1999) stated that a significant number of complaints about health provision relate to failures in communication with patients and their families. Inadequate communication skills lead to a delay in identifying the needs of people with learning disabilities (Robertson et al. 2010b). Buzio et al. (2002b) conducted a survey, by means of a questionnaire, on 31 adults with cerebral palsy. The findings revealed that many participants were dissatisfied with care due to communication difficulties. The participants felt that staff had limited knowledge and skills relating to this issue and thus were unable to use or

Chapter Four

apply AAC devices. Additionally, Banks and Kane (2004) and Hewitt-Taylor (2005d) emphasised that communication skills should be included in the nursing curriculum; the current content analysis shows that most of the modules covered effective communication, although sign language and Makaton were not specifically mentioned.

Hemsley et al. (2001) and Balandin et al. (2007) suggested that learning how to communicate with voiceless patients should be a priority in the training of nurses, since such a skill would lead to effective and fulfilling interaction between nurses and patients. Effective communication (85.7%) is one of the most important content areas identified by this content analysis. The learning outcome of Module 2 from University 3 emphasises communication skills as important to family-centred care. In addition, within the syllabus content of Module 1 from University 2, communication skills are claimed to be a requisite for building up a partnership with families. Meanwhile, Module 4 from University 3 focuses on how to apply communication skills in order to identify health education needs and understand service user experiences.

Kirschner and Curry (2009) noted that the curriculum should also cover special skills for communicating effectively with people who are voiceless, such as pictorial boards, assistive communications technologies, Braille or large print and TDDs (Telephone Devices for the Deaf). There is no evidence of communication technology being taught within the curriculum content currently under examination. Hemsley et al. (2001) and Balandin et al. (2007) pointed out that limited experience and formal training in utilising AAC is a challenge for nurses when communicating with voiceless patients.

4.3.2 Deficiency of Material Related to Disability within Curricula

Table 4.8 addresses the second issue, which relates to the deficiency of information on care for children with disabilities in the curricula under examination. Although it cannot be assumed that the lack of a citation within a curriculum document necessarily implies no teaching on the subject. Never the less an attempt has been made to identify the deficient curricula areas. An extensive literature review (see Appendix 3.4-3.5) and discussion with key informants in this field (one internal lecturer and one external lecturer) helped to identify topics important to care of disabled children.

Topics	University 1	University 2		University 3				No. of module citations (n=7)	Percentage of module citations (100%)
		Module 1	Module 2	Module 1	Module 2	Module 3	Module 4		
Disability Discrimination Act or other policies	√	√	x	x	x	x	x	2	28.5
Classification of disabilities	x	x	x	√	√	x	x	2	28.5
Measurement of disabilities	x	x	x	x	x	x	x	0	0.00
Epidemiology of disabilities	x	x	x	x	x	x	x	0	0.00
Independent living	x	x	x	x	x	x	x	0	0.00
How to organise and finance assistive technology	x	x	x	x	√	x	x	1	14.2
The effects of disability on access to healthcare	x	x	x	x	x	x	x	0	0.00
Growth and developmental issues across the lifespan	x	x	x	√	√	√	x	3	42.8
Discrimination by the healthcare system	x	√	x	x	x	x	x	1	14.2
Consistency of care	x	x	x	x	x	√	x	1	14.2
Transition	x	√	x	√	x	x	x	2	28.5
Coordinating care	x	x	x	x	x	x	x	0	0.00
How services for disabled people are organised, particularly in the community setting	x	x	x	√	√	x	x	2	28.5
Secondary prevention	x	x	x	x	x	x	x	0	0.00
Effect of disability on social and family life, mobility, play, education and employment opportunities	x	√	x	x	x	x	x	1	14.2
Knowledge about the nature, frequency and causes of disability	x	x	x	√	x	x	√	2	28.5

Chapter Four

Not developing attitude of student nurses towards positivism	x	x	x	x	x	x	x	0	0.00
Promoting recognition that disabled people have expertise in solving problems	x	x	x	x	√	x	x	1	14.2
Principles and philosophies of healthcare for people with disabled children	x	x	x	x	x	x	x	0	0.00
Respite care	x	x	x	x	x	x	√	1	14.2
Models of disability and focus on social model	x	x	x	x	x	x	x	0	0.00
Expert parents	x	√	x	x	x	x	x	1	14.2
The needs of disabled or special healthcare children and young adults	x	x	x	x	x	√	x	1	14.2
Health promotion	x	x	x	x	√	x	√	2	28.5
Family stress	x	√	x	x	x	x	x	1	14.2
Family adaptation to hospitalisation and chronic illness	x	√	x	x	x	x	x	1	14.2
Effective support	x	x	x	x	√	x	x	1	14.2
Care of infants, children and young people in the critical care environment	x	x	x	x	√	x	x	1	14.2
Risk identification and management	x	x	x	x	√	x	x	1	14.2
Health education needs	x	x	x	x	x	x	√	1	14.2
Psychosocial and spiritual needs	x	x	x	x	x	√	x	1	14.2
Advanced care plan	x	x	x	x	x	√	x	1	14.2
Early referral	x	x	x	x	√	x	x	1	14.2
Best practice	x	x	x	x	x	√	x	1	14.2
Holistic approach	x	x	x	x	x	√	√	2	28.5
School life	x	x	x	√	x	x	x	1	14.2
Loss, grief and chronic sorrow	x	x	x	√	x	x	x	1	14.2
Essential care needs	x	x	x	x	x	x	√	1	14.2
Working with charitable and third sectors	x	x	x	x	x	√	x	1	14.2
Pain assessment and management	x	x	x	x	√	x	x	1	14.2
Caring values and beliefs	x	x	x	x	x	√	x	1	14.2
Children who require complex technological dependent care	x	x	x	x	√	x	x	1	14.2
Counselling skills	√	x	x	x	x	√	x	2	28.5
Identifying and utilising the information resources available	√	x	x	x	x	x	x	1	14.2
Package of care	√	x	x	x	√	x	x	2	28.5
Developing students' knowledge and skills about caring for children/young people and families with complex and long term health	√	x	x	x	x	x	x	1	14.2

needs									
Reflective approach	×	√	×	×	×	×	×	1	14.2
Care planning	×	√	×	×	×	×	×	1	14.2
Empowering children and families	×	×	√	√	×	×	×	2	28.5
Decision-making	×	×	√	×	√	×	×	2	28.5
Advocacy role	×	×	√	×	×	×	×	1	14.2
Multicultural society	×	×	×	×	×	√	×	1	14.2
Negotiation role	×	√	√	×	×	√	×	2	42.8
Palliative care	×	×	×	√	×	√	×	2	28.5
Influence of the media on childcare/tele-media	×	×	√	√	×	×	×	2	28.5
Problem-based learning approach	×	×	√	×	×	×	√	2	28.5
Partnership approach	×	√	×	√	×	×	×	2	28.5
Impact of long term health problems on children and their families	√	×	×	√	×	×	×	2	28.5
Vulnerable groups: children with special needs/safeguarding issues	×	×	√	×	√	×	×	2	28.5
Preverbal communication	×	√	×	×	×	×	×	1	14.2
Play therapy	√	√	×	×	×	×	×	2	28.5
Supporting patients at diagnosis	×	×	×	×	×	×	×	0	0.00
Nutrition	×	√	×	×	×	×	√	2	28.5

Table 4.8: Curricula deficiencies related to caring for disabled children and young people and those with complex health needs

4.3.2.1 Discussion of Findings

This content analysis revealed that many areas of curricula relating to disabled children and young people and those with complex health needs were not fully covered by the three universities in this survey. There were substantial deficiencies in areas such as positive attitudes towards disabled children, expert parents, transition, respite care, sexual health and reproductive issues, the negotiation role, the UK Discrimination Disability Act (DDA), health promotion, supporting patients at diagnosis and care of patients with assistive technology needs.

The results of this content analysis to some extent replicate those of the study by Tanenhaus et al. (2000), who examined course syllabi from 30 public health schools in the USA. Significant gaps were identified in the syllabi, such as classification and measurement of disability, independent life, the American Disability Act and the organisation and financing of assistive technology and

Chapter Four

personal assistance as health services. This researcher suggests, therefore, that a broader coverage of issues related to disability in graduate public health curricula is necessary. Scullion (2000) pointed out that the disability theme is not embedded equally in all nursing curricula. This researcher believes that an ideal curriculum should address the holistic needs of children with disabilities and their families.

Some of the deficiencies identified by the current content analysis of curricula, such as DDA, supporting patients during diagnosis, sexual health, play roles, nutrition and negotiation roles, were also addressed by Banks and Kane (2004) and Hewitt-Taylor (2005d).

Nolan and Nolan (1999) conducted a literature review on the contemporary rehabilitation curricula and found a number of deficiencies, such as insufficient attention to ethnicity and cultural issues and the needs of family carers. Additionally, the researchers suggested that patients' need for advocacy and empowerment should be a learning outcome within the curricula. The current content analysis also found a deficiency in the area of empowering children and their families; this was confirmed by Tommet et al. (1993).

Health promotion is defined as the process of empowering people to gain control and improve their health (WHO 2012). Ayyangar (2002) states that its focus is health and function, rather than impairment and disability, when considering the impact on disabled people's daily life (Kalnins et al. 1992). Kalnins et al. (1992) pointed out that it is a shift towards recognising children as active respondents to the health promotion process. The results of the curriculum documents reviewed by Scullion (1999b) showed that health promotion and a relatively independent lifestyle were considered highly. The current examination of seven university modules identified coverage of health promotion and empowerment of children and their families within the care setting in only two out of seven modules, which is less significant than the Scullion (1999b) study. A statement from the learning outcomes of Module 1 from University 3 was, 'the nursing role is promoting and facilitating self-care and empowerment'. Rimmer (1999) mentioned that the role of health professionals was to sustain independence and enhance the quality of life of disabled people. Evans et al. (1995) found that the first priority for most patients with disabilities is independent daily life, which was accepted by

Kahtan et al. (1994). This content analysis has found that this particular need of disabled children and their families is ignored by nursing modules.

Scullion (1999c) showed that independent life for disabled individuals was not fully covered in curricula. This subject also constitutes a significant gap in the modules in the current study. Smeltzer et al. (2005) emphasised the paucity of programmes on health promotion for people with disabilities; this group of patients receives a lower quality of healthcare than their able-bodied counterparts.

Transition is defined as a holistic approach to preparing young people with chronic physical and medical conditions for transferring to adult-oriented services, with the aim of meeting their needs (Blum et al. 1993); this orientation was highlighted by the White Paper 'Aiming High for Disabled Children: Better Support for Families' (HM Treasury & DfES 2007). In this content analysis, only two out of seven curricula covered the transition theme, confirming the deficiency noted by Nolan and Nolan (1999). It is clear, therefore, that the transition theme needs more attention as it is a stressful and difficult event for adolescents with a chronic health problem (Garell 1986). Additionally, carers should be more sensitised to the need of disabled patients, in anticipation of the negative consequences of issues such as psychological distress, anxiety or premature death (Portsmouth Hospital NHS Trust 2012).

Sex and reproductive issues are not identified in any of the modules, which may reflect a larger incidence of health professionals avoiding this subject during work with disabled patients; this is called the 'solution by denial' model. This finding is supported by Smeltzer et al. (2005) and Nolan and Nolan (1999). Smeltzer et al. (2005) state that pregnancy, sexuality and parenting are common concerns among individuals with disabilities. However, disability can have a significant effect on sexuality, sexual function and occasionally female fertility (Basson 1998). Fitcher (2011) claimed that improving awareness among staff is vital in order to take a supportive approach to adults with learning disabilities when they express their sexuality.

Hollins (1988) suggested that the key concepts of family-centred care, cultural sensitivity and lifespan issues should be considered within nursing curricula related to learning disability. This content analysis also shows that areas such as family-centred care, family stress and adaptation to hospitalisation will

Chapter Four

require attention in the future. These deficiencies were also addressed by Tommet et al. (1993).

Bates et al. (2004) mentioned that half of their participants did not possess an up-to-date knowledge of the Mental Health Act (1983). It appears that a significant number of healthcare staff do not receive enough training in the field of mental health and recognising patients' mental health needs (Hatton 2002); the mental needs of disabled patients were also highlighted by Piachaud (2002). The psychological and spiritual needs of children with disabilities are also under-represented in training, as identified by the current content analysis.

Smeltzer (2005) suggested that DDA should be considered within the nursing curriculum; this would lead to an enhanced awareness of discrimination and empower nurses for advocacy roles relating to their interactions with disabled patients. Wasserbauer (1996) also recommended that nursing schools should include DDA in their undergraduate curricula. DDA is still an area which needs to be covered in the ideal curriculum, which is confirmed by the findings of the current content analysis.

Scullion (2000) mentioned that nursing educators and stakeholders in curricula have a responsibility to take action against discrimination in terms of learning outcomes. It was concluded that nursing training still does not have a robust anti-discrimination philosophy. This examination of recent curricula from three UK universities shows a lack of material related to DDA and access to health services.

Smeltzer (2005) also suggested that social policy, sociology, anatomy and physiology should be included in the general nursing curriculum, as well as health assessment and promotion within field of the nursing curricula relating to care of disabled children. The current content analysis shows that health promotion and health assessment still constitute 'insufficiencies' within the curricula.

4.3.3 Discussion of Frequency of Terms within the Modules

The literature suggests that these are the ideal terms (see Table 4.9) associated with educating nurses about disabled children.

Terms	University 1	University 2		University 3			
		Module 1	Module 2	Module 1	Module 2	Module 3	Module 4
Communication	0	3	1	1	1	1	1
Young people/young person/adolescent	2	1	0	2	11	1	0
Family-centred care	1	3	0	0	2	0	0
Skill	4	8	2	0	3	0	2
Knowledge	1	3	1	1	1	0	0
Attitude	0	0	0	0	0	0	0
Transition	0	1	0	1	0	0	0
Expert parents	0	0	0	1	0	0	0
Stigmatisation	0	0	0	0	0	0	0
Key worker	0	0	0	0	0	0	0
Negotiation role	0	0	1	0	1	0	0

Table 4.9: Frequency of terms within the modules

4.3.3.1 Discussion

Two possible factors in negative attitudes toward disability are insufficient coverage in the curricula and inadequate contact with disabled people during nurses' training (Smeltzer et al. 2005). Matziou et al. (2009) stated that well-designed curricula can impact on the attitudes of nursing students towards disabled children. It is surprising that negative attitudes and stigmatisation towards disability are not addressed by the contemporary modules in the current content analysis.

These findings are further highlighted by a British government document (DfES & DH 2003) which stated that health professionals within the NHS need to have more positive attitudes towards disabled children and their families.

Stigmatisation and negative attitudes among staff towards disabled people may

Chapter Four

result in lower standards of nursing care (Scullion 1999c). Smeltzer et al. (2005) stated that discrimination towards disabled patients should be considered. Nursing faculties should consider this issue in their curricula, as it could help to prepare nurses to play the role of advocate for disabled people. This advocacy role on the part of children's nurses is mentioned in Module 2 from University 2: 'examined in relation to rights, vulnerability and issues of power differentials within care settings and today's multicultural society'.

The result of the study conducted by Avis and Reardon (2008) showed that the role of parents as experts is not acknowledged; the negotiation of care between parents and hospital staff is not based on either child's or parents' needs. Hence, parents feel that their capabilities and caring attitudes are ignored by nurses. This may be a result of nurses' lack of skills in care of people with physical disabilities (Scullion 1999c). These findings were highlighted by Ford and Turner (2001) who conducted a small study of nurses' experiences of caring for children with additional needs in hospital. Iacono and Davis (2003) focused on the recognition of parental expertise and the difficulties in building up a trustful relationship with a health team. On the other hand, Sowney and Barr (2007) found that nurses' fear and vulnerability lead them to rely more on patients' carers and therefore accept criticism by parents. Another study by Fox and Wilson (1999) showed that parents were concerned about the insensitivity of nursing staff towards their child's needs. Therefore, they continued to carry out the fundamental nursing care of their children themselves. The current content analysis has identified that expert parents, negotiation roles and family-centred care all need to be addressed by nursing curricula. Within University 2, the learning outcomes relating to the subject include 'evaluate the role of negotiation in professional children's nursing'. Negotiation is therefore identified as a role and duty of children's nurses.

4.3.4 Common Nomenclature Used within the Modules Examined

Table 4.10 shows the terms that represent disability concepts in each module. The frequency of terms indicates how much importance is placed on each term.

Common nomenclature	University 1	University 2		University 3			
		Module 1	Module 2	Module 1	Module 2	Module 3	Module 4
Children with long term conditions	7	x	X	11	X	X	X
Children with long term healthcare needs	x	x	X	2	X	X	X
Children with complex illnesses/needs	5	2	X	X	7	X	X
Children with chronic illnesses	x	4	X	X	X	X	X
Children with disabilities	X	x	X	X	X	X	X
Children with special healthcare needs	X	2	1	X	X	2	X
Children who require complex technology-dependent care	X	X	X	X	1	X	X
Children with mental health needs/difficulties	X	X	X	X	X	X	2
Children with learning disabilities	2	X	X	X	X	X	1
Children in chronic states	1	x	X	x	x	x	x
Children with physical health needs	x	x	x	x	x	x	1

Table 4.10: Common nomenclature within the modules examined

4.3.4.1 Discussion of Findings

Jette (2006) suggested that applying the universal language of disablement, set out by the WHO, as a standard would help to tackle the problem with using nomenclature.

Chapter Four

The medical model is still influential on nursing curricula; this has been addressed in the UK by Goodall (1995) and Scullion (1999b) and in the USA by Tommet et al. (1993).

The medical perspective of disabilities presents the disabled individual and the sickness as equal (Barker 2010b). The modules in this study portray disability as a chronic illness; for instance, one learning outcome statement from University 1 'understands the provision of health and health care and practice for children and young people'. The term 'chronic illness' is used throughout all the modules under study, which may be a medical orientation; the learning outcomes of Module 2 from University 3 mention 'knowledge and application of pathophysiology and genetics in child health'. Bricher (2000) noted that the healthcare professional role is an obstacle to a disabled individual within the medical model. Seccombe (2007) stated that this medical model is still a substantial influence on nursing professionals. Goodall (1995) noted that the model as applied to nursing curricula leads to a domination of health professionals and encourages dependence on the part of disabled patients (Bricher 2000).

4.3.5 Learning Resources Identified Through Analysis of Curricula

Table 4.11 illustrates the issue raised by Question 5, which relates to the type (medical-surgical, paediatric, disability/special health needs) and number of nursing textbooks about disability/special health needs in the suggested learning lists.

Resources	University 1	University 2		University 3				Number of modules using these resources (n=7)	Percentage of modules using these resources (100%)
	Module 1	Module 1	Module 2	Module 1	Module 2	Module 3	Module 4		
Children and young people's nursing textbook	✓			✓	✓	×	✓	4	57.1
Special healthcare needs textbook	×			✓	✓	×	×	2	28.5
Textbook related to disability	×			×	×	×	✓	1	14.2
Medical-surgical textbook	×			✓	✓	✓	✓	4	57.1
Journal	×			✓	×	×	×	1	14.2
Policy for care of disabled children	×			×	✓	×	×	1	14.2
Website	×			✓	×	✓	×	2	28.5
Others	×	No suggestions	No suggestions	×	×	✓	✓	2	28.5

Table 4.11: Learning resources identified through analysis of curricula

Chapter Four

4.3.5.1 Discussion of Findings

The participants who contributed to the research of Banks and Kane (2004) noted that lack of resources acts as a barrier to sufficient training.

Table 4.11 shows that nursing textbooks are the most common source of information used. This finding is similar to that of Smeltzer et al. (2005), who observed that the use of textbooks with disability-related content was a primary resource for teaching. Medical-surgical textbooks were reported by 94% of nursing schools and paediatric textbooks by 90.1%. Few schools reported using videos, games, books or disability experiences. This analysis of three university curricula showed that half of the suggested sources on the reading lists are medical-surgical textbooks. Only one of the modules under examination suggested a book directly related to disability, while two modules from the same university referred to a couple of textbooks about special healthcare needs issues. These findings show that disability and special healthcare needs may not be covered equally in nursing modules; this is confirmed by a review of nursing curriculum documents by Scullion (1999c).

4.3.6 Teaching Methods Used within the Curricula

Table 4.12 presents a comparison between the universities in terms of teaching methods.

Teaching methods	University 1	University 2		University 3				Number of teaching methods delivered (n=7)	Percentage of teaching method delivered (100%)
		Module 1	Module 2	Module 1	Module 2	Module 3	Module 4		
Lectures/seminars/tutorials	✓	✓	✓	✓	✓	✓	✓	7	100
Small group activities	×	×	✓	×	×	×	×	1	14.2
Self-directed study/independent study time	×	✓	✓	✓	✓	×	✓	5	71.4
Simulated practice	×	×	×	×	✓	×	×	1	14.2
Technology-enhanced learning	×	×	×	✓	✓	✓	✓	4	57.1
Group work and discussion	×	×	×	×	×	✓	×	1	14.2
Guided reading	×	×	×	×	×	✓	×	1	14.2
Values-based learning group	×	×	×	×	×	×	✓	1	14.2
Practice time (fieldwork/professional practice/work experience)	✓	✓	✓	×	×	×	×	3	42.8
Workshops/practical/group projects	×	✓	✓	×	×	×	✓	3	42.8

Table 4.12: Comparison between universities in terms of teaching methods

4. 3.6.1 Discussion of Findings

Table 4.12 shows that didactic methods (lectures, seminars or tutorials) are still the major approaches to teaching disability-related subjects. This result is similar to that of Lennox and Diggins (1999b), who conducted an audit of the amount and nature of undergraduate teaching offered on disability in Australia. 66% of courses were taught by didactic methods. All medical schools in that study offered lectures, seminars and tutorials as a compulsory form of teaching. However, a comparison between Scullion's study (1999b) (66%) and this current content analysis (100%) shows that universities still emphasise the didactic approach. A survey conducted

Chapter Four

by Hollins (1988) showed that group discussions and seminars are more popular among students and teachers. Such deductive methods are known as a way of transferring factual information to students (Gardner & Lambert 1972; Piachaud 2002), but are less effective at conveying attitudes and skills (Watson & Uzzell 1980; Piachaud 2002).

Watson and Uzzell (1980) found that practicum training improves health professionals' skills in care delivery to disabled people; additionally, it helps nurses to gain a better understanding of disability and decrease negative attitudes (Tommet et al. 1993). Furthermore, Piachaud (2002) suggested that visits to clinics and services, problem-based learning and self-directed learning are all good approaches to raising levels of learning. Tommet et al. (1993) suggested that practicum-based education was crucial in assisting nurses to gain a better understanding of disabled patients and decrease negative attitudes towards them. This content analysis has shown that only Universities 1 and 2 offer practical experience, which can be categorised as experience with disabled patients.

Scullion (1999b) also found that among students, a case study video and subsequent discussion is the most popular approach to teaching on disability-related subjects. Furthermore, Hollins (1988) suggested that web-based modules or CD-ROMs are the best method for educational environments. However, Smeltzer et al. (2005) reported that few schools are using videos, games, books or disability experiences as teaching methods. Applied technology was used in four out of seven modules under examination in the current content analysis.

Scullion (1999) pointed out that simulation, as a teaching method, is still not employed frequently in this field. This point appears to be confirmed by the current study, in which simulation was only identified in one module from University 3. Scullion (1999b) also claimed that simulation can improve students' confidence in dealing with a disabled person. Furthermore, it improves the attitudes of nurses towards disabled people, a point that has been addressed by numerous researchers (Piachaud 2002; Thompson et al. 2003; Rillotta & Nettelbeck 2007; Seccombe 2007). Inviting disabled people to contribute to nursing education programmes by sharing their experiences and challenges has been recommended by a number of studies (Scullion 1997; Hahn 2003; Seccombe 2007). In accordance with this, Wells et al. (2002) conducted a workshop led by disabled presenters. Students claimed that direct teaching by disabled people was a notable experience. Disabled people, by

teaching, can transfer their experience and create partnerships; this point was however not considered by the seven modules under study.

4.3.7 Groups of Children and Young People with Disabilities Cited in the Curricula

Table 4.13 presents the groups of children and young people with disabilities addressed within the seven modules.

Groups of children and young people with disabilities/special health needs	Number of modules (n=7)	Percentage (100%)
Children with cognitive impairment	1	14.2
Infants and children with disabilities	5	71.4
Children with mental health needs	3	42.8
Children with physical health needs	1	14.2
Children and young people with behavioural problems	1	14.2
Children and young people with learning disabilities	2	28.5
Young adults with disabilities	2	28.5
Children and young people with neurodevelopment disease	1	14.2
Children and young people with special healthcare needs	1	14.2
Complex healthcare needs	1	14.2
Children and young people with communication disorder	0	0
Ethnic groups	0	0
Children and young people who are deaf/hard of hearing	0	0
Children and young people with visual impairments	0	0

Table 4.13: Groups with disabilities/special health needs addressed in nursing curricula

4.3.7.1 Discussion of Findings

The current study has shown that the selected UK curricula relating to care for disabled children places more emphasis on patients with mental health needs and learning disabilities than on other groups of patients such as young adults, those with communication disorders, minority ethnic groups and those with physical health needs. Some of these findings support the research conducted by Smeltzer et al. (2005), who concluded that lack of attention to other disability groups may be a result of stigmatisation, and that nursing students should be familiar with a variety of disabilities. Additionally, Newacheck (1989) identified that disabled adolescents were less noticeable in the eyes of policy-makers.

4.3.8 Conclusions of the Content Analysis

There is an enormous pressure on nursing education relating to recognition of the disabled population's experiences and needs (Tanenhaus et al. 2000). The results of the study by Tanenhaus et al. (2000) highlighted the importance of ameliorating the contemporary curriculum and teaching methods with the aim of enhancing the knowledge, skills and attitudes of undergraduate students towards disabled children. Hahn (2003) claimed that enhancing the curriculum in this field may provide direct benefits for an individual with a learning disability.

Numerous components of the disability contents of nursing students' curricula have insufficient coverage due to lack of teaching time (Duff 2000). Similarly, within the selected modules, many areas of content relating to care of disabled children are deficient, which might also be explained by lack of time. According to Holt et al. (2000), understanding disability requires a substantial amount of time, not just one session of awareness-raising (Goodall 1995).

It can be suggested that nursing schools should put more effort into coordinating courses related to disability, and provide an opportunity for the staff members teaching these modules to enhance their knowledge and experience in this field. Additionally, there is a need to involve disabled teachers in delivering these courses; this initiative may help students to better understand disabled people's needs. Providing experience for students by letting them work with a disabled individual was suggested by Lennox and Diggins (1999a). Lindgren and Oermann (1993) found that after a presentation by a disabled person at a one-day conference, students' attitude scores improved.

One approach to improving the quality of teaching is the involvement of disability organisations and charities in the planning and evaluation of the curriculum (Scullion 1999b). This point is not mentioned in any of the current modules under study. Another suggestion is that teachers with expertise in this field should directly contribute to designing and teaching the curriculum (Scullion 1999b).

In the modules under examination, opportunistic teaching does not appear to be recognised; this is a point of deficiency that merits attention.

All of the modules examined by the current content analysis show both strengths and weaknesses; therefore, maybe it would be a good time to suggest a national

Chapter Four

curriculum covering all aspects of disability in order to deliver higher standards of care for disabled children. Werner and Grayzman (2011b) suggested that universities should develop curricula with the aims of improving knowledge, promoting positive attitudes and reducing fear of working with disabled people. A robust examination of the contemporary nursing curriculum is therefore necessary, a point stressed by Roxburgh et al. (2008). The result of insufficient staff training

4.3.9 Limitations of the Content Analysis

There are limitations to this content analysis of curricula. The sampling technique was based on convenience, focusing on only seven modules from three selected universities. Any claim to generalise such results cannot therefore be substantiated.

4.3.10 Summary of the Section

The development of this content analysis was driven by a recognised need for education in the field of care delivery to disabled children, based on nursing staff's concerns raised in the first stage of this service evaluation. The content analysis that was conducted covered seven modules from three universities that relate to children with disabilities. The results suggest a need for broader curriculum content, with a holistic approach towards disabilities, in undergraduate nursing

4.4 Section 3: Results and Findings of the Service Evaluation Audit

4.4.1 Introduction

An audit was carried out as part of the service evaluation relating to the care and welfare of disabled children and young people and those with complex health needs, along with their families, who use the children's wards at an NHS Foundation Trust. 14 key informants representing the children's wards participated in this audit. The scope of the audit was to identify potential points of improvement for care delivery to children with disabilities.

4.4.2 Communication Benchmark Criteria (Score Range 0–10)

In this part of the audit, staff from the children's wards were questioned on a range of evidence criteria pertinent to the communication benchmark criteria.

4.4.2.1 Findings

Figure 4.1 and Table 4.14 show that most of the concerns of the key informants related to using (or not using) a variety of methods for non-verbal communication with disabled children (mean=0.72), access to advocacy support for minority ethnic communities (mean=1.10) and evidence related to staff communication training (mean=1.27).

The best evidence, with the highest mean (1.40), related to dialogue across all parts of the service provision pertinent to children with disabilities and the use of appropriate communication systems for disabled children with little or no verbal communication (mean=1.40).

Chapter Four

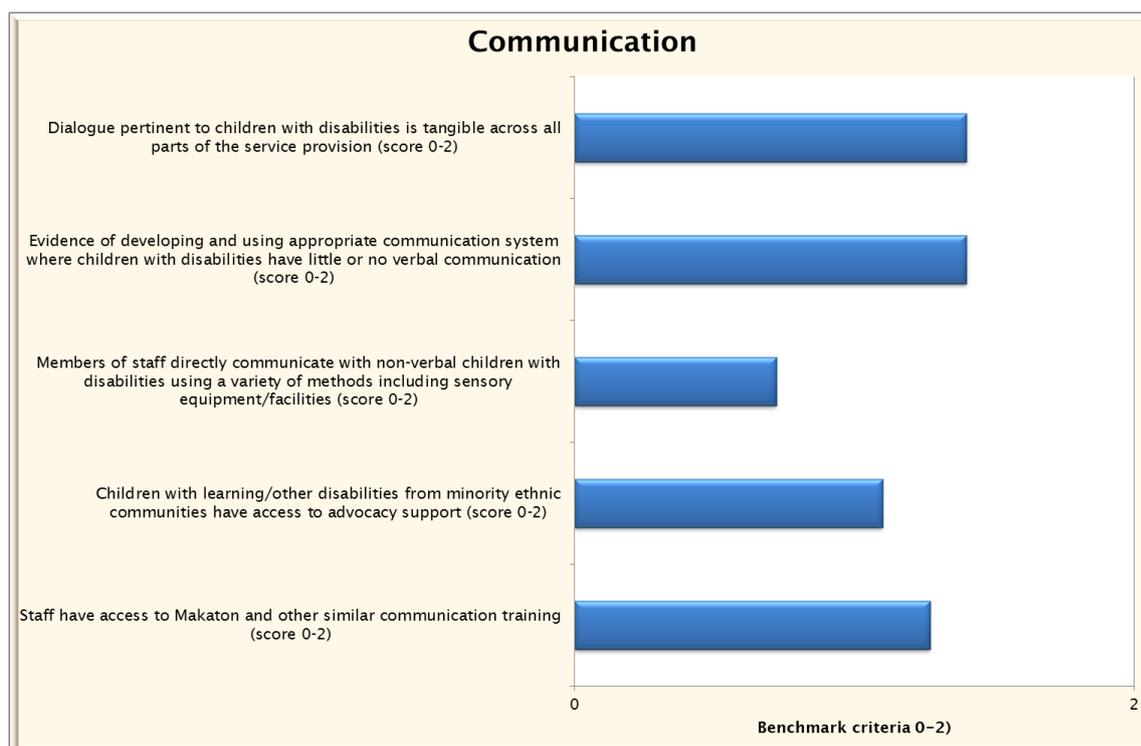


Figure 4.1: Bar chart for communication benchmark criteria

Evidence	Number of respondents	Mean
Dialogue pertinent to children with disabilities is tangible across all parts of the service provision	10	1.40
Evidence of developing and using appropriate communication system where children with disabilities have little or no verbal communication	10	1.40
Members of staff directly communicate with non-verbal children with disabilities using a variety of methods including sensory equipment/facilities	10	0.72
Children with learning/other disabilities from minority ethnic communities have access to advocacy support	10	1.10
Staff have access to Makaton and other similar communication training	11	1.27
Communication benchmark criteria		Score=5.89

Table 4.14: Frequency of communication benchmark criteria

Overall, the communication benchmark criteria scored 5.89 out of ten.

4.4.2.2 Discussion

The White Paper 'Valuing People' (DH 2009) provides a benchmark for avoiding discrimination against those from minority ethnic communities with learning disabilities. This audit suggests there is a lack of advocacy support for minority ethnic communities across the children's wards in question. However, the dialogue relating to children with disabilities across the service provision met the criteria satisfactorily (mean=1.40). Within the audit, the lack of a variety of methods for communication with voiceless disabled children across the children's wards was tangible. Wall-mounted posters relating to disabled children were utilised in all wards. There was also tangible evidence of the development of appropriate communication systems for voiceless children. However, the main method of communication was based on the verbal mode. The use of alternative interventions such as sign language, picture-point systems and electronic devices to assist disabled children in increasing their communication abilities has been supported by a number of researchers (Durand & Carr 1991; Reichle & Sigafos 1991; Charlop & Haymes 1994). The importance of developing and utilising appropriate communication systems for children who have little or no verbal communication has been highlighted by the policy documents 'Aiming High' (HM Treasury & DfES 2007) and 'Valuing People' (DH 2009). Emerson and Baines (2010) stated that a lack of communication skills among health professionals may reduce the capability of staff to identify effectively the health needs of disabled patients. Within this audit, only a small number of staff could use Makaton² (mean=1.27). Finke et al. (2008) pointed out that efficient nurse-patient communication is crucial. These authors noted that nurses usually receive little or no training in using augmentative and alternative communication (AAC), a deficit which may exert a negative effect on communication between nurses and patients with complex communication needs (CCN). This point was confirmed by the current audit. 'Together From The Start', a practical guide for professionals working with disabled children and their families, also emphasised the importance of effective communication (DfES & DH 2003).

It is recommended that the NHS Foundation Trust should review the development of nursing skills in communication with disabled children who have not developed speech.

² Makaton is a language programme designed for individuals who cannot communicate efficiently by speaking (Beukelman & Mirenda 2005).

4.4.3 Training Benchmark Criteria (Score Range 0–10)

In this part of the audit, the staff of the children's wards were questioned on a range of evidence criteria pertinent to the training benchmark criteria.

4.4.3.1 Findings

Figure 4.2 and Table 4.15 show that most concerns related to the availability of staff training for certain areas such as communication, inter-personal skills and behavioural management for working with children with disabilities (mean=0.41). Another major concern was joint multi-agency training between health, education and social services staff (mean=0.50). There were three prompts with a mean of less than 0.8: availability of specific technology instructions pertinent to the care of children with disabilities (mean=0.75), annual updating of staff training (mean=0.54) and availability of specific instructions for the care of children with disabilities in undergraduate curricula (mean=0.54). The highest evidence score related to new staff receiving information pertinent to children with disabilities during induction (mean=0.91). Overall, the training benchmark criteria scored 3.65 out of 10.

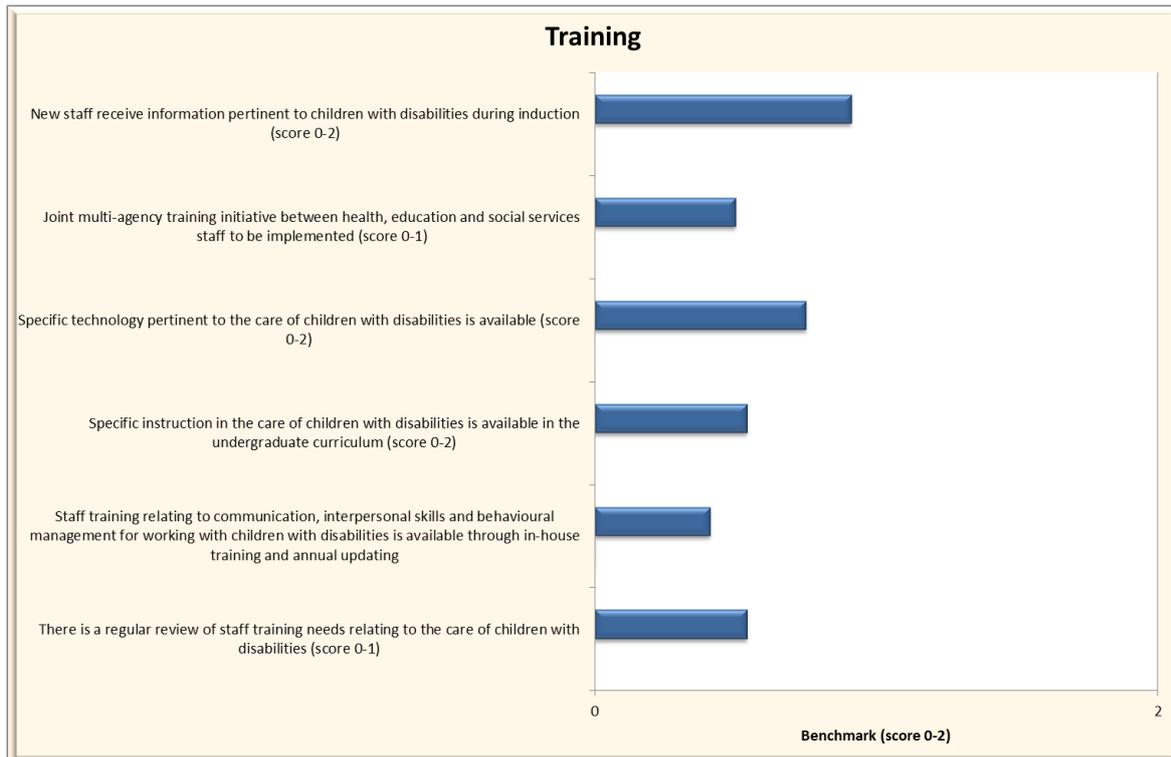


Figure 4.2: Bar chart for training benchmark criteria

Evidence	Number of respondents	Mean
New staff receive information pertinent to children with disabilities during induction	12	0.91
Joint multi-agency training initiative between health, education and social services staff to be implemented	11	0.50
Specific technology pertinent to the care of children with disabilities is available	12	0.75
Specific instruction in the care of children with disabilities is available in the undergraduate curriculum	11	0.54
Staff training relating to communication, interpersonal skills and behavioural management for working with children with disabilities is available through in-house training and annual updating	12	0.41
There is a regular review of staff training needs relating to the care of children with disabilities	12	0.54
Training benchmark criteria		Score=3.65

Table 4.15: Frequency of training benchmark criteria

Chapter Four

4.4.3.2 Discussion

This audit revealed that the children's wards of the NHS Foundation Trust do not have, as is best practice, a joint multi-agency training initiative between health, education and social services. However, there was evidence of customer care training for the care of children with autism, and the use of experts to communicate with disabled children during some procedures such as blood tests. 'Valuing People' (DH 2009) emphasised the importance of joint planning and working together. Watson et al. (2002a) suggested that joined-up approaches for professionals have a positive impact on the support needs of disabled children and their families. Additionally, such a model facilitates liaison and coordination between different service providers (Abbott et al. 2005) and promotes multi-professional skills (Horsburgh et al. 2001; Banks & Kane 2004). The joint agency training of staff did not meet the benchmarked criteria; therefore, the Trust's post-audit action plans will need to address this deficiency.

The Disabled Child Standard in the National Service Framework (NSF) (DH 2004) states that children with learning disabilities have higher levels of unmet needs than their healthy counterparts and require more nursing support. Additionally, 'Valuing People' (DH 2001b) emphasised the importance of highly-skilled and well-trained healthcare professionals who work with disabled people. The provision of staff training across the department in certain areas, such as communication and management of challenging behaviour, did not meet many of the benchmarked criteria. However, there is good evidence that, during induction, newly-qualified nurses receive adequate information relating to the care of disabled children.

4.4.4 Multi-Agency Teamwork Benchmark Criteria (Score Range 0–10)

This aspect of the audit sought to ascertain whether multi-agency teamwork was established in the children's wards of the NHS Foundation Trust.

4.4.4.1 Findings

Figure 4.3 and Table 4.16 show that most concerns related to areas such as establishing a family forum (mean=0.04) and multi-agency involvement in the transition to an adult services strategy (mean=0.36). The following scores were obtained as a result of looking into available procedures for managing disabled

children with challenging behaviour (mean=0.54), availability of a multi-disciplinary support team with experience of dealing with such children (mean=0.59) and multi-disciplinary assessment tools for children with disabilities (mean=0.72). These areas all scored a mean of less than 0.80. The best evidence related to an appointed lead for transition (mean=1.33) and coordination between the relevant agencies during transition to adult services with a formal care plan (mean=0.90). Overall, the multi-agency teamwork benchmark criteria scored 4.48 out of 10.

Chapter Four

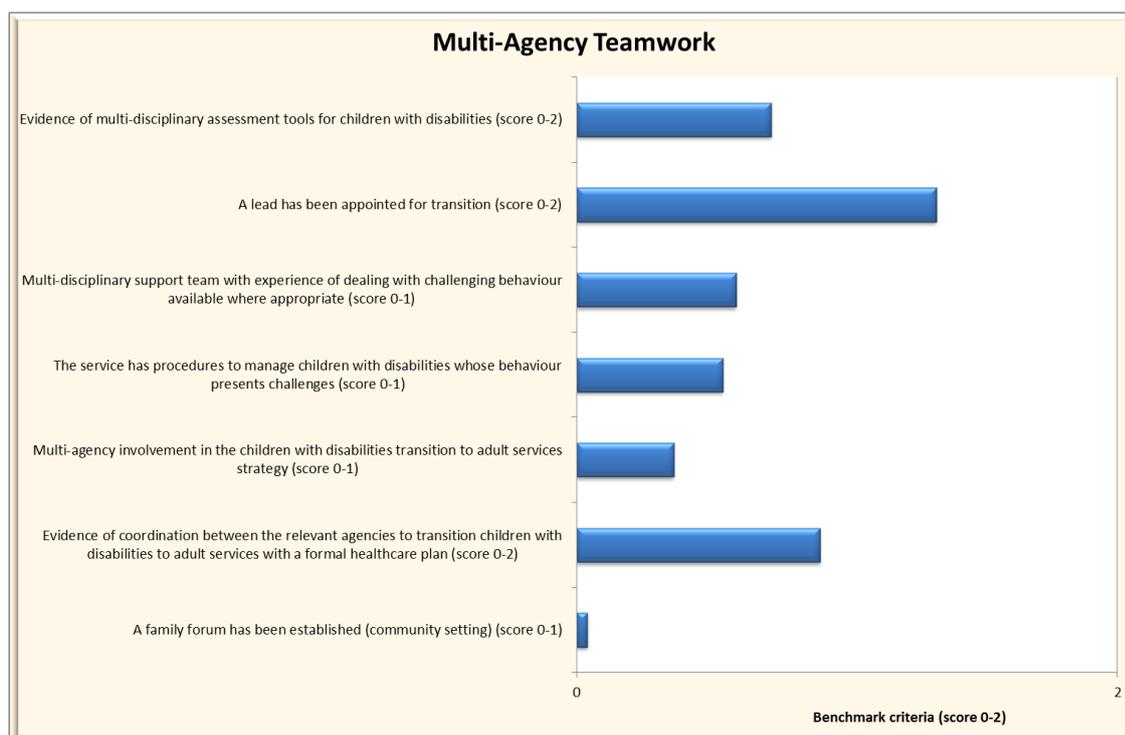


Figure 4.3: Bar chart for multi-agency teamwork benchmark criteria

Evidence	Number of respondents	Benchmark mean (0-2)
Evidence of multi-disciplinary assessment tools for children with disabilities	11	0.72
A lead has been appointed for transition	12	1.33
Multi-disciplinary support team with experience of dealing with challenging behaviour available where appropriate	11	0.59
The service has procedures to manage children with disabilities whose behaviour presents challenges	11	0.54
Multi-agency involvement in the children with disabilities transition to adult services strategy	11	0.36
Evidence of coordination between the relevant agencies to transition children with disabilities to adult services with a formal healthcare plan	11	0.90
A family forum has been established (community setting)	11	0.04
Multi-agency teamwork benchmark criteria		Score=4.48

Table 4.16: Frequency of multi-agency teamwork benchmark criteria

4.4.4.2 Discussion

All mental health disorders have a greater impact on children with disabilities than on their peers (DH 2001b). Gaskin and Mitchell (2005) found that between 11-14%

of children with special healthcare needs have unmet mental health needs. A holistic service approach with a focus on diagnosis and identification of the needs of disabled children and their families is essential for improving the quality and effectiveness of support (DH 2001b; Watson et al. 2002a; DH 2004). Families with disabled children believe that multi-disciplinary services should be one of the priorities of service provision (Beresford et al. 2005). The importance of a multi-disciplinary team is recognised by 'Valuing People' (DH 2001b). Additionally, the NSF mentioned that a criterion of the quality of care for disabled children is good multi-disciplinary care planning and treatment (DH 2004). The current audit has shown that multi-agency teamwork did not meet the benchmark criterion sufficiently; therefore, setting out a plan to improve this area is necessary.

The achievement of best practice is often the result of a compromise between several issues, such as dealing with disabled children with challenging behaviour via the use of multi-disciplinary assessment tools, support teams and available procedures. Bates' study (2004) found that only 15% of participants had access to the standard assessment tools used to recognise mental health problems. Within this audit, the availability of multi-disciplinary assessment tools obtained a low score (mean=0.72). The DH (2007) suggested that all health professionals who deal with challenging behaviour need to understand the causes of the problem, a point of view reinforced by 'Valuing People' (DH 2001b). The current audit has shown that the area of dealing with challenging behaviour in disabled children requires improvement throughout children's wards at the NHS Foundation Trust.

Collins (2008) highlighted that the transition agenda is an important issue; this was also brought up by 'Valuing People' (DH 2001b). A smooth transition to adulthood for disabled children by means of decreased levels of insecurity, increased awareness of available opportunities and the overcoming of barriers was also a factor emphasised by the policy 'Aiming High' (2007). The provision of this transition service across the wards satisfactorily meets the criteria.

NSF (DH 2004) also strongly recommended an improvement in service provision for disabled children and their families, and pointed out that their wishes and aspirations should be better met. The 'Aiming High' policy (2007) provided the benchmark for family forums; this is an opportunity to gain feedback on service provision from parents of disabled children. The family forum has still not been

Chapter Four

fully established in the children's wards. There is, however, good evidence of feedback from families.

4.4.5 Information Benchmark Criteria (Score Range 0–10)

This part of the audit sought information about care delivery to disabled children and their families within the children's wards of the NHS Foundation Trust.

4.4.5.1 Findings

Figure 4.4 and Table 4.17 show that most concerns related to transition information packs (mean=0.30), availability of a clear local directory listing relevant specialist and mainstream services for families with disabled children (mean=0.40) and availability of information in multimedia formats for families of children with disabilities (mean=0.45). Making specific information available in culturally appropriate terms and multiple languages scored a mean of 0.63. The Kite marketing process, which ensures that children with disabilities and their families receive consistent and up-to-date information, also scored a mean of 0.63. The highest scoring concerns were fully-instructed family carers involved in the provision of care (mean=0.8) and availability of age-specific and focused information (mean=0.72). The information benchmark criteria scored 3.93 out of 10.

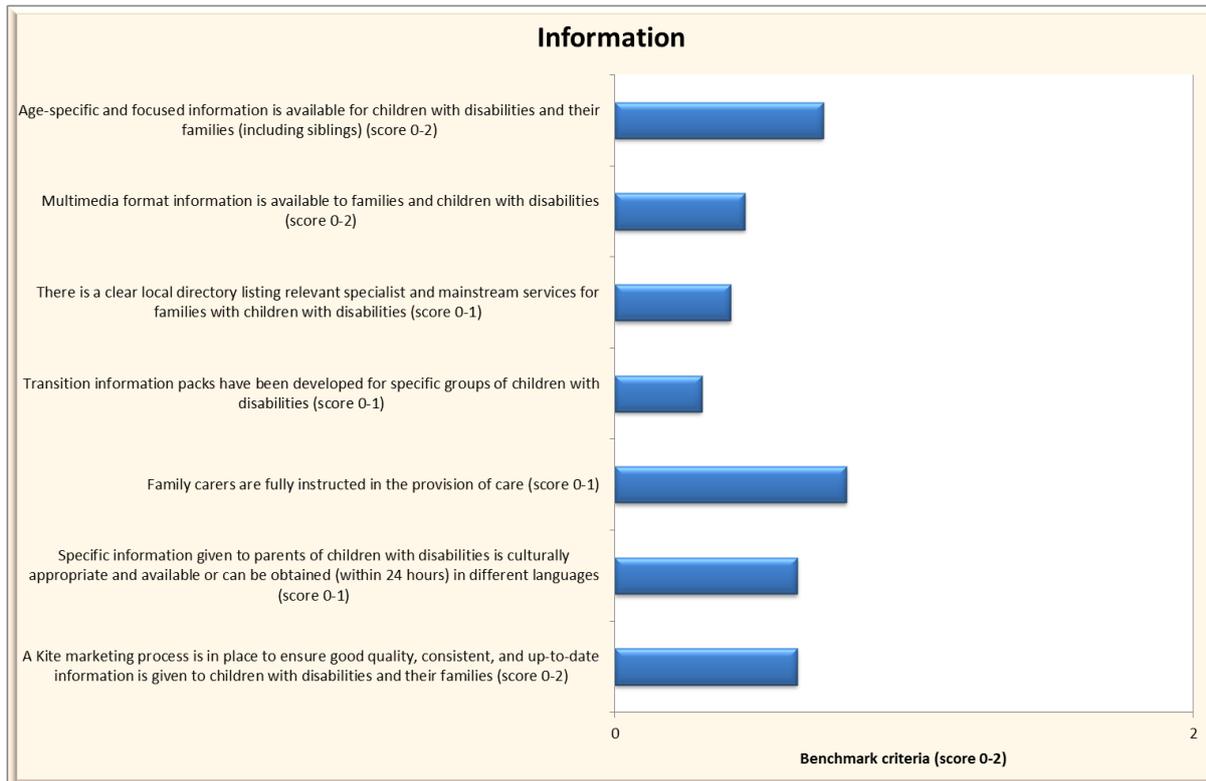


Figure 4.4: Bar chart for information benchmark criteria

Evidence	Number of respondents	Mean
Age-specific and focused information is available for children with disabilities and their families (including siblings)	11	0.72
Multimedia format information is available to families and children with disabilities	11	0.45
There is a clear local directory listing relevant specialist and mainstream services for families with children with disabilities	11	0.40
Transition information packs have been developed for specific groups of children with disabilities	10	0.30
Family carers are fully instructed in the provision of care	10	0.80
Specific information given to parents of children with disabilities is culturally appropriate and available or can be obtained (within 24 hours) in different languages	11	0.63
A Kite marketing process is in place to ensure good quality, consistent, and up-to-date information is given to children with disabilities and their families	11	0.63
Information benchmark criteria		Score=3.93

Table 4.17: Frequency of information benchmark criteria

Chapter Four

4.4.5.2 Discussion

The importance of giving culturally appropriate and age-specific information to disabled children and their families in a sensitive, timely and skilful manner, as part of high quality care standards, was emphasised by 'Valuing People' (DH 2001b). Additionally, 'Together from the Start - Practical Guidance' (2003) highlighted the right of parents to access comprehensive, accurate and relevant information relating to their children and service provision. In the children's wards audited, the provision of this culturally appropriate information in multimedia formats falls short of standards set out in best practice guidelines (see Figure 4.4). Randel et al. (1992) believed that using multimedia increased interactivity and independence among disabled children (Laszlo & Castro 1995). Moreover, multimedia systems can enhance memory (Sánchez & Flores 2003), thus developing children's skills and involving them in decision-making (Lee & Vail 2005; Franklin & Sloper 2009). DH (2001b) emphasised that providing culturally appropriate information in multimedia format for disabled children and their families is part of high quality care delivery.

The 'Better Care: Better Lives' policy (DH 2008) suggested that the process of transition should be appropriate in terms of both age and developmental stage of life, planned early and frequently reviewed. The transition pack and the information given to families did not meet the standards. However, a transition plans package was available within the children's wards.

The Carers' Act (2007) and 'Valuing People' (DH 2001b) both highlighted the importance of supporting and meeting carers' needs and providing them with training resources (Collins 2008). The issue of fully-instructed family carers was generally non-compliant with the desired benchmark. However, a booklet outlining the carers' service was available in the Trust.

Additionally, the DH (2001) claimed that training resources should be available so as to develop the skills of carers. The White Paper 'Valuing People' (DH 2001b) placed emphasis on giving sufficient information about local support and the national information centre to disabled children and their families.

A lack of transition information leads to dissatisfaction among patients (Ley 1982). Johnson et al. (2003) found that verbal and written health information together significantly improved the knowledge and satisfaction of parents of children newly discharged from hospitals.

Quine (1989) found that the provision of a booklet that covered local and national information increased the satisfaction of parents of severely disabled children. However, according to Philp and Duckworth (1982), the amount and supply of general printed information is limited. Information provision throughout the children's wards did not meet the benchmark criteria.

4.4.6 Support Services Benchmark Criteria (Score Range 0–10)

This aspect of the audit examined the availability of support services for children with disabilities and their families throughout the children's wards.

4.4.6.1 Findings

Figure 4.5 and Table 4.18 show that the biggest concern related to the process of liaising with the hospital and contributing to the Primary Care Trust early support programme; this scored a mean of 0.25. The following evidence was given a score of less than one: coordinating services to improve families' access to respite care (mean=0.38), allocating key workers to support groups for parents of children with disabilities (mean=0.55), availability of family support services (mean=0.63) and information about local and national support groups (mean=0.72). Access to free parking (mean=1.18) and availability of specialist teaching support (mean=1.00) obtained the highest score within the support services prompt. The support services benchmark criteria scored 4.71 out of 10.

Chapter Four

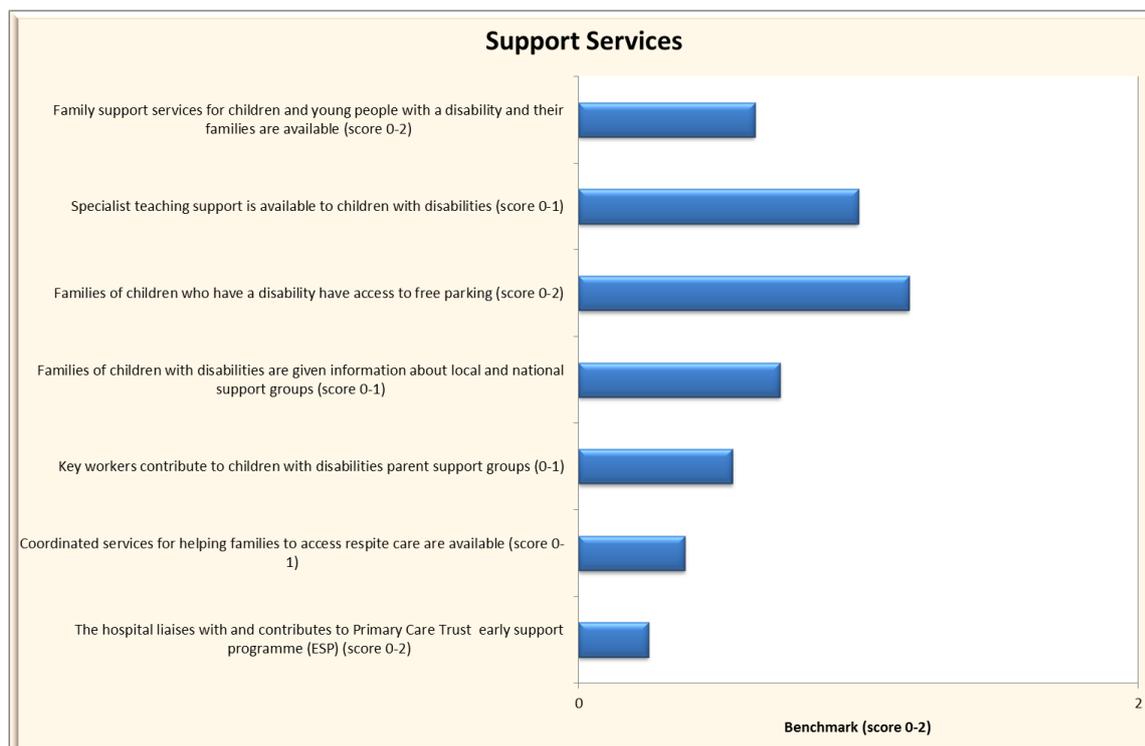


Figure 4.5: Bar chart for support services benchmark criteria

Evidence	Number of respondents	Mean
Family support services for children and young people with a disability and their families are available	11	0.63
Specialist teaching support is available to children with disabilities	11	1.00
Families of children who have a disability have access to free parking	11	1.18
Families of children with disabilities are given information about local and national support groups	9	0.72
Key workers contribute to children with disabilities parent support groups	9	0.55
Coordinated services for helping families to access respite care are available	9	0.38
The hospital liaises with and contributes to Primary Care Trust early support programme (ESP)	8	0.25
Support services benchmark criteria		Score=4.71

Table 4.18: Frequency of support services benchmark criteria

4.4.6.2 Discussion

The biggest concern that needs to be considered by the Trust related to liaising with the hospital and the Primary Care Trust's early support programme (see Figure 4.5). The 'Aiming High' policy (HM Treasury & DfES 2007) emphasised the

Early Support Programme, which offers support in meeting the needs of all disabled children aged 0-5 and their families.

Clarke (2006) reported that the lack of disability support services such as parking is a barrier for families who wish to access mainstream facilities; this might in turn have a negative effect on socialisation of disabled children and their families. Access to a blue parking badge for families of children with disabilities is suggested by 'Together From the Start - Practical Guidance' (DfES & DH 2003). Access to free parking within the NHS Foundation Trust under audit could be improved.

The 'Aiming High' policy (2007) proposes the provision of respite care for parents with disabled children. Short breaks can give a family brief access to a normal life (Langer et al. 2010) and help to improve relationships between parents (Stalker & Robinson 1994). Additionally, short breaks lead to decreased levels of stress for parents (Cowen & Reed 2002b) and provide experiences of new relationships, environments and social activities for disabled children (Robertson et al. 2010a). Short breaks may also prevent hospital readmission, thus achieving financial benefits for the NHS (Social Care Institute of Excellence 2008). The current audit revealed that this standard needs to be raised higher, as at present the coordination of respite services is inadequate (mean=0.38).

The standard eight points of the 'Getting the Right Start' Framework (DH 2003) placed great emphasis on coordinated, high quality, family-centred care for disabled children and young people, based upon an assessment of their needs. The current audit found that availability of family support services is not fully embedded in practice. However, there are good examples of information booklets being available throughout the Trust.

Areas such as availability of family support services, specialist teaching support, information about local and national support groups and coordination of respite care for families need to be developed. Ideally, according to the DH (DH 2001b), disabled children and their families should participate in planning design services, leading to improved support.

4.4.7 Decision-Making Benchmark Criteria (Score Range 0–10)

This element of the audit concentrated on the extent to which children with disabilities and their families are involved with decision-making relating to their treatment and the care plan across the children's wards under examination.

4.4.7.1 Findings

Figure 4.6 and Table 4.19 show that the most significant concerns related to the involvement of families of children with disabilities in the design and delivery of care packages (mean=0.30). The following concerns had a mean score of less than one: involvement of children with disabilities and their families in decisions about service planning, commissioning, innovation and unit design (mean=0.70) and evidence related to accessing and involving children with disabilities and their families in decisions about rehabilitation services (mean=0.72). The next-lowest mean score was for existing formal services for children with disabilities and their families to express their wishes, choices and aspirations to the organisation (mean=1.36). The two highest scoring aspects were: involving children with disabilities and their families in care planning and decision-making about treatment interventions, and taking into account the views of children with disabilities during the entire decision-making process (both had a mean of 1.54). In sum, the decision-making benchmark criteria scored 6.16 out of 10.

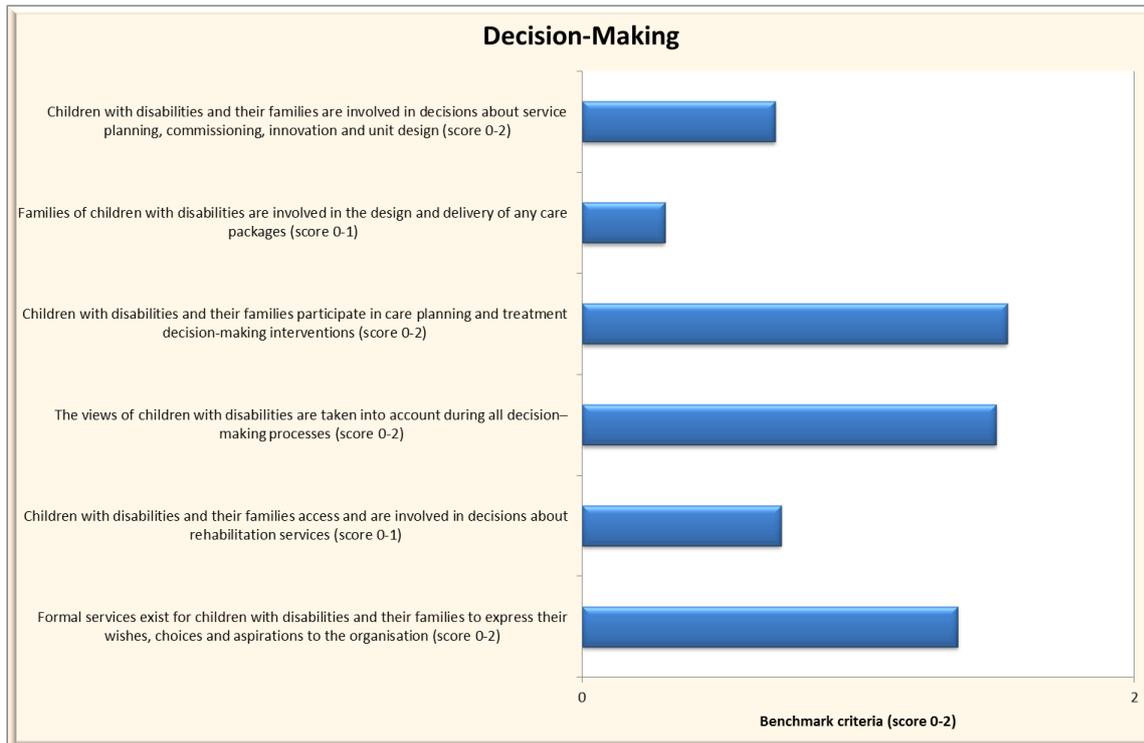


Figure 4.6: Bar chart for decision-making benchmark criteria

Evidence	Number of respondents	Mean
Children with disabilities and their families are involved in decisions about service planning, commissioning, innovation and unit design	10	0.70
Families of children with disabilities are involved in the design and delivery of any care packages	10	0.30
Children with disabilities and their families participate in care planning and treatment decision-making interventions	11	1.54
The views of children with disabilities are taken into account during all decision-making processes	11	1.54
Children with disabilities and their families access and are involved in decisions about rehabilitation services	9	0.72
Formal services exist for children with disabilities and their families to express their wishes, choices and aspirations to the organisation	11	1.36
Decision-making benchmark criteria		Score=6.16

Table 4.19: Frequency of decision-making benchmark criteria

4.4.7.2 Discussion

A person-centred approach is one which actively and completely involves people with learning disabilities in all decisions which impact on their lives, an approach

Chapter Four

highlighted by the 'Valuing People' White Paper (DH 2001b). Additionally, the 'Aiming High' policy (2007) claimed that, in order to improve the outcome of care and to meet the needs of disabled children and their families, their perspectives should be taken into account when shaping services. This audit revealed that the involvement of children with disabilities and their families in decision-making is generally at a low level of development. The person-centred philosophy, addressed by 'Valuing People' (DH 2001b) and 'Together From The Start - Practical Guidance' (DfES & DH 2003), suggests that professionals should be working in partnership with families and disabled children and involving them in any decision-making process that might impact on the provision of support to and for the child. The views of children with disabilities were taken into account during every decision-making process throughout the children's wards. This area, therefore, meets the required standards (score=6.16).

4.4.8 Key Worker Benchmark Criteria (Score Range 1–10)

This element of the audit concentrated on the role of key workers in supporting disabled children and their families.

4.4.8.1 Findings

Figure 4.7 and Table 4.20 indicate that the biggest concern related to parents being fully informed about the role of the key worker, the necessary training and experiences of key workers who are working with and supporting disabled children and their families and the multi-disciplinary team (mean=0.80). The next-lowest score related to the need to identify the key worker to families during the admission assessment process (mean=1.20). The highest mean score was for the issue of allocating a key worker during hospital admission (mean=1.60). In sum, the key worker benchmark criteria scored 5.20 out of 10.



Figure 4.7: Frequency of key workers benchmark criteria

Evidence	Number of respondents	Mean
Children with disabilities are allocated a key worker during hospital admission and this is documented	10	1.60
The key worker is identified to the family during the admission assessment	10	1.20
The parents/carers are fully informed of the role of the key worker	10	0.80
The role of the key workers is fully understood by all members of the multi-disciplinary team	10	0.80
The key workers have the necessary training competencies and experiences to work with children with disabilities and their families	10	0.80
Key worker benchmark criteria		Score=5.20

Table 4.20: Frequency of key workers benchmark criteria

Chapter Four

4.4.8.2 Discussion

The 'Together from the Start' policy (DfES & DH 2003) emphasised that children with complex needs and their families should be assigned a key worker. Additionally, the policy stated that the key worker should be chosen at the same time as the initial assessment of the child. The vast majority of studies have shown that key workers have positive effects for parents of disabled children, such as better communication with professionals (Beresford 1995), more practical help, increased satisfaction with respite facilities and feeling less isolated due to having someone to talk to (Glendinning 1986). It has also been noted that the key worker helps the family's needs to be met efficiently (Appleton et al. 1997; Sloper & Turner 2006).

This audit showed that families of disabled children are still not aware of the role of key workers; additionally, experience and training for key workers is still not sufficient. Greco et al. (2007) state that induction and on-going training are important as they give key workers a sense of their responsibilities; furthermore, such training experiences are essential for effective delivery of services (Mukherjee et al. 1999).

4.4.9 Assessment Benchmark Criteria (Score Range 0–10)

This part of the audit sought to investigate how multi-disciplinary teams collaborate in order to utilise and record the common assessment framework, and the accessibility of mental health services for disabled children.

4.4.9.1 Findings

The NSF recommended that a comprehensive multi-agency assessment should take place during diagnosis of disabled people in order to determine their needs (DH 2004). Furthermore, the 'Best Value Review Report' emphasised that disabled children and young people and their families should be involved throughout the assessment and planning at all levels (Peterborough City Council 2005). Within this audit, the most serious concerns were the availability of assessment tools for carers (mean=0.18) and the availability of a common format for multi-disciplinary records during the admission of children with disabilities (mean=0.60). However, utilising the common assessment framework (mean=0.70), collaboration between professionals during the assessment process (mean=1.20) and accessibility of

mental health services (mean=1.90) were shown to meet the highest standards (see Table 4.21 and Figure 4.8). The total score for this benchmark was 4.58 out of 10.

Chapter Four

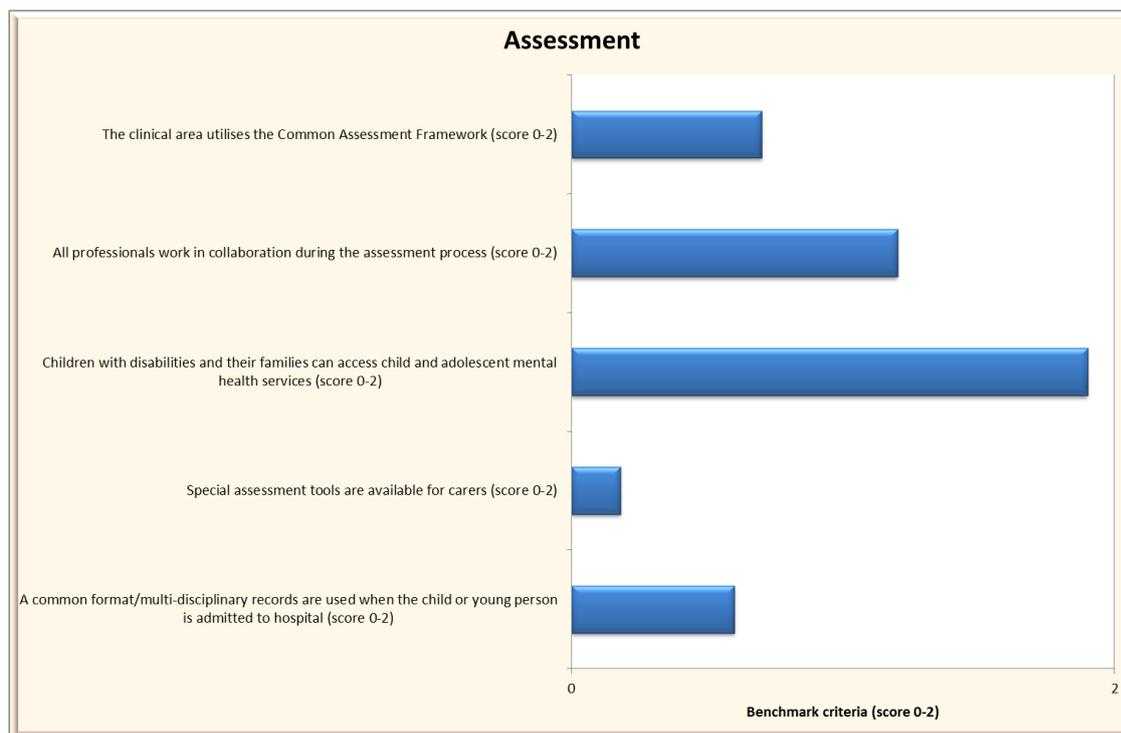


Figure 4.8: Bar chart for assessment benchmark criteria

Evidence	Number of respondents	Mean
The clinical area utilises the Common Assessment Framework	10	0.70
All professionals work in collaboration during the assessment process	10	1.20
Children with disabilities and their families can access child and adolescent mental health services	10	1.90
Special assessment tools are available for carers	11	0.18
A common format/multi-disciplinary records are used when the child or young person is admitted to hospital	10	0.60
Assessment benchmark criteria		Score=4.58

Table 4.21: Frequency of assessment benchmark criteria

4.4.9.2 Discussion

Multi-disciplinary assessment and common records failed to meet the minimum standards required by the NSF (2004); the 'Best Value Review Report' suggested that disabled children and young people and their families should be involved

throughout the assessment and planning process (Peterborough City Council 2005). The 'Valuing People' policy recommended that carers should be considered a care partner by all services (DH 2001). The use of the 'Carers' Guide to a Carer's Assessment' (available via the DH (2001b)) and common records for health professionals should be considered by the Trust, as this could help improve care delivery to disabled children.

The major aim of the White Paper 'Every Child Matters' was to improve teamwork and share information that would lead to improved outcomes for children and their families (2004a). 'Every Child Matters' therefore proposed the Common Assessment Form (CAF), designed to increase the quality of assessment processes and referrals between agencies and to promote the sharing of information. The audited Foundation Trust generally demonstrated good compliance with this, showing collaboration between all professionals during the assessment process and good access to mental health services (Figure 4.8).

Walsh (1998) stated that multi-disciplinary records can improve the quality of documentation and inter-disciplinary communication. Across the Trust, the issue of common records and the adoption of a common assessment framework fell short of best practice guidelines.

4.4.10 Equipment Benchmark Criteria (Score Range 0–10)

This benchmark criterion sought to ascertain the accessibility of appropriate equipment for disabled children, and how it was assessed, throughout the children's wards under examination.

4.4.10.1 Findings

Figure 4.9 and Table 4.22 show that the biggest concerns related to making sure equipment is provided before disabled children are discharged (mean=0.66). Availability of special equipment or assistive technology for children with disabilities scored a mean of 0.88, and availability of individual assessment for the provision of technology/equipment/wheelchair support scored a mean of 1.20. The best evidence score was for availability of appropriate, safe and age-specific equipment for children with disabilities (mean=2.90). Overall, the equipment benchmark criteria scored 5.64 out of 10.

Chapter Four

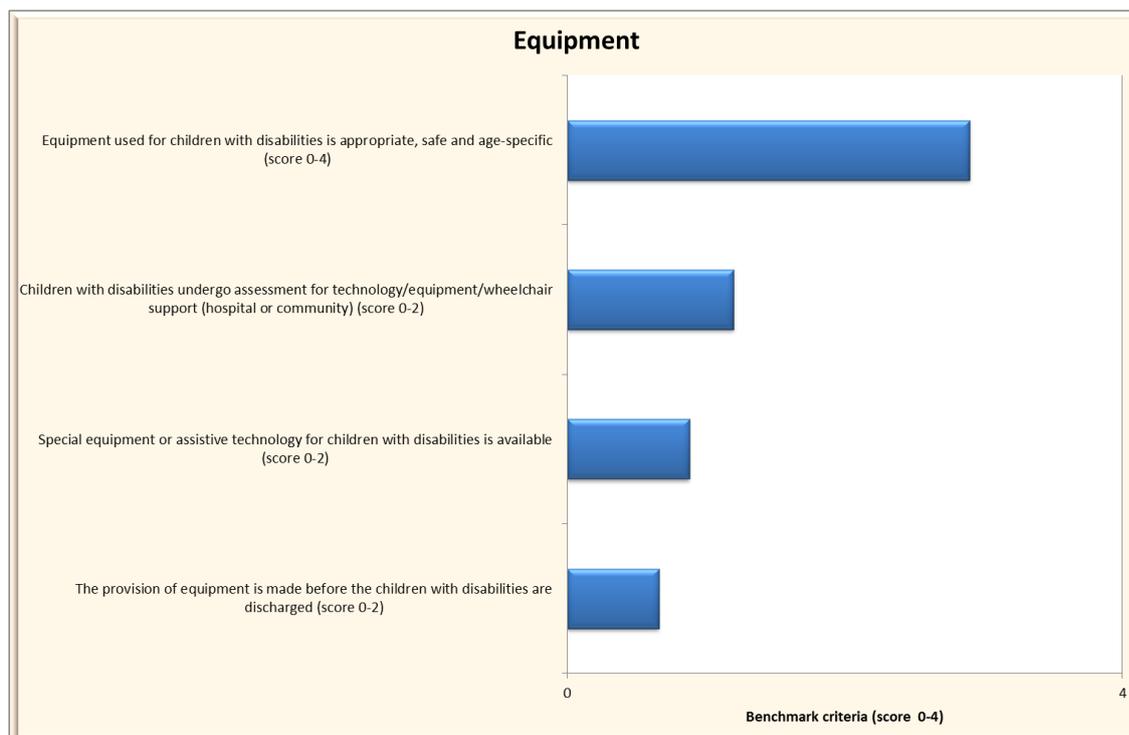


Figure 4.9: Bar chart for equipment benchmark criteria

Evidence	Number of respondents	Mean
Equipment used for children with disabilities is appropriate, safe and age-specific	11	2.90
Children with disabilities undergo assessment for technology/equipment/wheelchair support (hospital or community).	10	1.20
Special equipment or assistive technology for children with disabilities is available	9	0.88
The provision of equipment is made before the children with disabilities are discharged	9	0.66
Equipment benchmark criteria		Score=5.64

Table 4.22: Frequency of equipment benchmark criteria

4.4.10.2 Discussion

Lack of access to special equipment and failure to provide equipment before discharge were clearly tangible across the children's wards. This audit showed that only one wheelchair is available for disabled children throughout the Foundation Trust. The 'Aiming High' policy (2007) focused on assessment and provision of

special equipment for disabled children, which, it was claimed, would lead to an improvement in the efficiency of service provision.

In the Trust audited, there were some examples of good practice relating to the availability of appropriate, safe and age-specific equipment for children with disabilities and the assessment of the suitability of technology, equipment and wheelchair support given to disabled children. However, both the pool of special equipment and the provision of equipment before discharge were inadequate, an issue which needs to be considered.

4.4.11 Palliative Care Benchmark Criteria (Score Range 0–10)

This benchmark criterion examined palliative care for disabled children and their families across the NHS Foundation Trust.

4.4.11.1 Findings

Figure 4.10 and Table 4.23 show that the biggest concerns related to supporting families who need palliative care (mean=0.60), skilled staff for palliative care (mean=0.87), availability of a formal plan for the provision of palliative care (mean=1.00) and making arrangements for the palliative care environment (mean=1.33). The best evidence score was for establishing a good link with a local hospice (mean=2.00). Overall, the palliative care benchmark criteria score was 5.80 out of 10; there is a number of missing data that should be taken into account, as palliative care topics were not applicable to some of the wards involved in the audit.

Chapter Four

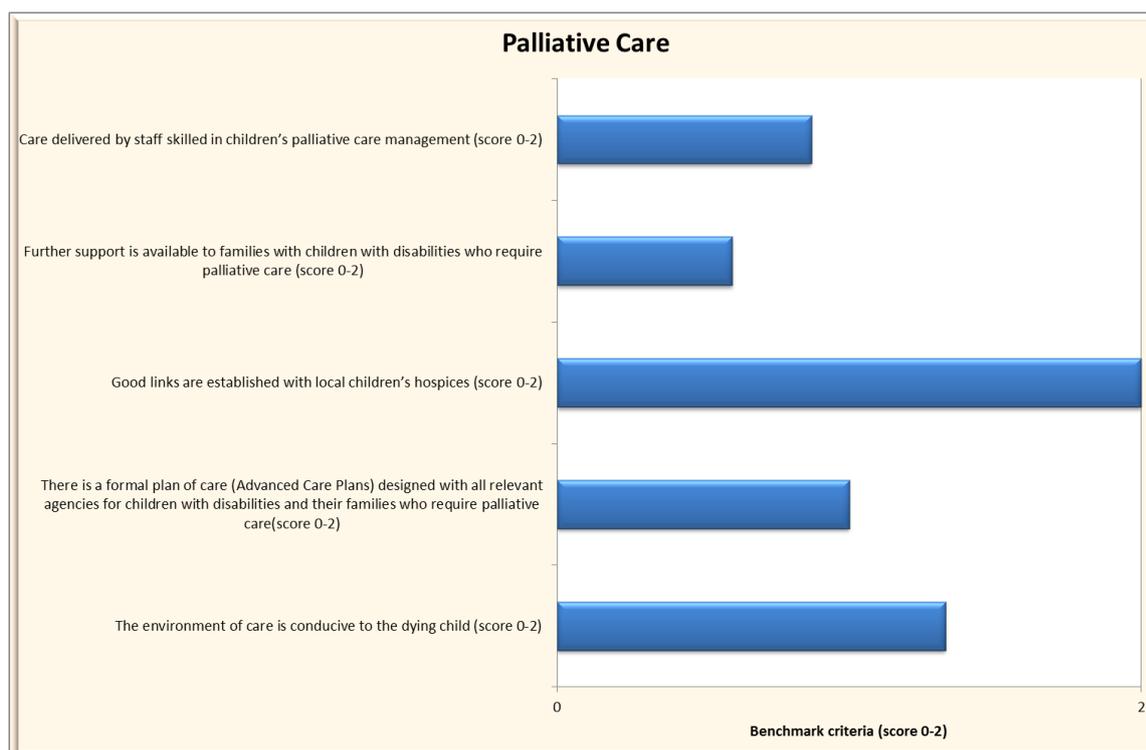


Figure 4.10: Bar chart for palliative care benchmark criteria

Evidence	Number of respondents	Mean
Care delivered by staff skilled in children's palliative care management	8	0.87
Further support is available to families with children with disabilities who require palliative care	5	0.60
Good links are established with local children's hospices	6	2.00
There is a formal plan of care (Advanced Care Plans) designed with all relevant agencies for children with disabilities and their families who require palliative care.	5	1.00
The environment of care is conducive to the dying child	3	1.33
Palliative care benchmark criteria		Score=5.80

Table 4.23: Frequency of palliative care benchmark criteria

4.4.11.2 Discussion

The 'Better Care: Better Lives' policy document (DH 2008) emphasised well-managed and sufficient support at the end of life care stage as the key element for

palliative care services. It was also suggested that disabled children and their families should have 24-hour access to advice and support, and receive specialised end of life care. The areas relating to full support of families who need palliative care and a formal plan for palliative care did not meet the standard in the audited children's wards. The policy 'Better Care: Better Lives' emphasises the importance of the role of the health professionals who work with children with life-threatening conditions (DH 2008). Moreover, the DH (2008) focused attention on the reliable, responsive and well-skilled health professionals that provide palliative care. Highly skilled and well-informed staff should therefore be considered in terms of the palliative care context.

4.4.12 Bereavement Benchmark Criteria (Score Range 0–10)

This part of the audit examined bereavement support for families of disabled children in the children's wards.

4.4.12.1 Findings

Figure 4.11 and Table 4.24 demonstrate that the biggest concern related to maintaining contact with families after the death of a child (mean=1.50). The care of bereaved children and young people, and the effect on families of children being placed in the end of life care plan, scored under 3 (mean=2.66). The highest scoring aspects related to the availability of psychological, spiritual and bereavement support for families, siblings and carers during end of life care (mean=3.71). Overall, the bereavement benchmark criteria scored 7.87 out of 10; again, there is a significant number of missing data, as palliative care topics were not applicable to some of the wards involved in the audit.

Chapter Four

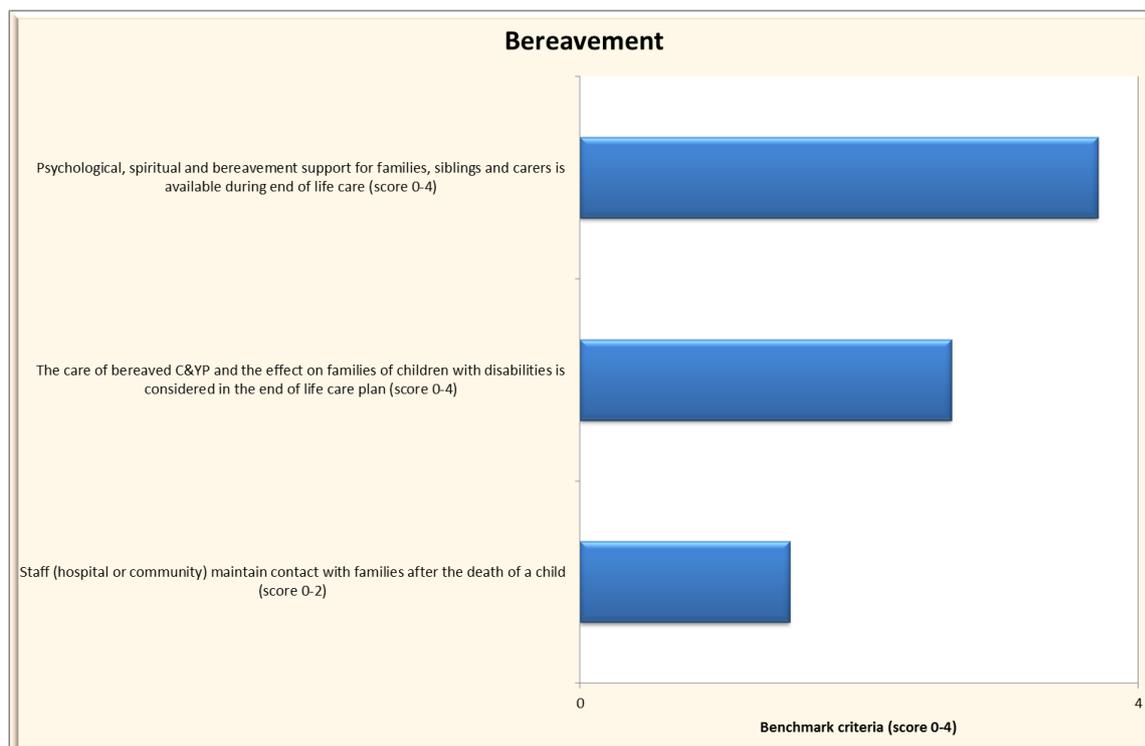


Figure 4.11: Bar chart for bereavement benchmark criteria

Evidence	Number of respondents	Mean
Psychological, spiritual and bereavement support for families, siblings and carers is available during end of life care	7	3.71
The care of bereaved children and young people (C&YP) and the effect on families of children with disabilities is considered in the end of life care plan	6	2.66
Staff (hospital or community) maintain contact with families after the death of a child	8	1.50
Bereavement benchmark criteria		Score=7.87

Table 4.24: Frequency of bereavement benchmark criteria

4.4.12.2 Discussion

Psychological, spiritual and bereavement support for disabled children and their families meet the required standards across the children's wards. A booklet relating to bereavement support was available throughout the Foundation Trust. Sustaining contact with bereaved families in order to improve end of life care is an important part of maintaining care to high standards (Field & Behrman 2003; Emond & Eaton 2004). However, this area does require further attention by the Trust.

4.4.13 Total Score of the Audit

Figure 4.12 and Table 4.25 show that there are major concerns about areas of care delivery to disabled children and their families. The areas that require improvement are training (3.65), delivery of information (3.93), multi-agency teamwork (4.48), assessment (4.58) and support services (4.71). Some fields, such as equipment (5.64), palliative care (5.80), communication (5.89) and key workers (5.20) raised moderate concerns, which need to be considered with a view to improvement. The bereavement benchmark criteria scored 7.87, but it must be remembered that there were a significant number of missing data.

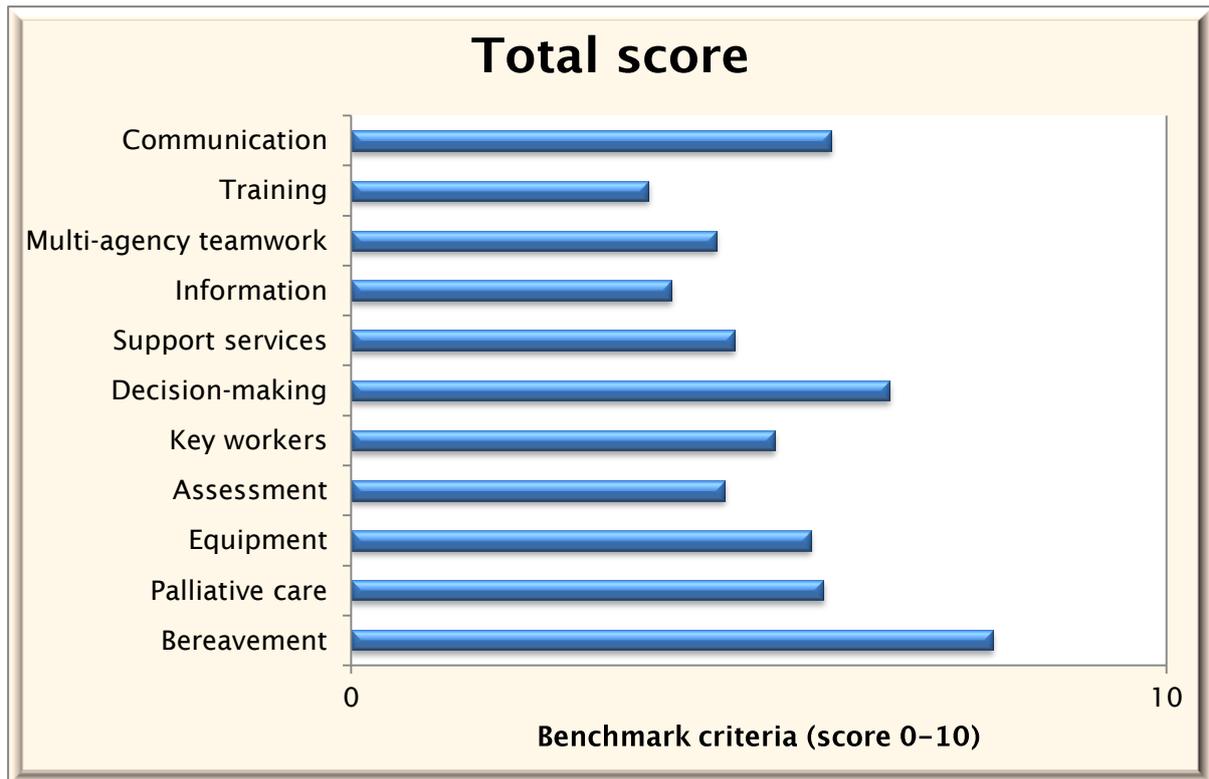


Figure 4.12: Bar chart for total score of benchmark criteria

Benchmark criteria	Score average
Communication	5.89
Training	3.65
Multi-agency teamwork	4.48
Information	3.93
Support services	4.71
Decision-making	6.61
Key workers	5.20
Assessment	4.58
Equipment	5.64
Palliative care	5.80
Bereavement	7.87

Table 4.25: Frequency of total score of benchmark criteria

4.4.14 Conclusion

An audit was undertaken throughout an NHS Foundation Trust as part of a service evaluation relating to disabled children and young people and those with complex health needs, as well as their families.

This audit revealed that many areas, such as information, training, assessment and support services, require significant improvement. Furthermore, some of the benchmark criteria, such as equipment, communication, key workers and palliative care, still need to be considered carefully.

This audit was based solely on the Audit Compliance Assessment Form; therefore, further studies of the perspectives of children with disabilities and their families may need to be planned in the future.

4.4.15 Summary of the Section

This section has discussed the results of the audit by utilising the Audit Compliance Assessment Form across the children's wards of a Foundation Trust. This may throw light on the healthcare provision areas identified by the audit which need to be improved.

Chapter Four

4.5 The Results and Findings of Service Evaluation

Four key issues were developed from the findings of the three components of the service evaluation, namely effective communication, provision of training, provision of equipment and unfavourable environment.

4.5.1 Effective Communication

Effective communication was selected as a key issue. This key issue was categorised into two sub-components: promoting communication and communication barriers (see Appendix 4.1).

Both registered children's nurses (RNs) and HCSWs strongly emphasised the importance of communication with disabled children. The sub-component of 'communication barriers with disabled children as a concern' was considered by registered nurses (statement 4, 2, 26) and HCSWs (statement 44, 2, 7, 33, 46, 15, 6, 18). Additionally, within the audit components of the current study, the communication benchmark criteria scored 5.89 out of 10, which shows that this area still needs to develop. Furthermore, despite the nursing staff's concerns about communication with disabled children, the content analysis of the nursing curricula revealed that five modules out of seven placed great emphasis on communication.

The lack of knowledge in the area of communication was highlighted by both groups (RNs/statement 34, HCSWs/statement 17). This sub-theme is well illustrated by the following comment from a respondent: 'More teaching on Makaton and signing' (RNs/statement 34). However, the audit revealed that staff do have access to Makaton and other similar communication training (mean=1.27/2).

Promoting communication as a sub-component was considered by both the NGT groups (RNs and HCSWs). Furthermore, within the nursing curricula, effective communication as a topic was given good coverage in six out of seven modules (85.7%). This finding was confirmed by the results of the audit, which showed that dialogue pertinent to children with disabilities is tangible across all parts of the service provision (mean=1.40/2). Figure 4.13 illustrates the 'effective communication' key issue.

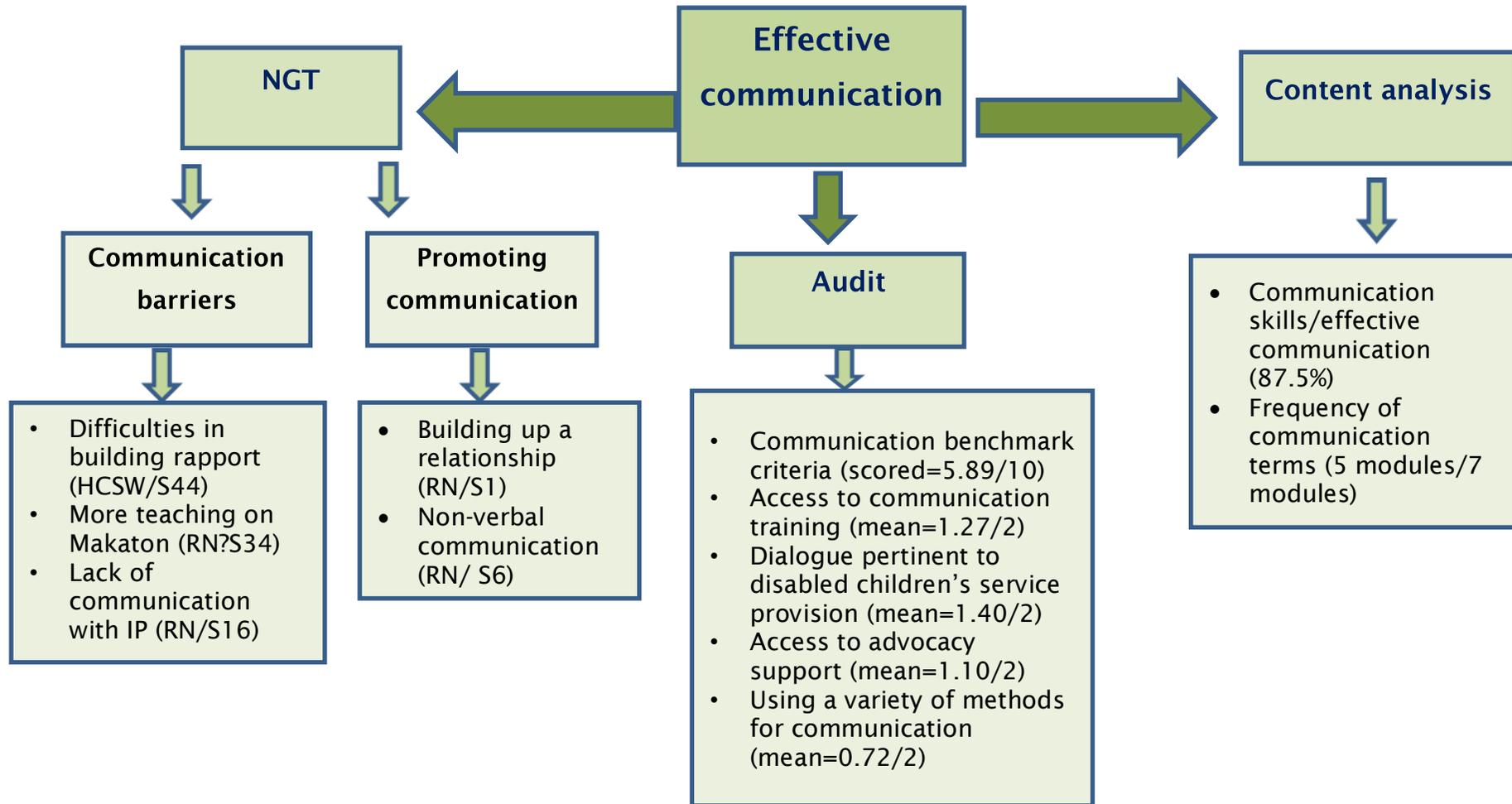


Figure 4.13: Communication key issue

4.5.2 Provision of Training

Training as a key issue emerged from the integrated data analysis and was classified into three sub-components: improving skill, improving knowledge and not specified (Appendix 4.2).

The sub-component of 'improving skill' was considered by both groups in the NGT. The RN group emphasised 'teaching disabled children about independence in life' (statement 7). The HCSWs' concerns related to 'care restriction applied to their job status' (Statement 4). Furthermore, within the content analysis, the skills required to care for a child with long term health needs were covered by only one of the modules. Conversely, the term 'skill' was highly emphasised within the content analysis of modules (19 times within five modules). Developing skills related to the advocacy role and assessment was highlighted by only one out of seven modules.

'Improving knowledge' was perceived enthusiastically by the RN group. Within the content analysis, 'developing knowledge' and 'continuing education relating to care of disabled children' were only included in one module. Furthermore, the nature, frequency and causes of disability were not sufficiently covered within the modules under examination. Training was also a major concern which emerged from the audit. The training benchmark criteria only scored 3.64 out of 10.

'Learning from families of disabled children' was a privilege for RNs; this and 'finding out more about day to day living', were two items that emerged from the NGT under the sub-component of 'not specified'. Annual updating of staff training was an encumbrance (mean=0.54/2) within the audit component of the study. The 'provision of training' key issue is depicted in Figure 4.14.

Chapter Four

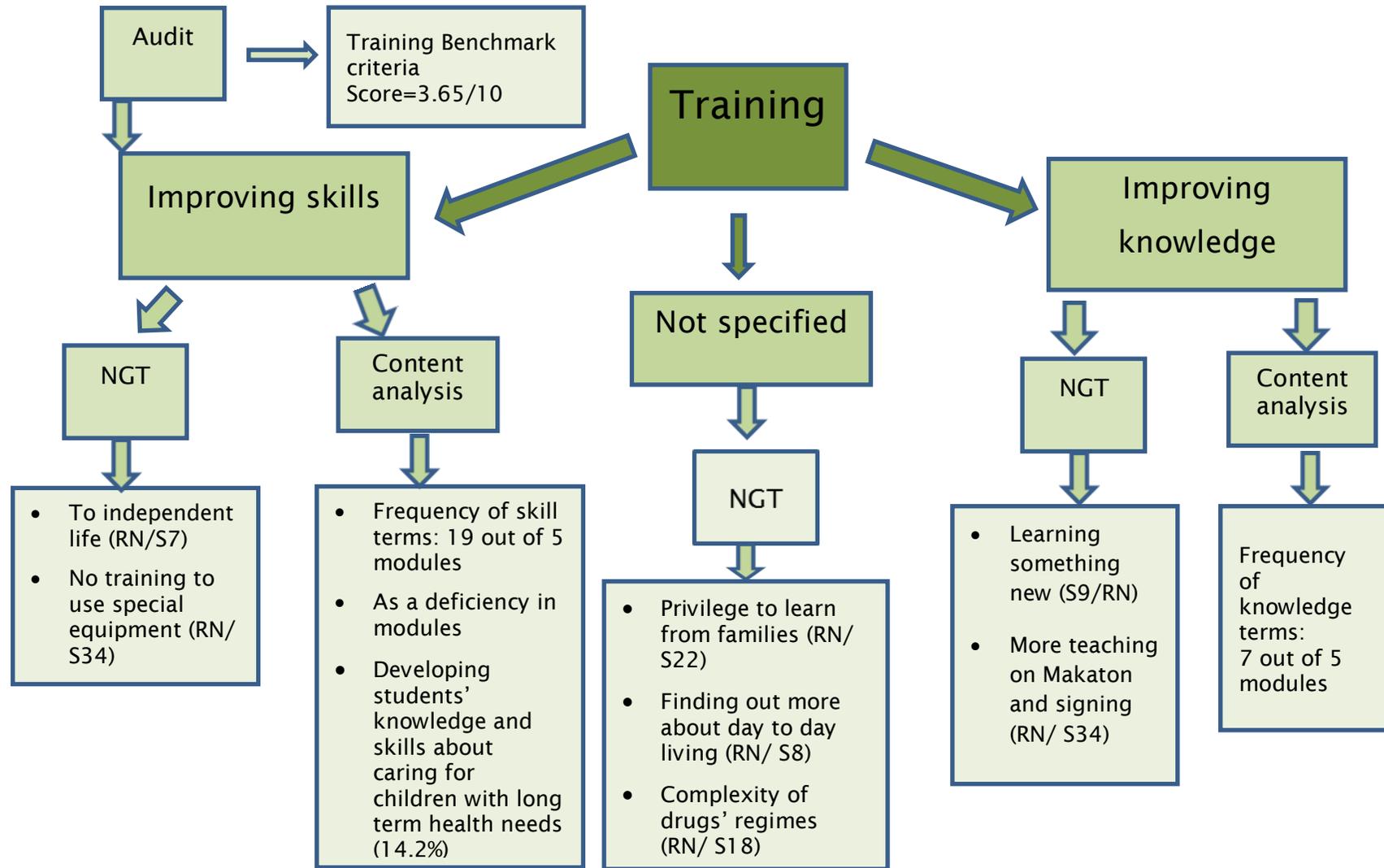


Figure 4.14: Training key issue

4.5.3 Provision of Equipment

'Provision of equipment' as a key issue is illustrated in a table (see Appendix 4.3). The equipment theme has been categorised into three sub-components: special equipment, discharge plan and not specified

Availability of appropriate equipment is recognised as a sub-component. Availability of special equipment was emphasised by both groups in the NGT meetings (RNs/statement 8 and HCSWs/ statement 1). Additionally, this finding was confirmed by the result of the audit, which showed that there was inadequate access to special equipment or assistive technology for children with disabilities (mean=0.88/2). On the other hand, availability of appropriate, safe, and age-specific equipment for children with disabilities gained a better score (mean=2.90/4), but this area still needs to improve. However, the content analysis of the nursing curricula revealed that the 'care needs of children and young people who require technologically dependent care' was covered by only one of the modules under examination, which shows that this field needs more attention.

An equipment prompt within the audit revealed that the provision of equipment before discharging disabled children was not sufficient (mean=0.66/2). This inadequacy was a concern of the HCSWs, expressed in the NGT meeting by the statement 'slow unnecessary proceedings, such as getting funding for wheelchair'.

Both groups in the NGT meetings claimed that they were not satisfied with the training in the use of special equipment. The audit part of this study revealed that access to assessment for the provision of technology/equipment/wheelchair support (mean=1.20/2) requires more development.

Figure 4.15 illustrates the 'provision of equipment' key issue.

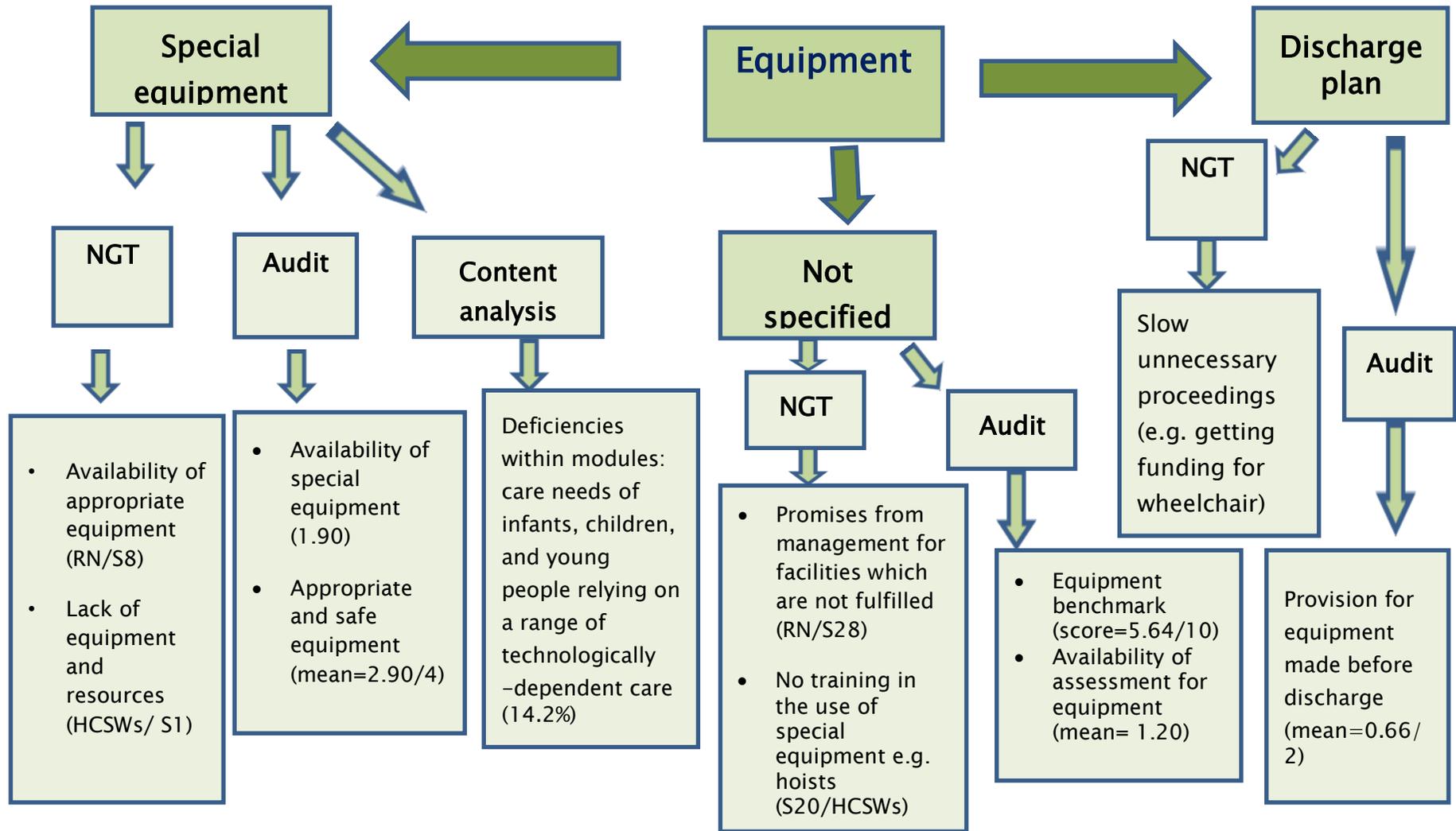


Figure 4.15: Equipment key issue

4.5.4 Unfavourable Environment

All data that emerged from the three components of the study that related to the issue of unfavourable environment was logged into a table (see Appendix 4.4).

Registered children's nurses and HCSWs strongly emphasised the effectiveness of a favourable environment on improving care delivery to disabled children.

The result from the audit showed that arrangements for creating an environment in which to provide palliative care scored a mean of 1.33/2, which is adequate but can be developed. Figure 4.16 illustrates the 'unfavourable environment' key issue.

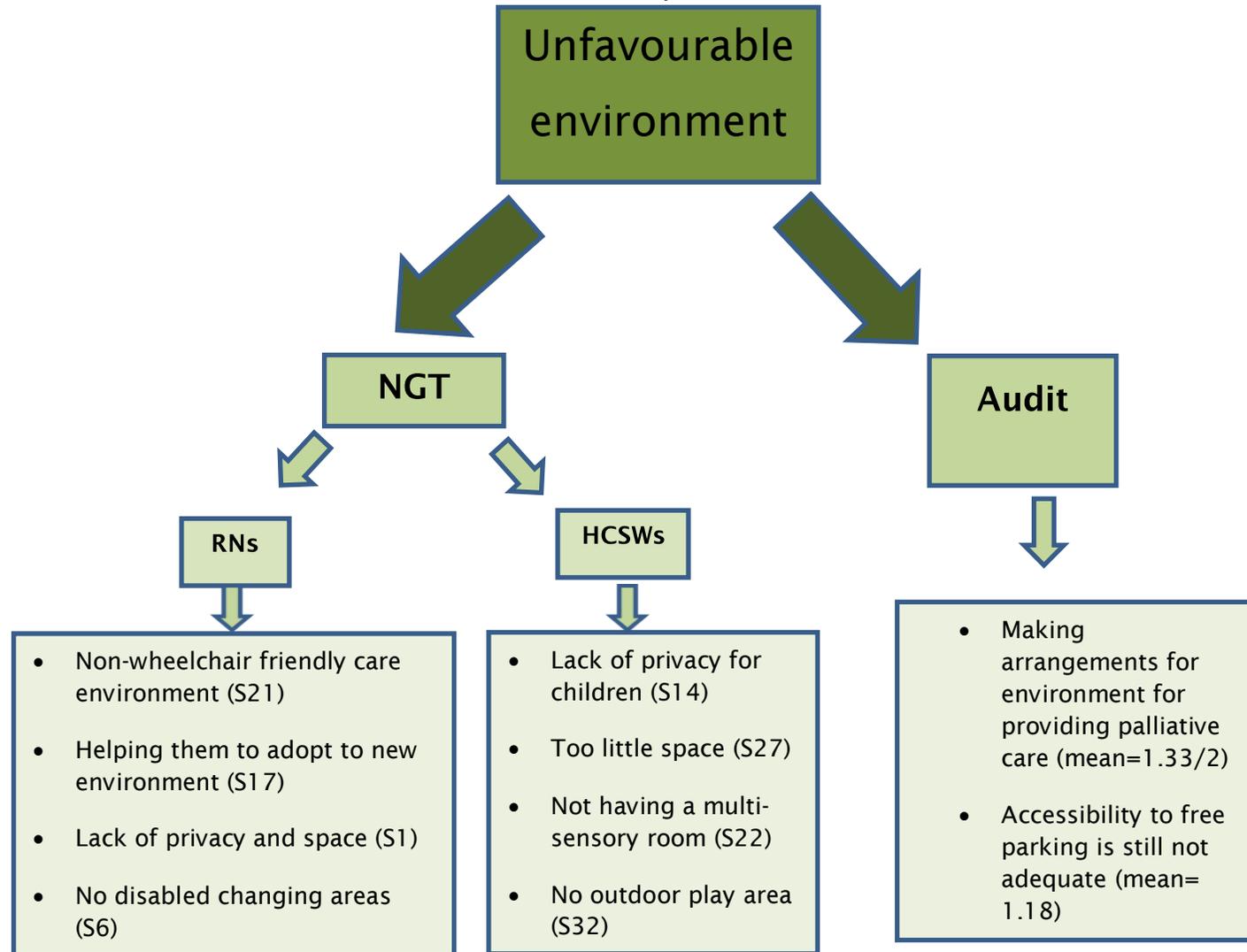


Figure 4.16: Unfavourable environment key issue

Chapter Four

4.6 Summary of the Chapter

This chapter has presented the results and discussion of the three components of the study and additionally the overall result of service evaluation. Chapter 5 will concentrate on an overall discussion.

Chapter 5 : Overall Discussion

5.1 Introduction

Four key issues have been generated from the findings of the current service evaluation, namely:

1. Effective communication
2. Provision of training
3. Provision of equipment
4. Unfavourable environment

This chapter will expand on these four key issues.

5.2 Effective Communication

The United Nations (1989) claimed that communication is a right of children. For disabled children in particular, this was emphasised by the NSF under Standard 3 as exemplified by the statement: 'listening and involving them with decision making' (DH 2004). This issue was also identified by HCSWs who contributed in the NGT meeting; they emphasised 'being there to listen'. The importance of direct nurse-patient communication has been highlighted by several studies (Hart 1998a; Balandin et al. 2001; Hemsley et al. 2001). The parents who participated in the study of Hewitt-Taylor (2008a) expressed that their children's efforts at communication were not valued. One mother stated that 'many people won't actually talk to her, but she understands' (p.22), emphasising her child's desire to communicate. A study by Darrah et al. (2002) confirmed that adolescents and young people felt ignored during conversations between service providers; this is supported by the current service evaluation, with HCSWs raising the concern about 'talking over the child while on medical rounds'.

A great number of studies flagged up health professional teams' insufficient or poor communication with disabled people (Kottaridi 2000; Sowney & Barr 2006; Seccombe 2007; Sahin & Akyol 2010). Despite this, effective communication was a central issue identified in this service evaluation. Finke et

Chapter Five

al. (2008) and Sahin and Akyol (2010) noted that effective communication is essential for quality care. The study by Atkinson et al. (1987) showed that enhancing communication between nurses and patients actually improves the nursing assessment of disabled patients. This suggests that identifying patients' communication style before admission and planning in advance can improve interaction between nurses and patients.

Both the NGT groups in this study emphasised the importance of communication with disabled children. Additionally, the service evaluation revealed that the coverage of effective communication within the content analysis of nursing curricula was high (six out of seven), which is a new finding in the field of communication and contrasts with former studies (Scullion 1999c; Balandin et al. 2001; Hemsley et al. 2001). However, the patients with cerebral palsy who participated in the survey conducted by Buzio (2002a) expressed that knowledge and skills among staff relating to communication are limited. Additionally, Hewitt-Taylor (2005d) noted that communication skill constitutes a deficiency in nursing curricula and should be better included. On the other hand, the communication benchmark criteria scored 5.89 out of 10 within the audit part of the service evaluation, which shows that some areas of communication within children's wards of the NHS need to be improved. Nursing teams are eager for effective communication with patients, as their education emphasises, but this area is still relatively deficient in nursing practice. Therefore, providing more training in the workplace is recommended. Additionally, guidelines and advice on effective communication throughout the NHS Foundation Trust are necessary.

Within this service evaluation, relationships with families were emphasised by both of the NGT groups. The need to improve communication and partnership between clinicians and families of children with chronic conditions has been confirmed by Garwick et al. (1998) and Hemsley et al. (2008a). Furthermore, 'communication improved through familiarity with the staff' and 'negotiate with nursing staff related to their role' were highlighted as positive aspects of communication for parents by Neill (1996). Conversely, in the current content analysis, there is only moderate emphasis on 'partnership with families', which is mentioned in just two of the modules under examination (Module 1/University 2, Module 1/University 3). The deficiency within nursing education relating to the partnership between nursing staff and parents of disabled

children has been expanded upon by the current service evaluation. However, Perkins (1993) suggested that it should be a requirement to create this partnership with parents in order to reduce the stress caused by hospitalisation. A number of studies have emphasised partnership with parents of disabled children (De Geeter et al. 2002; Sen & Yurtsever 2007a). Sowney and Barr (2006) suggested a healthy relationship and more collaborative approach with disabled patients and their families. It can be suggested that an individualised service delivery (based on disabled children's needs) and the development of a greater partnership with their families require attention.

The result of McCabe's study (2004) revealed that nurses are good at communicating with patients, which leads to a positive nurse-patient relationship; this finding is backed up by the current service evaluation. Both groups of nursing staff emphasised 'developing trust with child and family', a theme also raised by Neill (1996). Furthermore, the study conducted by Garro et al. (2005) showed that nurses can create positive experiences for parents of children with chronic problems, due to their unique roles in patient care.

Bryan (1977) found that disabled people comprehend via non-verbal communication. The current service evaluation shows that nurses and HCSWs both considered non-verbal communication with patients to be rewarding. They felt that 'delivering a human touch' (statement 14) and 'giving a hug to the child' (statement 11) were non-financial incentives for them. The positive feeling among nursing staff working with disabled children towards non-verbal communication has extended the current knowledge regarding care delivery to disabled children. Using non-verbal communication to interact with clients with learning disabilities was suggested by Purcell et al. (2000). The researchers emphasised that staff should be more responsive towards clients with limitations in verbal communication. Therefore, non-verbal communication requires more attention, as it can lead to improved standards of care.

Half of the cerebral palsy patients who participated in the study of Balandin et al. (2001) claimed that they continued to apply non-verbal methods of communication, such as body language, due to a lack of AAC (Augmentative and Alternative Communication) resources and knowledge among nurses, which created many communication difficulties for them. Furthermore, Hemsley et al. (2001) highlighted that the inability of nurses to use AAC

Chapter Five

created communication difficulties for parents of voiceless children. The current NGT is in accordance, as reflected by the need for 'more teaching on Makaton and signing' (S34) identified by registered children's nurses. The audit part of the current service evaluation also showed that using a variety of methods for communication was not sufficient (mean=0.72/2). Therefore, more training in Makaton or other methods of communication needs to be considered.

Access to AAC resources, and knowing how to use them, will have a strong impact on effective communication between nurses and patients; this conclusion is confirmed by numerous studies (Balandin et al. 2001; Hemsley et al. 2001; Buzio et al. 2002a; DH 2004; Happ et al. 2004b; Hemsley & Balandin 2004), which all support the findings of the current NGT. Both the NGT groups expressed concern about 'lack of appropriate equipment and resources' (RNs/ statement 8 and HCSWs/statement 1). It is suggested that hospital managers be required to ensure the provision of communication devices and resources throughout the Trust.

Hemsley et al. (2001) and Fried-Oken et al. (1991) found that nurses receive little formal training in AAC systems; nurses felt that caring for a patient with CCN (Complex Communication Needs) was extremely challenging for them without this training. This view is at odds with the results of this study's content analysis of nursing curricula, which shows that communication skills (but not Makaton in particular) are recognised in six out of seven modules under examination. Furthermore, this finding was confirmed by the result of the audit part of the current service evaluation, in which Makaton training scored 1.27 out of 2, showing that staff do receive some degree of training related to communication with disabled children. The need for staff training within NHS Trusts in order to enhance conversations and use AAC was reinforced by Cottrell and Davies (2004) and Balandin et al. (2001). Therefore, the provision of more training, support and skills for staff in using AAC resources is recommended.

Melville et al. (2005) found that only 8% of the participants in their study received training in communication with disabled patients; interestingly, nurses were aware of a discrepancy between their knowledge and the health needs of people with learning disabilities. The greatest area in which training

was lacking, according to Johnson et al. (2012) and Melville et al. (2005), related to communicating with disabled children. Additionally, the standard 3 within the NSF stated that all healthcare professionals who deliver care to disabled children require sufficient skills, knowledge and competencies to meet this vulnerable population's needs (DH 2004).

The importance of skill and knowledge to enabling effective communication between disabled patients and healthcare teams has been acknowledged by numerous studies (Worrall-Davies et al. 2004; Sanders et al. 2007; Finke et al. 2008); these skills lead to an enhanced responsiveness of staff towards disabled patients (Purcell et al. 2000). These findings are in accordance with HCSWs' feelings about training in this area, as reflected by the statement 'lack of knowledge about the special communication needs of a particular child' (HCSWs/ statement 17). A study by Burke et al. (2001) demonstrated that effective communication skills among nurses lead to decreased stress for parents.

The strongest finding of a multi-method evaluation study conducted by Danvers et al. (2003) related to inter-professional communication; it was noted that this area needed to improve, and the researchers placed particular emphasis on establishing links between nurses. Additionally, Margolan et al. (2004) found that there is insufficient communication between agencies, with no individual establishment for coordinating services. This concern was also raised by both of the NGT groups as a challenge to the area of communication, as highlighted by the statement 'Lack of communication with the inter-professional team' (RNs/statement 16 and HCSWs/ statement 9). Therefore, the establishment of a nurse lead (who is an expert in this field) to plan and coordinate the care of disabled children in order to meet their needs, with particular emphasis on communication, is recommended.

One barrier to effective communication between nursing staff and parents of disabled patients is misinterpretation. Sigafos et al. (2003) found that misunderstandings between staff and patients might lead to aggressive and/or violent behaviour; HCSW groups raised some related concerns such as 'difficult aggressive parents' (S6) and 'difficult challenging rude visitors' (statement 35). The negative impact of poor communication with patients and families was further highlighted in the study by Balandin et al. (2007).

Chapter Five

5.3 Provision of Training

Training was one theme developed from the current integrated analysis data. The deficiency in nursing education relating to disabled children has been acknowledged in much of the UK literature (Cumella & Martin 2000; Buzio et al. 2002a; Iacono & Davis 2003; NPSA 2004; Balandin et al. 2007; Hemsley et al. 2008c). It leads to failures in care and lack of awareness of the needs of disabled people (Glasby 2002). Sowney and Barr (2006) claimed that traditional nursing education is inadequate for equipping nurses to deal with disabled patients. The training benchmark criteria within the current audit obtained a low score (3.65/10). Furthermore, regular reviews of staff training were not carried out sufficiently in the children's wards under audit (mean=0.54/2). The analysis of nursing curricula showed that 'developing students' knowledge and skills about caring for children with long term health needs' was covered by only one module under examination. Despite nursing staff's enthusiasm ('I learn something new', RNs/ statement 9), it appears that nursing training in this field is still not inclusive and needs more attention. This finding, which emerged from the service evaluation, is confirmed with previous studies (Buzio et al. 2002a; Balandin et al. 2007; Hemsley et al. 2008b)

Carson (1995) reported that willingness among nurses to provide patient care resulted in a desire to gain experience. The gaps in training of hospital staff are a barrier to meeting the needs of people with learning disabilities (Slevin & Sines 1996; Duff 2000; Melville et al. 2006). 'Continuing education' was one of the gaps identified by the content analysis of nursing curricula, and thus requires more consideration.

Training has a positive effect on hospital staff's knowledge and confidence relating to care for disabled children, as confirmed by a number of studies (McConkey & Truesdale 2000; DH 2001b; Sowney & Barr 2006; McMurray & Beebee 2007); such training can also improve nursing staff's capabilities in meeting the needs of patients with learning disabilities (Melville et al. 2006). The White Papers 'A Service with Ambition' (DH 1996) and 'Valuing People' (DH 2001b) emphasised that service staff need to be more confident and competent in supporting people with learning disabilities. All the participants who contributed to the study conducted by Balling and McCubbin (2001) believed that hospital staff would know how to meet the fundamental care

needs of the disabled. Surprisingly, the needs of disabled children were not emphasised strongly within the modules under analysis (only in one out of seven modules). Therefore, this point has been expanded upon by the current service evaluation. It is recommended that awareness be raised of disabled children's needs among nursing staff.

One theme from the study conducted by Garwick et al. (1998) was 'improving the health professional team's training'. The families who participated in that study also emphasised interpersonal skill training for nursing staff, a necessity confirmed by Roberts (2001). The results of the current audit confirmed those previous studies, which showed that staff training in some areas, such as communication, interpersonal skills and management of behavioural challenges, is not adequate (mean=0.41/2). Therefore, the involvement of academic nursing staff (who are experts in this field) in leading and teaching skill workshops and training sessions requires consideration.

One of the nurses who participated in the study carried out by Sowney and Barr (2007) remarked, 'you have no background knowledge really on how to communicate with these people' (p.168); this view was also held by the registered nurses at this study's NGT meeting, who wanted 'more teaching on Makaton and signing' (statement 34).

Tervo and Palmer (2004) reported that nursing students did not have a positive attitude toward disabled patients. The researchers emphasised the provision of specific education for improving attitudes. Numerous other studies have also emphasised training to improve attitudes towards disabled people (Slevin & Sines 1996; Cumella & Martin 2000; Byron et al. 2005; Sowney & Barr 2006; McMurray & Beebee 2007). Surprisingly, 'attitudes' are not cited in any of the modules under examination. Therefore. This particular point has been expanded upon by the current service evaluation

Different training approaches have been suggested for improving the knowledge and skills of hospital staff relating to care of disabled children, namely ward-specific resource packs, workshops, pre and post-registration and induction training (Fitzsimmons & Barr 1997; Hart 1998a). Within the audit component of the service evaluation, it was found that nursing staff did not receive sufficient information during induction (mean=0.91/2). This point, which is a new finding, indicates that one potential strategy for improving care

Chapter Five

of this population is greater emphasis on induction training. Another finding from the current audit was that, from nurses' perspectives, undergraduate curricula are not adequate (mean=0.54/2). This was confirmed by Sweeney (2004) who pointed out that there was no obligation to learn about care for patients with learning disabilities in preregistration nurse education in the UK.

5.4 Provision of Equipment

Technology-dependent children require expensive equipment tailored to their needs and on-going nursing care (Noyes 1999; DH 2004). The NSF reported that one out of three parents with disabled children use more than three pieces of equipment on a daily basis in order to provide fundamental care (DH 2004). Appropriate equipment and assistive technology is one factor in enhancing the well-being of families with disabled children (DH 2004); it improves their mobility, decreases physical tiredness and enhances their ability to live an independent life. These advantages were highlighted by the White Papers 'Better Care: Better Lives' (DH 2008) and 'Aiming High for Disabled Children: Better Support for Families' (HM Treasury & DfES 2007). The lack of hospital facilities for patients with disabilities reported by Cumella and Martin (2000) was also highlighted by the current audit, which showed that availability of special equipment or assistive technology for disabled children is insufficient (mean=0.88/2). The NSPA (2004) emphasised 'appropriate equipment' as a requirement for caring for patients with profound disabilities. Furthermore, Hemsley et al. (2008a) found that inaccessibility of equipment, or equipment that needs repositioning, is a challenge for families with disabled children. Both NGT groups in the current study also stated that lack of appropriate equipment and resources is an impediment to a high standard of care for disabled children. This problem was also identified by respondents in the surveys conducted by Buzio et al. (2002a) and Iacono and Davis (2003); parents reported bringing their own special equipment such as communication aids and wheelchairs to hospital (Iacono & Davis 2003). It is clear that access to appropriate equipment contributes to high standards of care and helps to meet disabled children's needs.

Providing training for hospital staff relating to skills in customising equipment for disabled children was highlighted by the White Papers 'Better Care: Better Lives' (DH 2008) and 'Aiming High for Disabled Children: Better Support for

Families' (HM Treasury & DfES 2007). The problem of knowing how to move a person with cerebral palsy was identified by hospital staff who contributed to the study conducted by Iacono and Davis (2003). Additionally, a decrease in nurses' confidence in delivering care to disabled patients, due to lack of special training related to using equipment, was identified by Roberts (2001). The result of the current audit shows that instruction on specific equipment is not sufficient in the children's wards examined (mean=0.75/2); this data echoes the RNs' concerns about 'not accessing training to use special equipment' (statement 34) brought up at the NGT meeting. This finding was also confirmed by a pilot study by Happ et al. (2004a); several nurses in that study noted that they did not know what devices were for or how to use them. Additional findings from the reports by Roberts (2001) and Backer et al. (2009) indicated that knowledge of equipment use leads to a better-performing healthcare team. There is a gap within the nursing modules under examination relating to special equipment and resources used by disabled children, which have been expanded upon by the current service evaluation. This point needs to be considered.

The effective provision of equipment during the hospital discharge of a disabled child requires great coordination and support (DH 2004). One concern raised by the RNs in this NGT was 'unfulfilled promises by management related to facilities'; this point was confirmed by Margolan et al. (2004). Parents of long term ventilation children who contributed to that survey noted that one of the predominant causes of delays in discharge was not receiving equipment to take home. The results from the current audit showed that the provision of equipment before discharge for disabled children is not sufficient (mean=0.66/2). This echoes the concern raised by HCSWs at the NGT meeting about problems with getting funding for a wheelchair. The provision of timely and effective equipment for disabled children during discharge, therefore, needs to be considered.

5.5 Unfavourable Environment

Disabled children are often accompanied by a lot of equipment and consumables (Kirk et al. 2005). In the study conducted by Bull (1993), one of the main themes that emerged relating to children with disabilities was 'the

Chapter Five

impact and importance of the hospital environment', a point confirmed by the present study.

Noisy and unfamiliar environments can increase anxiety and stress among people with learning disabilities and their families (Hayes & Kjioux 1984; Houghton 2001). Additionally, an unpredictable hospital environment can create frustration and increase challenging behaviour, communication problems and risk of injuries among hospital staff and disabled children (Grossman et al. 2000; Burke et al. 2007; Lunskey et al. 2008; Shilling et al. 2012). Scarpinato et al. (2010) argued that disabled children need more time to cope with their environment; nurses who contributed to the current NGT agreed that disabled children and their families need help in adapting to new environments (statement 17).

'Valuing People' (2001b) emphasised accessibility to health services for disabled people. The inadequacy of physical environments for disabled patients has been identified by a number of studies (Cumella & Martin 2000; Glaysher 2005; Drainoni et al. 2006a; Brown & Guvenir 2009). Hospital staff who contributed to the study conducted by Lunskey et al. (2008) indicated that inappropriate environments were a challenge for them when delivering care to disabled patients. Wharton et al. (2005) and Cumella and Martin (2000) also emphasised the importance of sufficient facilities to creating a positive experience during hospital admission. Additionally, 'making hospital experience positive' was a point generated by nursing staff during the NGT meeting, they also registered their concerns about environment with the statement 'too little space' (HCSWs/ statement 27).

Glaysher (2005) explained that physical environment (layout of chairs, signs and maps, cluttered rooms) can be a barrier to accessing health services and may provide negative experiences for disabled patients. Kirschner et al. (2007) identified some related issues, including 'low technology' structure, limited access to healthcare services and a failure to care for disabled patients. Hewitt-Taylor (2008b) found that parents of disabled children encountered major problems with suitable toilets and adequate changing facilities, which can make a big difference to experience of care. 'Lack of disabled changing area' (RNs/ statement 6), 'not having a multi-sensory room' (HCSWs/ statement 22)

and 'no outdoor play area' (HCSWS/statement 32) constitute new physical environment barriers revealed by the current service evaluation.

Problems with the impact of physical space on the parents of wheelchair-using children have been identified by several studies (Schopp et al. 2002; Wharton et al. 2005; Drainoni et al. 2006a). Several statements by nurses in the NGT group were related to negative environments for wheelchair users, such as 'non-wheelchair-friendly care environment' (RNs/ statement 21). Cumella and Martin (2000) suggested that improving hospital design standards could provide better access for wheelchairs.

Roden (2005) identified that most parents of disabled children need a calm and secure environment in order to provide care and support for their children within the hospital environment. Neill (1996) found that parents of young children were not happy with sleeping arrangements in hospital. All respondents in the study conducted by Brown and Guvenir (2009) expressed that having one's own room (side room) is a better choice for disabled children; this is exemplified by the statement 'I have felt vulnerable and exposed in open ward'. A lack of privacy was a challenge for providing a high standard of care for disabled children and their families, as identified by nurses in the NGT meetings.

In the study carried out by Wharton et al. (2005), parents of disabled children reported some difficulties with parking at the hospital site, such as insufficient space, not being close to the hospital department, misuse of disabled parking spaces and unavailability of free parking, as well as safety issues. The current audit showed that accessibility to free parking is still not adequate (mean=1.18); concerns relating to family parking expenses (RNs/statement 14) were also raised in the NGT meeting.

Surprisingly, creating a favourable environment for caring for disabled children was not covered by the nursing modules under examination. This point has been expended upon by the current service evaluation; this gap needs to be considered.

Chapter Five

5.6 Summary of the Chapter

This chapter has provided a discussion of the four predominant issues which emerged from the current service evaluation: effective communication, provision of training, provision of equipment and unfavourable environment. Chapter 6 will present conclusions and some suggestions for further work.

Chapter 6 : Conclusion and Recommendation

6.1 Introduction

This chapter will present the conclusions and contribution of the current service evaluation and provide recommendations in two sections: implications for further work and implications in practice.

6.2 Conclusion

Building up good interaction with disabled children and their families is vital. Hemsley and Balandin (2004) noted that task-focused interaction between nurses and patients is not effective for meeting patients' needs and leads to a feeling of frustration on the part of nurses, patients and their caregivers. The findings from this service evaluation have emphasised the importance of communication with disabled children and their families.

Communication is valued by the families of disabled children (Avis & Reardon 2008), and nurses are in a good position to improve interaction with these families (Beukelman et al. 2007). This service evaluation has highlighted that better communication with disabled children will require well-organised and on-going training related to both communication and using and accessing AAC. Finke and Quinn (2012) emphasised that nurses need access to tools and skills that allow them to communicate with voiceless patients.

From a practice standpoint, the current service evaluation has suggested that nursing staff are enthusiastic about working with disabled children and their families but do not feel well-equipped in the skills they need. As such, they need more training in order to develop their skills and knowledge in providing a high quality of care. The study has also highlighted that a necessary change has been incorporated into nursing education, which has made a positive impact on attitudes and has also improved nursing staff confidence in and commitment to caring for disabled children (Slevin & Sines 1996; Cumella & Martin 2000; Byron et al. 2005; Sowney & Barr 2006; McMurray & Beebee 2007).

Boyd and Hunsberger (1998) found that the physical hospital environment can have an impact on the independence and control of children with chronic

Chapter Six

diseases and also help them cope with their conditions. This normalisation of the physical and social environment for these children was confirmed by the study of Sartain et al. (2000). Unfavourable environments have been identified as a barrier to care delivery for disabled children by this service evaluation.

This evaluation has also shown that in addition to placing more consideration on the challenges of caring for disabled children, rewards for nursing staff require more attention as they may lead to improved self-satisfaction (Coyle-Rogers & Cramer 2005) and increase commitment. Khowaja et al. (2005) suggested that reducing workload by ensuring an adequate nurse-patient ratio and providing rewards and recognition for their performances would be the best way to attain high standards of care.

6.3 Contribution of the current service evaluation to the development of scholarship in the area of caring for disabled children

This section will show how four key issues have emerged from the current service evaluation contributing to the development of scholarship in the subject under study.

6.3.1 Effective communication

This service evaluation revealed that lack of effective communication skills among nursing staff depends more on training in the workplace than deficiency in their undergraduate education. However, this finding contradicts other studies (Scullion 1999c; Balandin et al. 2001; Hemsley et al. 2001).

The service evaluation also showed that difficulties relating to relationship with families and concept of partnership is based on a lack of emphasis on formal nursing education.

Non-verbal communication with disabled patients were identified as a reward by nursing staff participating in the current service evaluation. This finding contrasts with that of the study conducted by Bryan (1977).

The service evaluation revealed that communication skill was well-covered within undergraduate education. This suggests that lack of training and continuing education in the workplace have the largest effect on communication skills among nursing staff working with disabled children.

6.3.2 Provision of training

The current service evaluation showed that there are deficiencies in the areas of 'developing students' knowledge and skills about caring for children with long term health needs', 'positive attitude towards disabled children' and 'needs of disabled children' in children's nursing education.

The service evaluation also revealed that induction training is an important point at which to deliver information to nursing staff caring for disabled children.

6.3.3 Provision of equipment

This service evaluation showed that one of the deficiencies within nursing education relates to 'special equipment and resources used by disabled children'.

The findings relating to 'lack and access of special equipment' and 'lack of training in customising equipment for disabled children' were in accordance with other studies (Buzio et al. 2002a; Iacono & Davis 2003; Hemsley et al. 2008c).

6.3.4 Unfavourable environment

The service evaluation identified that in not having a multisensory room or an outdoor play area, the children's unit was creating physical and environmental barriers to the optimum care of disabled children and young people and those with complex health needs. Importantly content analysis of the child nursing curricula failed to reveal that this aspect of care environment was formally taught as a stand-alone subject. Furthermore, 'lack of privacy', 'insufficient space in wards' and 'unavailability of access to free parking' were also recognised as physical environment barriers, in accordance with other studies (Cumella & Martin 2004a; Drainoni et al. 2006a; Brown & Guvenir 2009).

Chapter Six

6.3.5 Feedback the Findings

The detailed analysis of the data will be presented by the auditor to key stakeholders and the Trust, as an executive summary (Appendix 6.1), to help ensure that the required changes take place.

6.4 Recommendations

The results of the present service evaluation have a number of implications for further service evaluation and practical applications.

6.4.1 Implications for Future Work

The present service evaluation was conducted in one local NHS Hospital Trust only; therefore, a further service evaluation would require a greater variety of subject samples, a different design and a larger context in order to glean additional findings and a deeper understanding of care issues for disabled children and their families.

6.4.2 Implications for Practice

- To improve the provision of care delivery to disabled children: this requires good, knowledgeable staff with sufficient expertise and positive attitudes (see page 170)
- To consider an adequate nurse-patient ratio in order that nurse managers can better meet the needs of disabled children and their families (see page 92)
- To identify the most effective training methods for improving the knowledge and clinical skills relating to the care of disabled children (see page 171)
- To provide more training in the workplace by experienced staff who are well aware of disabled children's needs (see page 166)
- To identify AAC resources and ways of accessing these resources (see page 160)

- To establish a nurse lead or link, who is an expert in this field, to plan and coordinate the care of disabled children with the aim of meeting their needs (see page 169)
- To provide guidance for staff on supporting disabled children and their families (see page 159)
- To consider individualised service delivery and nursing care depending on disabled children's needs (see page 166)
- To raise awareness of disabled children's needs among nursing staff (see page 170)
- To ensure the provision of advice or guidelines on effective communication is applied throughout the NHS Foundation Trust (see page 168)
- To ensure the provision of communication devices and resources is utilised by hospital managers (see page 167)
- To identify a communication style for patients before admission and plan for it (see page 166)
- To involve academic nursing staff, who are experts in this field, in leading and teaching skill workshops and training sessions (see page 170)
- To provide more training, support and skills for staff in using the special equipment and devices required to care for disabled children (see page 161,168)
- To develop a greater partnership with families and carers of disabled children (see page 160)
- To consider a family forum for this population (see page 129)
- To identify environmental barriers to accessing health services and make the necessary changes (see page 95,173,174)

Chapter Six

- To ensure greater involvement and commitment to meeting the needs of disabled children and their families on the part of policy-makers and hospital managers (see page 167, 92)

This list of recommendations will be presented to the Trust Board and Executive Group in the form of an action plan.

6.5 Utilising the Findings

Dissemination is the process of transferring new information from producer to consumer (Mulhall & Le May 1999). It is hoped that the results from clinical studies will lead to improved nursing practice (Polit & Hungler 1999). New information was produced by this service evaluation; a plan for disseminate the results is presented below:

- Incorporating this service evaluation into children's nursing curricula in order to include the findings of the project
- Dissemination by conference, colloquia and workshop presentations
- Reporting the results in a range of speciality journals relating to care for disabled children, targeted at practicing nurses in this area
- Presenting summary findings to stakeholders involved in care delivery to disabled children
- Providing executive summary to policy-makers (see Appendix 6.1)
- Educational sessions with nursing managers relating to rewards and challenges for nursing staff involved in care delivery to disabled children
- Media and public service engagement relating to the findings from the service evaluation
- Informing clinical governance and related activities in order to maximise population benefits
- Providing an awareness section within the Trust relating to barriers and improvement points for improving care delivery to disabled children and their families

- Providing a clinical handbook about working with disabled children and their families to nursing staff
- Developing clinical guidelines for care delivery to disabled children, using a panel of experts in this field and the results of the current service evaluation

6.6 Summary of the Thesis

This service evaluation has highlighted a number of barriers and deficiencies in providing a high quality of care to disabled children and their families in a local NHS Foundation Trust. It has also shown that challenges and rewards are encountered by nursing staff during care delivery to disabled children and their families, and has identified gaps in nursing training via a content analysis of modules from three universities. Furthermore, the audit part of the service evaluation has revealed a lack of adherence to best practice relating to care of this population. Four themes were identified by this service evaluation which have a significant impact on care of disabled children and their families, namely effective communication, provision of training, provision of equipment and unfavourable environment.

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Appendices

Appendix 1: Databases for Search

Databases	Description
Cumulated Index of Nursing and Allied Health Literature (CINAHL)	CINAHL provides access to a wide range of full text articles, many published in the USA, relating to nursing and allied health, health sciences education, behavioural sciences and management. In the USA, it is considered the premier database for nursing topics (Burnham & Shearer 1993).
The Allied and Complementary Medicine Database (AMED)	AMED is a bibliographic database produced by the Health Care Information Service of the British Library. It covers a selection of journals in complementary medicine, palliative care and several professions allied to medicine including physiotherapy, occupational therapy, podiatry and rehabilitation.
MEDLINE	MEDLINE is produced by the National Library of Medicine in Maryland which began coverage in 1966. MEDLINE covers all areas of biomedicine, including allied health fields and the biological and physical sciences. MEDLINE indexes the latest articles from more than 3,900 biomedical journals published in over 70 countries.
Excerpta Medica Database (EMBASE)	EMBASE, which came online in 1974, is considered to be an excellent mainstream health and medicine database. Topics covered include human medicine.
Web of Knowledge	The Web of Knowledge provides access to current and retrospective multi-disciplinary information from approximately 8,700 of the most prestigious high impact research journals in the world. It also provides a unique search method and cited reference searching. Users can navigate forward, backward and through the literature, searching all disciplines and time spans to uncover all the information relevant to their research.
British Nursing Index (BNI)	BNI provides full text articles from all the major British nursing and midwifery titles.
PsycINFO	Worldwide English language coverage of psychological, social behavioural and health sciences literature.
Cochrane Library	The Cochrane Library provides access to the full text of the Cochrane Collaboration's systematic reviews, which are excellent resources for evidence-based medicine.

Adapted from: University of Southampton (2012); Royal College of Nursing (2012)

Appendices

Appendix 2.1: Initial Studies Identified from Main Search

Author(s)	Title	Journal Year & Ref	Database	Outline of study & included or excluded
Avis and Reardon (2008) UK	Understanding the views of parents of children with special needs about the nursing care their child receives when in hospital: a qualitative study	Journal of Child Health Care (2008), 12(7), pp 7-17	MEDLINE Web of Knowledge	A qualitative study designed to explore parents' views on how their child with additional needs had been cared for by hospital nursing staff. 12 interviews with parents of children with additional needs conducted.
Fox and Wilson (1999) UK	Parents' experiences of general hospital admission for adults with learning disabilities	Journal of Clinical Nursing (1999), 8, pp 610-614	CINAHL	A qualitative study about parents' experiences of general hospital inpatient care for their adult sons and daughters with LD. Ten parents were semi-structured interviewed. Findings in the areas of placement, occupation, basic nursing care, feeding, toileting, nursing attitudes, staffing and procedures were presented.
Weiss et al. (2009) Canada	Emergency psychiatric services for individuals with intellectual disabilities: caregivers' perspectives	Journal of Applied Research in Intellectual Disabilities (2009), 22, pp 354-362	PsycINFO	A qualitative study using focus groups to understand the experience of caregivers and adults with ID and mental health issues, according to caregivers' perspectives.

Author(s)	Title	Journal Year & Ref	Database	Outline of study & included or excluded
Lunsky et al. (2008) Canada	Emergency psychiatric services for individuals with intellectual disabilities: perspectives of hospital staff	Intellectual and Developmental Disabilities (2008), 46(6), pp 446-455	PsycINFO	The purpose of this study was to identify clinical and systemic issues surrounding emergency psychiatry services for people with intellectual disabilities, from the perspective of hospital staff.
Kirk, S (1999) UK	Caring for children with specialized health care needs in the community: the challenges for primary care	Health and Social Care in the Community (1999), 7(5), pp 350-357	CINAHL	This research investigated how services can be developed to support families caring for children with complex healthcare needs by using qualitative interviews which were conducted with the parents of 24 children who were dependent on technology and with four of the children themselves and 38 professionals involved in supporting the families at home.
McConkey and Truesdale (2000) Ireland	Reactions of nurses and therapists in mainstream health services to contact with people who have learning disabilities	Issues and innovations in nursing practice (2000), 32(1), pp 158-163	CINAHL	The study investigated reactions of nurses and therapists in mainstream health services to contact people who have learning disabilities by using a questionnaire.
Ford and Turner (2001) Australia	Stories seldom told: paediatric nurses' experiences of caring for hospitalised children with special needs and their families	Issues and Innovations In Nursing Practice (2001), 33(3), pp 288-295	MEDLINE	This study explored paediatric nurses' experiences of caring for children with special needs and their families in an acute care setting by using in-depth, semi-structured interviews.

Appendices

Author(s)	Title	Journal Year & Ref	Database	Outline of study & included or excluded
De Geeter et al. (2002) Netherlands	Parents as experts: the position of parents of children with profound multiple disabilities	Child: Care, Health & Development (2002), 28(6), pp 443-453	PsycINFO	<ul style="list-style-type: none"> This study involved descriptive research by means of a questionnaire which aimed to demonstrate the supposition that cooperation occurs between parents and professionals during study in school. Excluded
Sowney and Barr (2007) Ireland	The challenges for nurses communicating with and gaining valid consent from adults with intellectual disabilities within the accident and emergency care service	Journal of Clinical Nursing (2007), pp 1678-1686	PsycINFO	This paper reported the challenges experienced by nurses within accident and emergency departments in communicating with and gaining valid consent from adults with intellectual disabilities.
Sowney and Barr (2006) Ireland	Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units	Journal of Advanced Nursing (2006), 55(1), pp 36-45	PsycINFO	This was a study exploring the experiences of nurses in accident and emergency units caring for people with intellectual disabilities by using focus groups conducted with 27 accident and emergency nurses from five hospitals in Northern Ireland.
Perkins (Perkins 1993) UK	Parent-nurse collaboration: using the caregiver identity emergence phases to assist parents of hospitalised children with disabilities	Journal of Pediatric Nursing (1993), 8(1), pp 2-9	CINAHL	This paper was a qualitative study of 23 parents of hospitalised or recently hospitalised children (two to 13 years) with cognitive impairments about parental caregiving experience.
Hewitt-Taylor (2008b) UK	Young people with complex health needs: the organisation of support	Primary Health Care (2008), 18(8), pp 36-39	CINAHL	This research explored the provision of support from the perspectives of an adolescent with complex health needs, her family and those involved in providing day to day support.

Author(s)	Title	Journal Year & Ref	Database	Outline of study & included or excluded
Hewitt-Taylor (2008a) UK	Parents' views of their children who have complex health needs	Paediatric Nursing (2008), 20(8), pp 20-23	CINAHL	This study explored parents' perceptions of their children with complex health needs and their experience of communication, play, socialising and learning by using semi-structured interviews with 14 parents.
Hewitt-Taylor (2005b) UK	Caring for children with complex needs: staff education and training	Journal of Child Health Care (2005), 9, pp 72-86	PsycINFO	The study aimed to provide a broad description of the perceived education and training needs of those who care for children with complex needs outside the hospital setting. A questionnaire was used to ascertain the perspective of service providers' views on staff education needs.
Lewis and Stanfert-Kroese (2010) UK	An investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in general hospital setting	Journal of Applied Research (2010), 23, pp 355-365	PsycINFO	This study aimed to investigate the attitudes and emotional reactions reported by nursing staff working in general hospitals towards caring for patients with intellectual disabilities by using a self-report vignette style questionnaire.
Dinsomre and Higgins (2011) UK	Study of patients' experiences of treatment by hospital staff	Learning Disability Practice (2011), 14(5), pp 18-22	CINAHL	This study aimed to investigate the levels of access to services in hospital for patients with learning disabilities in Merseyside.
Iacono and Davis (2003) Australia	The experiences of people with developmental disability in Emergency Departments and hospital wards	Research in Developmental Disabilities (2003), 24, pp 247-264	PsycINFO	The aim of this study was to determine whether the needs of people with developmental disabilities were met during visits to Emergency Departments and stays in hospital.

Appendices

Author(s)	Title	Journal Year & Ref	Database	Outline of study & included or excluded
Phua et al. (2005) Australia	Inpatient care of children with cerebral palsy as perceived by their parents	Journal of Paediatric Child Health (2005), 41, pp 432-436	<ul style="list-style-type: none"> • MEDLINE • Web of Knowledge • EMBASE 	The aim of the study was to evaluate the inpatient care of children with CP, as perceived by their parents.
Slevin and Sines (1996) UK	Attitudes of nurses in a general hospital towards people with learning disabilities: influences of contact, and graduate-non-graduate status, a comparative study	Journal of Advanced Nursing, 24(6), pp 1116-1126	Web of Knowledge	This study measured the attitudes of a randomly selected sample of nurses in a general hospital (n=31) towards people with learning disabilities by using in-depth interviews.
Matziou et al. (2009) Greece	Attitudes of nurse professionals and nursing students towards children with disabilities. Do nurses really overcome children's physical and mental handicaps?	International Nursing Review (2009), 56, pp 456-460	CINAHL Web of Knowledge	The objective of this study was to investigate the attitudes of nurse professionals (paediatric nurses) and nursing students towards disabled children.
Milner et al. (1996) UK	Needs of disabled children and their families	Archives of Disease in Childhood (1996), 75, pp 399-404	CINAHL Web of knowledge	The aims of this study were to develop a parent's satisfaction checklist and determine the extent to which parents considered that these criteria had been fulfilled and which criteria were most important to parents.
Cumella and Martin (2000) UK	Secondary health care for people with a learning disability	A report completed for the Department of Health	CINAHL	This study aimed to define important issues and identify innovations and solutions for people with LD.
Roberts (2001) UK	The Views of Family Carers on the Contribution of Nurses to	Thesis, University of Dundee	<ul style="list-style-type: none"> • CINAHL • MEDLINE 	A survey by means of a mailed questionnaire conducted.

Author(s)	Title	Journal Year & Ref	Database	Outline of study & included or excluded
	the Care and Support of People with Profound and Multiple Learning Disabilities (PMLD)		<ul style="list-style-type: none"> • AMID 	
Sen and Yurtsever (2007b) Turkey	Difficulties Experienced by Families with Disabled Children	JSPN, 12(4), pp 238-251	<ul style="list-style-type: none"> • CINAHL • Web of Knowledge 	This descriptive study was carried out in Turkey to determine the difficulties experienced by families with disabled children.
Hart (1998a) UK	Learning-disabled people's experience of general hospitals	British Journal of Nursing, 7(8), pp 470-7	<ul style="list-style-type: none"> • CINAHL • MEDLINE • Web of Knowledge 	The researcher interviewed 13 people with ID. The findings highlighted that some areas needed to be improved, such as fears about treatment, communication, general nursing, gaining consent and doctors.
Hayes and Knox (1984) Canada	The experience of stress in parents of children hospitalized with long-term disabilities	Journal Advance Nurse, Jul, 9(4), pp 333-41	Web of Knowledge	This paper discussed long term disabled children's parents' perceptions of their stress when their children are hospitalised. Data were collected with 40 parents through in-hospital interviews.
Chung and Corbett (1998) UK	The burnout of nursing staff working with challenging behaviour clients in hospital-based bungalows and a community unit	International Journal of Nursing Studies, 35(1-2), pp 56-64	CINAHL	This pilot study aimed to compare the burnout of nursing staff who worked with challenging behaviour clients in hospital-based bungalows and a community unit.
Brown and Guvenir (2009) UK	The experiences of children with learning disabilities, their carers and staff during a hospital admission	British Journal of Learning Disabilities, 37, pp 110-115	CINAHL	This study used qualitative research by means of interviews with children with disabilities and nursing staff. It aimed to explore the experiences of children with learning disabilities, their carers and staff during a hospital admission.
Balandin et	Communicating with nurses:	Brain Impairment,	CINAHL	Interview protocol developed by 3 nurses and 3

Appendices

Author(s)	Title	Journal Year & Ref	Database	Outline of study & included or excluded
al.(2001) Australia	The experiences of 10 individuals with an acquired severe communication impairment	2 (2), pp 109-118 CINAHL		disabled patients. Six questions were included within the protocol, and then structured interviews conducted for ten adults with cerebral palsy and CCN.
Hemsley et al. (2008c) Australia	Professionals' views on the roles and needs of family carers of adults with cerebral palsy and complex communication needs in hospital	Journal of Intellectual & Developmental Disability, 33(2), pp 127-136	CINAHL	This study used qualitative research by means of a focus group with six hospital and disability service staff. Its aim was to explore the views of hospital and disability service staff related to the roles and needs of family carers of adults with cerebral palsy (CP) and complex communication needs (CCN) in hospital.
Hatton et al. (1999) UK	Factors associated with staff stress and work satisfaction in services for people with intellectual disability	Journal of Intellectual Disability Research, 43(4), pp 253-267	CINAHL	This study was a survey investigating factors directly and indirectly related to staff general distress, job strain and work satisfaction amongst staff who worked with people with intellectual disabilities.
Liptak et al. (2006) USA	Satisfaction with primary health care received by families of children with developmental disabilities	Journal of Pediatric Health Care, 20 (4), pp 245-252	CINAHL	300 survey were mailed to families with disabled children during 2003-2004, which included a Multidimensional Assessment of Parental Satisfaction for Children with Special Needs.

Appendix 2.2: The Steps of the Parahoo Model

Title of Study

Does the title convey the study clearly and accurately?

Abstract

Does the abstract give a short and concise summary of the following aspects of the study?

Background

- Aim
- Designs
- Results
- Conclusions

Literature Review/Background

- Is the importance of the study justified?
- What is the context of this study?
- Does the literature review show the gap/s in knowledge which this study seeks to fill?

Aims/Objectives/Research Questions/Hypotheses

- Are the aims of the study clear?

Design of Study

- What is the design of the study? Is it the most appropriate for the aims of the study?
- Are the main concepts (to be measured) defined?
- What are the methods of data collection? Are they constructed for the purpose of the current study or do the researchers use existing ones?
- Who collected data? Can this introduce bias in the study?
In studies where there are more than one group, is there a description of what intervention/treatment each group receives?
- Is the setting/s where the study is carried out adequately described?
- Who was selected? From what population were they selected? What was the precise method of selection and allocation? Was there a sample size calculation?
- Was ethical approval obtained? Are there any other ethical implications?

Data Analysis

- Was there a separate section in the paper that explained the planned analyses prior to the presentation of the results?
- Which statistical methods were relied on?

Appendices

- Is it clear how the statistical tests were applied to the data and groups?

Results

- Are the results clearly presented?
- Are the results for all the aims presented?
- Are the results fully presented?

Discussion

- Is it a balanced discussion? Have all possible explanations for the results been given?
- Are the results discussed in the context of previous studies?
- Are the results fully discussed?
- Are the limitations of the study discussed?
- Are the results discussed in the context of previous studies?
- Are the results fully discussed?
- Are the limitations of the study discussed?

Conclusions/Recommendations

- Are the conclusions justified?
- Are there recommendations for policy, practice or further research?
- Are the results/conclusions helpful for my practice?
- Are the results generalisable?

Funding

Is there potential conflict of interest (if information on funding is provided)?

Adapted from: Glasper and Rees (2012)

Appendix 3

Appendix 3.1: Operational Definitions of Research, Clinical Audit and Service Evaluation

	Research	Clinical Audit	Service Evaluation
Definition	Attempts to produce new knowledge that has potential to be generalisable or transferable.	Designed to produce information related to best care, with the aim of improving the quality of care and clinical outcomes. Review of practice against evidence-based standards and use of findings to change services.	Designed to define or judge the current care in terms of effectiveness or efficiency through systematic assessment of aims, objectives, activities, outputs, outcomes and costs.
Attempts to answer the question	Addresses defined questions/hypothesis by using systematic and rigorous processes: 'What is best practice?'	Addresses defined audit questions using a robust methodology: 'Is the organisation following the best practice?' or 'Does this service reach a predetermined standard?', and 'What is happening to patients due to the results?'	Addresses specific questions about the service concerned: 'What standards are achieved within this service?'
Initiated by	Researcher	National bodies (e.g. Healthcare Commission, NICE, Royal Colleges) or service providers	Service managers/leaders
Methodology and design	Qualitative or quantitative research, involves evaluating or comparing intervention and experiencing relationships.	Involves an intervention in use only.	Involves an intervention in use only.
Data collection	Usually involves collecting data that are not collected routinely.	Usually involves analysis of existing data but may include interview or questionnaire.	Usually involves analysis of existing data but may include interview or questionnaire.

Appendices

	Research	Clinical Audit	Service Evaluation
End product	Generates evidence and supports or develops a hypothesis, which may lead to the development of new practices or new services.	Generates evidence of the levels of compliance with agreed standards, which may lead to changes in practice.	Generates evidence of effectiveness of a service, which may lead to service redesign and reconfiguration.
One-off or continuing	Usually a one-off study.	May be one-off, but usually 25% of Trust audit activity involves re-audit.	Usually a one-off study, but may be repeated to compare changes over time.

Adapted from: (NRES Ethics Consultation 2007; United Bristol Health Care NHS Trust 2007)

Appendix 3.2: Consent Form



Consent form

Study title: The Challenges and Rewards of Working with Disabled Children and Young People and those with Complex Health Needs

Investigator: Mahnaz Ilkhani, Doctorate in clinical practice student, Postgraduate Research office (2011), School of Health Sciences, University of Southampton, Highfield, Southampton, SO17 1BJ

Explanation of Procedures

You are invited to participate in a focus group being discussed within the children unit at a general hospital.

This discussion group is designed to help the child health division to understand your views about the challenges and rewards of working with disabled children and young people and those with complex health needs.

Statement of Agreement to Participate in this Service Evaluation

You have read this consent form in a language that you can speak, and its contents have been explained to you. Your rights and privacy will be maintained. You will be given a copy of this consent form.

Please tick the boxes if you agree with the statement(s).

If you do not agree with a statement, please a X in the appropriate box.

Appendices

I have had the opportunity to ask questions about the service evaluation and have had these answered to my satisfaction.	<input type="checkbox"/>
I agree to take part in this project and agree for my data (i.e. information about me collected in this service evaluation) to be used for the purpose of this service evaluation.	<input type="checkbox"/>
I understand that my participation is voluntary and I may withdraw at any time without my legal rights or health care being affected.	<input type="checkbox"/>
I understand that if I withdraw from the service evaluation, no further data will be collected from or in relation to me, and any data already collected will be destroyed, unless I specifically ask to keep any such data, already collected, in the service evaluation.	<input type="checkbox"/>
I agree for my data to be stored confidentially at the University of Southampton, Faculty of Health Sciences, for 10 years, in accordance with university policy. All information which contains personal data participants in the service evaluation (such as name, contact details, etc., and code breaker linking participants names to participants' codes) will be destroyed within 10 years after the completion of this service evaluation.	<input type="checkbox"/>
I agree that my anonymous data may be used by other investigator, including non-University of Southampton investigator, for the purposes of study in the future.	<input type="checkbox"/>
I agree to allow the investigator to share (publish or present) the results of service evaluation and use direct quotes in reports and publications, provided that my name and other identifying information are kept confidential.	<input type="checkbox"/>
I would like to have a summary of the final report sent to me and/or my representative (named below) at the completion of the service evaluation.	<input type="checkbox"/>

Name of participant (print name).....

Signature of participant.....

Date.....

Date of birth of participant.....

Contact details of participant.....

Name of investigator (print name): Mahnaz Ilkhani

Appendix 3.3: Literature Review of Content Analysis of Disability within Nursing Curricula

A brief review was conducted on two databases: CINAHL and MEDLINE. The search was refined between the years of 1982 and 2011, with the terms 'content analysis', 'nursing education' and 'curricula' in the title (Figure 1). The results revealed that only six research articles during these 29 years contained all the keywords 'content analysis', 'disability' and 'curriculum' (Tommet et al. 1993; Lennox & Diggins 1999b; Tanenhaus et al. 2000; Wells et al. 2002; Banks & Kane 2004; Erevelles 2005). Two research articles contained the keywords 'content analysis', 'disability' and 'nursing education' (Scullion 1999c; Smeltzer et al. 2005), but no article contained the keywords 'content analysis', 'children with disabilities', and 'curriculum'. All articles identified by the main search were logged onto a table (Appendix 3.4).

Appendices

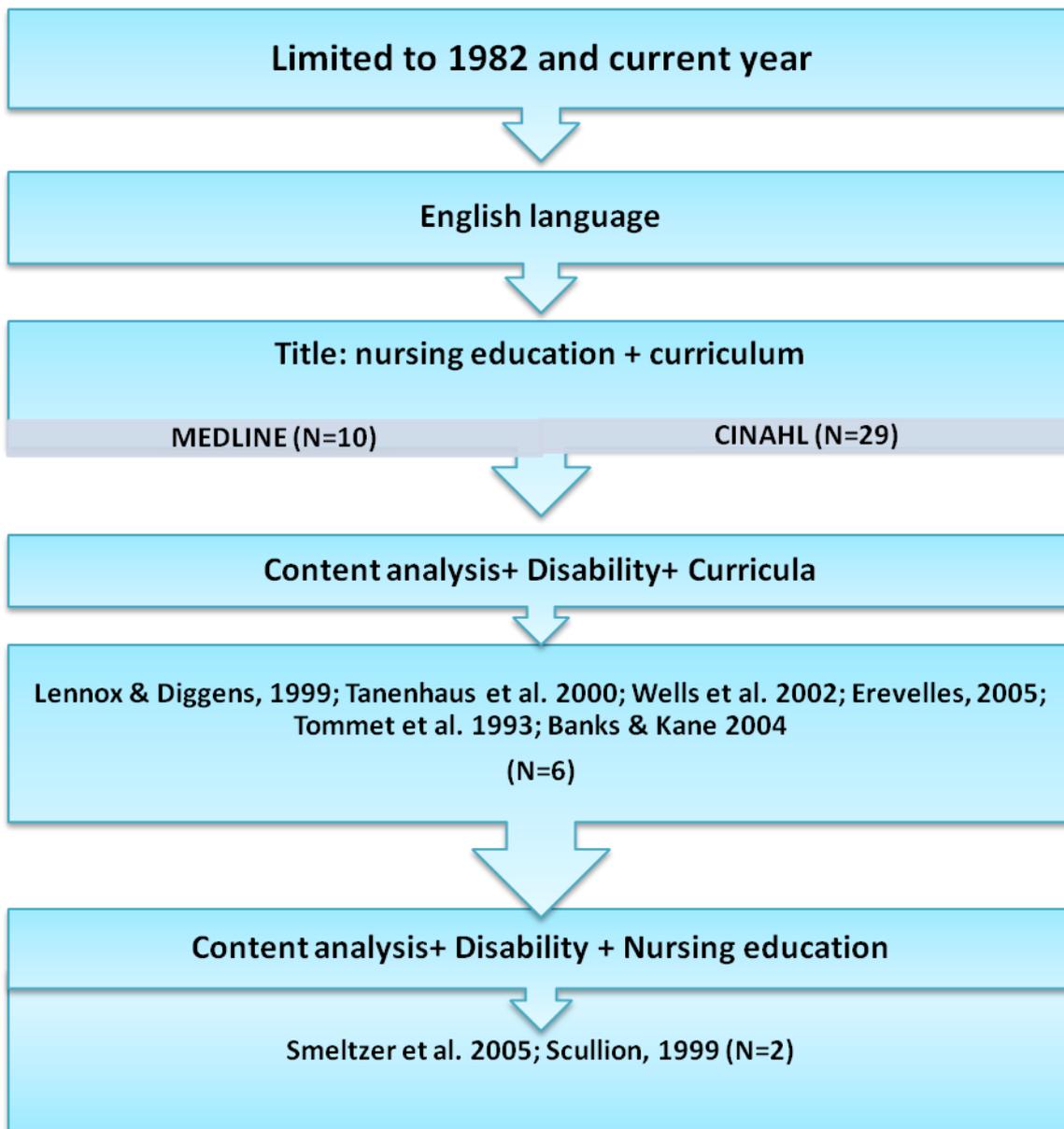


Figure 1: Literature review related to content analysis of disability within curricula

Smeltzer et al. (2005) conducted a descriptive study by surveying 1,000 nursing schools in the USA about integration of disability-related content within the nursing curricula. The researcher found that textbooks were the major sources for teaching. Additionally, insufficient time and lack of faculty interest or expertise were obstacles to developing disability-related content. The researcher suggested that disability content in nursing curricula should be revised so as to be relevant to people with disabilities.

The limitations of this study were a low rate of response (23.4%) and the fact that data was gathered through a self-report questionnaire developed by the

investigators, leading to questionable accuracy. Respondents answered the questions and evaluated their own curricula, which may have led to bias. On the other hand, the researcher did conduct an additional pilot study involving a substantial sample size of American nursing schools (n=324), which was the study's strong point.

Three research articles mentioned gaps within the contemporary curricula related to disability: Tanenhaus et al. (2000) (USA), Lennox and Diggins (1999a) (Australia) and Marshall and Haines (1990) (UK). Therefore, the lack of an ideal curriculum in this area is an important concern.

Tanenhaus et al. (2000) conducted a survey by means of a questionnaire posted to 35 public health schools in the USA. The findings revealed that 60% of the 35 schools (21/35) have comprehensive graduate-level courses related to disability. In addition, the respondents examined the curricula. The result of this part of the study showed that fundamental gaps exist in these syllabi. In addition, the researchers suggested that disabled persons' experiences and their needs should be employed as an educational resource.

This study was a national survey of public health schools with an 85.7% response rate. However, the researcher did not provide clear explanations about sampling, validity, reliability of the study and the method of examining the curricula.

Lennox and Diggins (1999a) carried out a mixed methods study in Australia. First, the researchers determined the ideal knowledge, skills and attitudes and prioritised the curricula content for undergraduate medical students by means of a questionnaire delivered to expert members of this field (n=8). Next, by utilising the findings, an ideal curriculum was developed. The second part of the study was a telephone interview with academic members of ten medical schools about the extent of their teaching that covered the 'ideal' knowledge, skills and attitudes. Half of the schools covered all areas of knowledge and attitudes. The contemporary curricula were not presented as ideal. The knowledge area covered more than skills and attitudes. The medical school lecturers were chosen randomly rather than structurally or precisely. Additionally, the lack of resources, absence of an ideal curriculum and lack of well-experienced staff impacted on the quality of the teaching. The researchers suggested that this lack of sufficient knowledge and expertise among teaching

Appendices

members led to less enthusiasm for investing time in this field. Additionally, the quality of teaching, even within the limited time, would be improved if a teaching guideline model was available. The researcher concluded that it is essential for lecturers to concentrate on this subject and not allow other topics to dominate the disability theme due to a lack of time.

This study had a sampling bias, due to the fact that participants were chosen by the researchers and interview respondents were thus likely to be inappropriate; this was flagged up by the researchers. Additionally, the study represented the view of medical experts but did not involve all sectors. Furthermore, a survey cannot provide strong data about the reality of perspectives within the medical schools. However, qualitative analysis of the questionnaire by the researcher and co-investigator independently improved the inter-reliability of the study.

Marshall and Haines (1990) conducted a survey of 25 medical schools in the UK. The researchers revealed gaps in the teaching of disability and rehabilitation, along with excess pressure on the curriculum from other subjects and insufficient academic structure in this field. Significant positive responses received from students related to opportunistic teaching such as ward rounds.

The conclusion reached in the UK by Scullion (1999b) and in the USA by Tommet et al. (1993) was that the medical model still has a significant impact on the nursing curricula.

Scullion (1999b) conducted a case study with the aim of exploring the conceptualisation of disability by students and nursing teachers and their role in improving or challenging those with disabilities. The researcher utilised a questionnaire to gather data about students' perspectives of the curriculum documents; this was followed by semi-structured interviews (n=16) with both the students and teachers involved in delivering the curriculum. This study supported the view that the medical model of disability has had a strong impact on nursing training. The researcher suggested that stakeholders in academic areas should consider an anti-discrimination philosophy in terms of learning outcomes and transfer a social model onto disability. It was also claimed that disability does not attract as much attention as other themes within the curriculum. Moreover, the researcher suggested that simulation as a

method of teaching should be considered in order to provide the necessary skills to deal with disabled people.

The researcher used a purposive sampling approach and did not provide any explanation of the validity and reliability of the study. However, a pilot study was conducted for the interviews and questionnaire.

In Minnesota, Tommet et al. (1993) conducted a qualitative study by approaching a focus group of 25 nurses in leadership positions. This study revealed that nurses felt the need for an academic preparation with emphasis on supporting people with disabilities and their families. The participants recognised that contemporary training was not sufficient for delivering care to this population.

Tommet et al. (1993) recommended using interdisciplinary members of the faculty for teaching, which would encourage partnership models and increase interaction with different majors.

This study had a good-sized sample and chose a qualitative methodology by approaching focus groups. Its limitations included generalisability of findings, the dominance of participants in leadership positions with facilitator bias and no mention of either validity or ethical considerations. The findings of this study were confirmed by Banks and Kane (2004), whose mixed methodology focused on multi-disciplinary teams working with the families of disabled children. Banks and Kane (2004) suggested that any health professional who had contact with disabled children or young people with disabilities requires a basic knowledge of disabilities.

Wells et al. (2002) conducted two nominal group techniques in order to extract the essential curriculum themes for undergraduate medical education in Bristol. After two years, the core elements were again revised by the panel members and an audit of the medical curriculum was carried out. The researcher concluded that managing disability should be considered an essential part of medical practice. This study was followed by workshops led by disabled presenters. The findings showed that disabled people, as teachers, are competent at role playing and transferring their expertise and the idea of partnership; furthermore, the students' responses to this experience were positive.

Appendices

This study was conducted on only one medical school in Bristol, by researchers who were members of the disability and rehabilitation panel of Bristol University. Furthermore, the researcher did not mention anything about the validity and reliability of the study.

Appendix 3.4: Initial Study of Content Analysis of Papers

Author	Title	Reference	Outline of study	Databases
Smeltzer et al. (2005) USA	Integration of Disability-Related Content in Nursing Curricula	Nursing Education Perspectives, July/August, pp 210-216	The researcher conducted a descriptive study by surveying 1000 nursing schools in the USA about integration of disability-related content in nursing curricula. The researcher found that the use of textbooks to teach disability-related content was the major teaching strategy. Lack of time and lack of faculty interest or expertise were barriers to including disability-related content. The researcher suggested that the extent and breadth of disability-related issues in nursing curricula should be considered.	MEDLINE CINAHL
Lennox and Diggins (1999a) Australia	Knowledge, skills and attitudes: Medical schools' coverage of an ideal curriculum on intellectual disability	Journal of Intellectual & Developmental Disability, 24(4), pp 341-347	The researchers conducted a two-part mixed methods study. In the first part, the researcher determined the ideal knowledge, skills and attitudes and prioritised these items for undergraduate medical students by means of a questionnaire about expertise (n=8) in this field. From these findings, an ideal curriculum was developed. The second part was a telephone interview with academic professionals from 10 medical schools about whether their teaching covered the knowledge, skills and attitudes determined by the experts.	CINAHL
Lennox and Diggins (1999b) Australia	Medical education and intellectual disability: A survey of Australian medical schools	Journal of Intellectual & Developmental Disability, 24(4)	The researchers conducted a survey on medical school staff (n=10) in Australia about the amount and nature of learning disability teaching for undergraduate students by means of a telephone questionnaire.	Web of Knowledge
Marshall and Haines (1990) UK	Survey of the teaching of disability and rehabilitation to medical	Medical Education, Volume 24, Issue 6, pp 528-530	A survey was conducted to find out the extent to which undergraduates in medical schools in the UK were being exposed to structured teaching of disability and rehabilitation (i.e. seminars, lectures, group discussions) and explore how the teaching was performed and whether it utilised the active	MEDLINE

Appendices

Author	Title	Reference	Outline of study	Databases
	undergraduates in the UK		involvement of disabled people and/or their carers. It also attempted to ascertain the prevalence of interdisciplinary teaching.	
Seccombe (2007) New Zealand	Attitudes towards disability in an undergraduate nursing curriculum: the effects of a curriculum change	Nurse Education Today, 27, pp 445-451	The researcher conducted a comparative study on two different streams of student nurses in New Zealand, with the aim of evaluating the effect of a curriculum change on their attitudes towards people with disabilities by using a questionnaire (ATDP scale) with pre-test and post-test design.	CINAHL MEDLINE
Werner and Grayzman (2011a) Israel	Factors influencing the intention of students to work with individuals with intellectual disabilities	Research in Developmental Disabilities, 32, pp 2502-2520	The researchers conducted a cross-sectional study to examine the factors that contribute to students' intentions to work with ID people. The researcher used a structured self-administered questionnaire on 512 students from various fields of study.	CINAHL MEDLINE
Hollins (1988) UK	How Medical Handicap is Taught in U.K. Medical Schools	Medical Teacher, 10(3/4), pp 289-296	This study carried out a questionnaire survey of all medical schools.	Web of Knowledge
Walsh et al. (2000) USA	Caring for People With Developmental Disabilities: Survey of Nurses about Their Education and Experience	Medical Retardation, 38(1), pp 33-41	This study conducted a mailed survey of nurses in New Jersey.	MEDLINE
Tommet et al. (1993) USA	Graduate Nursing Education: Developmental Disabilities and Special Health Care Needs	Comprehensive Pediatric Nursing, 16, pp 239-258	A focus group study of 25 nurses that aimed to determine the need for an academic emphasis on preparing nurses to deliver care to individuals with development disability and special healthcare needs, as well as discuss content design, implementation and recruitment.	CINAHL MEDLINE

Author	Title	Reference	Outline of study	Databases
Bates et al. (2004) UK	The education and training needs of learning disability staff in relation to mental health issues	Nurse Education in Practice, 4, pp 30-38	Bates et al. (2004) conducted a survey by using a self-completed questionnaire on 365 nurses from 10 agencies across the UK, with the aim of first exploring and identifying the contemporary level of the knowledge, skill and confidence of learning disability care staff relating to the mental health needs of the users on their services, and then designing and delivering an appropriate programme.	CINAHL MEDLINE

Appendix 3.5: Comparison between the Teaching Characteristics of the Programmes

Characteristic	University 1	University 2		
		Module 1	Module 2	
Module Title	Caring for Children with Long Term Needs	Therapeutic Skills for Children’s Nursing	Role of the Children’s Nurse: Professional, Ethical and Legal Context	
Credit Level	Level 2–20 CATS point	Level 2–30 Credit Point	Level 2–15 Credit Point	
Total study time	42	300	150	
Characteristic	University 3			
	Module 1	Module 2	Module 3	Module 4
Module Title	Long Term Conditions and Care	Complex Care	End of life and palliative care	Principles of Nursing Practice
Credit Level	HES	HE6	HE5	HE4
Total study time	187.5	375	187.5	187.5

Appendices

Appendix 3.6: Content Analysis of Nursing Curricula

Theme 1	Needs of disabled children and young people and those with complex health needs		
Main category	Assessment of needs	Intervention/management of needs	Support of needs
Generic category	Individual/child or young person		Family/carer
Sub-category	Hospital		Community setting
Codes	Healthcare needs Palliative care needs Long term healthcare needs Complex needs	Psychosocial dimension	Physical dimension
Sub-codes	No data	<ul style="list-style-type: none"> Counselling skills Genetic skills Bereavement service education Breaking bad news 	<ul style="list-style-type: none"> Principles of chemotherapy Transfusion of blood and blood production Identifying and utilising resources available Constructive care package End of life care Care of child and family following death Care of the neonate with complex needs Care of children requiring intensive care Care of children with central line

Table 1: Content analysis for curricula of University 1 – first theme

Theme 2	Care for disabled children and young people and those with complex health needs		
Main category	Perspective/provision		Impact of disability
Sub-category	Health perspective	Historical perspective	Statutory perspective
Codes	<ul style="list-style-type: none"> • Children’s nursing perspective • Inter-professional provision • Multi-agency/multi-professional groups provision • Health promotion • Hospital community provision • Effective care provision • Family-centred care 		<ul style="list-style-type: none"> • Care setting • Family • Child <p>No data</p>

Table 2: Content analysis for curricula of University 1 – second theme

Appendices

Theme	Children's Nursing	
Main category	Delivery of Care	
Generic category	<ul style="list-style-type: none"> • Model/framework for care • Care tailored to the age and stage of development of child • Factors influencing the care needs of the child/family • Assessment, plan, implementation and evaluation of care • Care of children with chronic illness • Care of children with disability in different care setting • Variety of childcare settings • Partnership approach • Family-centred care • Multi-disciplinary approach • Reflective approach • Evidence-based approach 	
Sub-category	Knowledge	Skills
Codes	<ul style="list-style-type: none"> • Knowing different intervention • Family adaptation • Parental • Growth and maturation • Fundamental knowledge • Normal child development • Deviation from the norm development • Clinical pharmacology • Pharmacokinetic • Infection control • Psychosocial principles of disorder 	<ul style="list-style-type: none"> • Essential communication • Preverbal and verbal language • Effective support • Identification of children/families at risk of illness, disability, mental health • Identification needs of a child with disability • Identification of client problem • Pain assessment • Identifying nutrition and malnutrition • Assessment of children with special healthcare needs • Principle of clinical monitoring • Safe administration of medication to children • Therapeutic administration • Early referral

Table 3: Content analysis for curricula of University 2 /Module 1: Therapeutic Skills for Children's Nursing

Theme	Children's Nursing Training						
Main category	Knowledge			Skill			
Generic category	Impact			Role			
Sub-category	Ethical	Lawful	Professional	Empowerment	Communication and negotiation strategies	End of life care	Advocacy
Codes	<ul style="list-style-type: none"> Ethical theories Ethical framework Ethical principles Managing ethical conflicts in practice Ethical dilemmas Challenges 	<ul style="list-style-type: none"> NSF children Safeguarding children (policy and practice) Government inquiries Government guideline Government policies Legal principles Case Law relating to children and families Current public legislation relating to children Current policy 	<ul style="list-style-type: none"> Principles Boundaries Limitation Practice Safety Decision-making model/practice Information sharing NMC Code of Professional Conduct 	<ul style="list-style-type: none"> Power differentials Empowering children Empowering families Issues of power Partnership Multicultural concept 		Rights	Vulnerable groups

Table 4: Content analysis for curricula of University 2/Module 2: Role of the Children's Nurse: Professional, Ethical and Legal Context

Appendices

Theme	Long Term Conditions (LTC) and Care in Complex Health Needs Children					
Main category	Experience of LTC	Impact of LTC	Exploring LTC	Provision of care		
Sub-category	<ul style="list-style-type: none"> • Age continuum • Families • School life • Continuation of education • Expert parents 	<ul style="list-style-type: none"> • Children • Young people • Family • Siblings • Loss • Grief • Chronic sorrow 	<ul style="list-style-type: none"> • Evidence • Aetiology • Symptoms • Treatment • Psychosocial management • Palliative care • End of life care 	<ul style="list-style-type: none"> • Legal • Ethical • Framework • Policy • Tele-health 	Healthcare provision needs	Role of nurses

Theme	Long Term Conditions (LTC) and Care in Complex Health Needs Children					
Codes			Variety of diseases	<ul style="list-style-type: none"> • The Children Act • Mental Capacity Act • Human Rights Act • Equalities Act 	<ul style="list-style-type: none"> • Lay care • Community resources/services 	<ul style="list-style-type: none"> • Partnership • Supporting • Assessment of care • Management of care • Effective communication • Administration of therapeutic intervention • Self-treatment • Promote health and well-being • Multi-disciplinary team • Transition

Table 5: Content analysis for curricula of University 3/Module 1: Long Term Conditions

Appendices

Theme	Complex care	
Main category	Delivery of care	
Sub-category	<ul style="list-style-type: none"> • Care package • Primary, secondary, tertiary care • Evidence-based care • Family-centred care • Care within critical care environment • Complex care • Critical care • Holistic care • Care planning and management • Pain management • Complex healthcare setting • Care needs of children and young people with complex healthcare needs • Technologically dependent care • Evidence-based management • Legal and ethical issues of critical complex care • Care of fabricated illness • Challenges of caring for people with complex care needs • Person-centred care • Policy and service developments in relation to complex care • Anticipating care needs • Provision of care 	
Codes	Skill	Knowledge
Sub-code	<ul style="list-style-type: none"> • Physical assessment skill • History-taking • Assessment of an infant, child or young person with complex healthcare needs • Decision-making • Safe assessment • Communication • Negotiation • Pain assessment 	<ul style="list-style-type: none"> • Pathophysiology • Treatment of different diseases • Knowledge of different diseases • Trauma • Personal Development Portfolio and continuing professional development • Principles of major incident management • Safeguarding of an infant, child or young person with complex healthcare needs

Theme	Complex care	
	<ul style="list-style-type: none"> • Risk identification • Evidence-based assessment • Positive risk-taking • Medicine management including: Patient Group Directives 	<ul style="list-style-type: none"> • Role of the nurse and other members of the multi-disciplinary team

Table 6: Content analysis for curricula of University 3/Module 2: Complex Care

Appendices

Theme	End of Life and Palliative Care in Children		
Main category	Care		
Sub-category	<ul style="list-style-type: none"> • End of life care • Palliative care • Best practice • Care planning • Delivery of care for clients and their carers/families • Care team • Advanced care planning • Caring values and beliefs • Multi-disciplinary team • Last office • Death and dying care • Loss, grief and bereavement care • Therapeutic use of self • Variety of settings: hospice, hospital, home • Care team • Psychosocial support • Self-care and management 		
Codes	Assessment		Knowledge
Sub-codes	Holistic assessment	<ul style="list-style-type: none"> • Psychosocial needs • Spiritual needs • Sensitive patient and relative needs • Communication 	<ul style="list-style-type: none"> • Symptom pattern and recognition • Death and dying at different stages of life • Loss, grief and bereavement • Illness trajectories and journey • Unexpected death • Ethical, legal, policy and professional issues on the delivery of nursing care • Organ donation • Nursing role

Table 7: Content analysis for curricula of University 3/Module 3: End of Life and Palliative Care

Theme	Nursing Practice				
Main category	Nursing care			Professional values	Recognition of needs
Sub-category	Skills	Practice	Communication	<ul style="list-style-type: none"> • Evidence practice • Ethical issues and consideration • Structured reflection • Clinical supervision • Therapeutic use of self and therapeutic presence • Legal and ethical framework • Local, national and international guidelines • Clinical governance and clinical effectiveness • Responding to feedback and complaints 	<ul style="list-style-type: none"> • Coexisting physical needs • Socioeconomic needs • Health needs • Health education needs • Immediate needs • Essential needs • Psychosocial well-being needs
Codes	<ul style="list-style-type: none"> • Clinical risk assessment • Essential nursing skills • Research evidence • Nursing assessment skills • Problem-solving approaches • Self-care • Teamwork • Pain assessment 	<ul style="list-style-type: none"> • Research evidence • Holistic and structured approach • Lay and professional care • Patient safety • Infection control • Holistic and structured approach • Assessment, planning, 	<ul style="list-style-type: none"> • Building relationships • Experience of service users 		

Appendices

Theme	Nursing Practice				
		implementation and evaluation of care <ul style="list-style-type: none"> • Risk to self and others • Continence management • Nutrition • Fluid and hydration 			

Table 8: Content analysis for curricula of University 3/Module 4: Principles of Nursing Practice

Appendix 3.7: Differences between Audit and Research

Differences	
Research	Audit
To establish the effectiveness of practice (College of Occupational Therapists 1998)	To evaluate how local practice close to the best practice (College of Occupational Therapists 1998)
Process is linear which starts with the question and ends with findings (Closs & Cheater 1996)	Process is cyclical, repeated until a required standard is reached (Closs & Cheater 1996)
Produce new knowledge and testing or generating theory (Closs & Cheater 1996)	Followed by local needs/problems or interest (Closs & Cheater 1996)
May be based on randomised sampling (Closs & Cheater 1996)	Usually uses small and local sample (Closs & Cheater 1996)
Collects new and detailed data (Smith 1992; Closs & Cheater 1996)	Mainly uses the existing data (Smith 1992; Closs & Cheater 1996; Gould 2008)
The result can be generalised (Closs & Cheater 1996; Gould 2008)	It is an investigation of local interest which cannot be generalised (Closs & Cheater 1996; Gould 2008)
Research findings takes many years to change practice (Closs & Cheater 1996)	Can make changes in practice shortly after finishing (Closs & Cheater 1996)
Collects complex data (Smith 1992)	Applies routine data collection (Smith 1992)
Findings should be disseminated broadly (Closs & Cheater 1996)	Findings usually used locally (Closs & Cheater 1996)
Defines the best practice (Smith 1992)	Objectives directly rely on improving services (Smith 1992)
Concerned about validity and reliability (Closs & Cheater 1996)	The rigour of the audit is important (Closs & Cheater 1996)
Ethics committee approval must be obtained (College of Occupational Therapists 1998)	Ethical approval is not normally required (College of Occupational Therapists 1998)
Confidentiality is an important issue (College of Occupational Therapists 1998)	Ethical practice is an accepted part of audit
Seeks to approve or disapprove a theory (College of Occupational Therapists 1998)	Seeks to achieve standards or guidelines

Appendices

Similarities
<ol style="list-style-type: none">1. Starting with a question (Wade 2005)2. Providing a basis for good quality of care (Black 1992)3. Providing an answer for making changes or influencing practice (Wade 2005)4. Collecting formal data on patients (Wade 2005)5. Using an appropriate design and method (Smith 1992; Wade 2005)7. A systemic scientific investigation (Closs & Cheater 1996)

Source: (Smith 1992; Closs & Cheater 1996; Gould 2008)

Appendix 3.8: Are the Children's and Young People's Units Disabled Friendly? A Preliminary Inquiry

Ilkhani, M., Battrick, C., Glasper, G., Jarrett, N.

Abstract

A pilot audit using a discrete aspect of a new children's and young people nursing audit tool was undertaken within a children's outpatient department at a NHS Foundation Trust prior to a full audit of compliance to child health policy related to disability. The aspect of the audit tool pertinent to disability consists of eleven individual sections utilising a 0-10 grading scale. The pilot results demonstrate that the Trust is making good efforts in the areas of multi-agency team work, decision-making, and assessment. However, there are some aspects of policy standards that need more careful consideration, such as communication, equipment, training, and delivery of information.

Key words: disabled children, care, health policy standards, benchmarks, compliance

Introduction

In the NHS, providers of services and those who deliver care to disabled children, in particular those with complex needs must measure and demonstrate the effectiveness of the services they are providing (Milner et al. 1996; The children's Trust Tadworth , Every Disabled Child Matters 2011). This audit was precipitated following dialogue with a parent of a disabled child regarding the standards of inpatient care their child received whilst in hospital. An audit was planned as part of a service evaluation related to the care and welfare of families with children and young people with disabilities who use the children's ward within a NHS Foundation Trust. This paper presents the results of a pilot preliminary audit of a NHS Foundation Trust in the south of England.

Developing the Audit Tool

The audit tool is a discrete aspect of the Association of Chief Children Nurses (ACCN) generic health care audit tool. The Association of Chief Children's Nurses is a group of senior nurses representing children's and young people services. The Compliance Assessment Instrument for this individual audit tool was configured from a comprehensive range of policy documents:

- Aiming High for Disabled Children: Best Practice to Common Practice (DH 2009)
- Aiming High for Disabled Children: Better Support for Families (HM Treasury, DfES 2007)
- Better Care: Better Lives (DH 2008)
- Disabled Child Standard, National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with Complex Health Needs (DH 2004)

Appendices

- Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs (DH 2007)
- Together from the Start-Practical Guidance for Professionals Working with Disabled Children (birth to third birthday) and Their Families (DfES, DH 2003)
- Valuing People: a new Strategy for Learning Disability for the 21st Century (DH 2001b)
- Valuing People Now: a New Three-Year Strategy for People with Learning Disabilities (DH 2009)

The Disability Audit Compliance Assessment Instrument comprises of 11 individual sections reflecting all aspects of the policies related to care delivery to disabled children and their families (Table 1).The ACCN as an organisation is attempting to standardise audits to facilitate metricisation of benchmarks, and comparability of data to help member hospital partners more effectively benchmark. Each section is made up of a number of specific benchmarks metricised to facilitate scores which make up a total of 10, which indicates full compliance for the section being audited. Specific benchmarks are weighted and can attract differing scores (Table 2).

- | |
|--|
| <ol style="list-style-type: none">1. Communication2. Training3. Multi-agency team work4. Information5. Support services6. Decision making7. Key workers*8. Assessments9. Equipment10. Palliative care *11. Bereavement |
|--|

Table 1. Sections of the Disability Audit Compliance Assessment Instrument
(* indicates sections of the audit instrument not relevant for this pilot audit)

The key workers and palliative care sections were not applicable for this pilot study due to the short duration of visits for children with disabilities within this department; therefore, this current paper considers nine sections.

Care Quality Commission Prompts	Evidence
Multi-agency team working	<ul style="list-style-type: none"> • Evidence of multidisciplinary assessment tools for children with disabilities. Score 2 • A lead has been appointed for transition. Score 2 • Multidisciplinary support team with experience of dealing with challenging behaviour available where appropriate. Score 1 • The service has procedures to manage children with disabilities whose behaviour presents challenges. Score 1 • Multiagency involvement in the children with disabilities transition to adult services strategy. Score 1 • Evidence of co-ordination between the relevant agencies to transition children with disabilities to adult services with a formal health care plan. Score 2 • A family forum has been established (community setting).Score 1
Total	

Table 2. One Section of Disability Audit Tool

N.B. key informants providing evidence to complete the audit may award themselves benchmark scores of less than 1 (e.g. 0.5). Maximum scores of up to 4 are achievable for some sections.

Aim

The aim of this pilot audit was to identify areas of optimum and less than optimum compliance to best practice benchmarks relating to the care delivery for disabled children and young people with complex health needs and their families within a children’s outpatient department.

Process and Methodology

Approval for the audit exercise was given by the clinical governance department of the children’s division of the hospital (in the North America, outpatient departments are referred to as ambulatory care units). Arrangements were made with the Matron to visit the children’s outpatient department and to complete the benchmarking exercise over one day. The evidence for the audit comprised observation of the unit, verbal information from staff and written information. This was collected, documented, and verified in terms of the range of areas scored against the best practice benchmarks. Rawlins and Hine (2002) suggest that Bar charts are the most common format for audit presentation. The findings are presented here with Bar charts generated using a proprietary data analysis package.

Appendices

Summary and Discussion of Results

1. Communication (score range 0–10)

In this element of the audit, staff were questioned on a range of evidence criteria related to communication.

The White paper 'Valuing People Now: A New three year strategy for people with intellectual disabilities' (DH 2009) provides a benchmark for avoiding discrimination in minority ethnic communities with learning disabilities. This pilot audit suggests there is a lack of advocacy support for minority ethnic communities across the children's outpatient department (Figure 1). However, the dialogue related to children with disabilities across the service provision met the criteria satisfactorily. Wall mounted posters, related to children with disabilities were used around the children's outpatient department. There was tangible evidence of the development of appropriate communication systems for children with little or no verbal communication. However, the main method of communication was based on the verbal mode. Reichle and Sigafoos (1991) and Charlop and Haymes (1994) support the use of alternative interventions, such as sign language, picture-point systems, and electronic devices to assist disabled children to increase their speech ability and communication skills (Durand & Carr 1991). The importance of developing and using appropriate communication systems where people have little or no verbal communication is emphasised by the policies "The Aiming High for Disabled Children: Better Support for Families" policy (HM Treasury, DfES 2007), and the White Paper "Valuing People Now: A New three year strategy for people with intellectual disabilities" (DH 2009).

Emerson and Baines (2010) highlight that limited communication skills among health professionals may reduce the capability of staff to effectively identify the health needs of people with disabilities. Within this pilot audit, only a small number of staff were aware of Makaton, which is a language programme designed for individuals who cannot communicate efficiently by speaking (Beukelman and Mirenda, 2005). Therefore, the NHS Foundation Trust needs to review how to develop nursing skills in terms of communication with disabled children who have not developed speech.

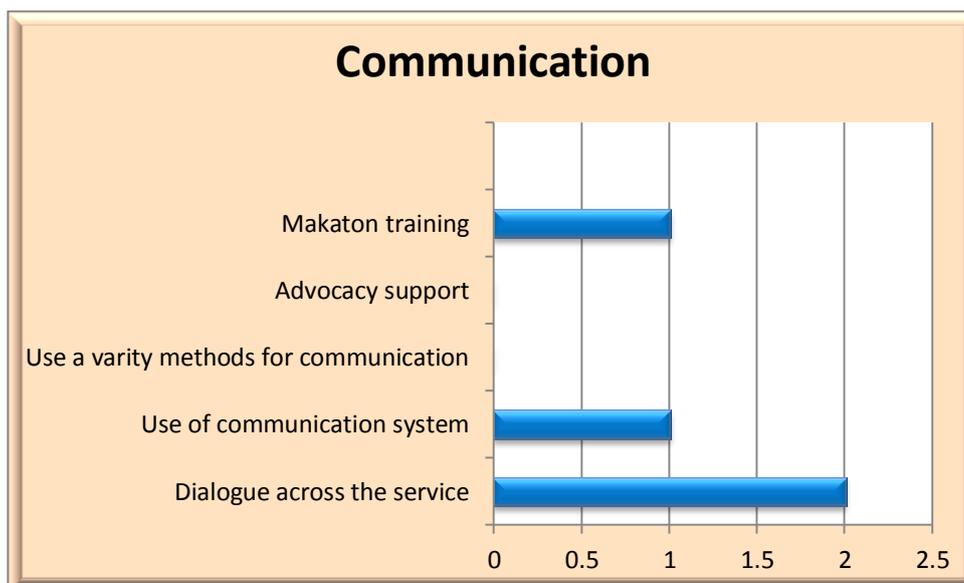


Figure 1. Evidence scores for communication

2. Training (score range 0–10)

In this element of the pilot audit, staff were questioned on a range of evidence criteria pertinent to training (Figure 2).

The children’s outpatient department of the NHS Foundation Trust does not have, as is best practice, a joint multi-agency training initiative between health, education and social services. However, there was evidence of customer care training related to the care of children with autism, and the use of experts to communicate with disabled children during some procedures, such as blood tests. The White Paper “Valuing People Now: A New three year strategy for people with intellectual disabilities” (DH 2009) emphasizes the importance of joint planning and working together. Watson et al. (2002a) suggests that joined-up approaches for professionals have a positive impact on the support needs of disabled children and their families, facilitates the liaison and coordination between different service providers (Abbott et al. 2005), and improves the skills of health staff relative to care delivery to disabled children (Banks & Kane 2004). The joint agency training of staff did not meet the benchmarked criteria and therefore, the Trust post audit action plans will need to address this deficiency.

The Disabled Child Standard, National Service Framework (Department of Health 2004) states that children with learning disabilities have higher levels of unmet needs than their healthy counterparts; therefore, some of them require more nursing support. Additionally, the White Paper “Valuing People: A New Strategy for Learning Disability for the 21st Century” (DH 2009) emphasis the importance of health care professionals having competent skills and being well-trained in working with people with learning disabilities. The provision of staff training across the department in some areas, such

Appendices

as communication and management of challenging behaviour, did not meet many of the benchmarked criteria. However, there is good evidence that, during induction, newly qualified nurses receive sufficient information related to care of disabled children.

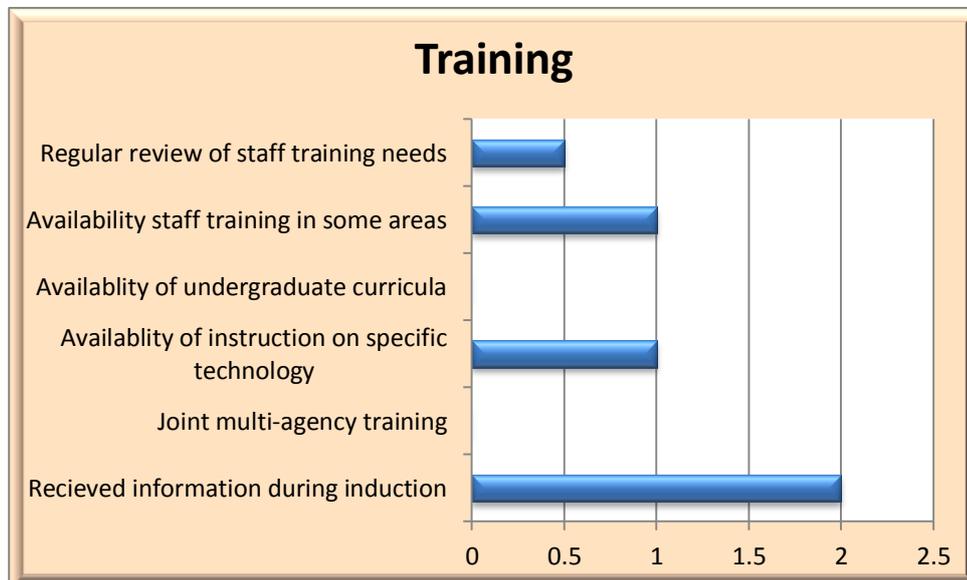


Figure 2. Evidence scores for training

3. Multi-Agency Team Work (score range 0–10)

This aspect of the audit seeks to ascertain whether multi-agency team work was established throughout the children’s wards of the NHS Foundation Trust.

Although the standard for multi-agency team work judged by the audit tool is generally satisfactory throughout the outpatient children’s department, there are a number of issues which compromise the achievement of best practice, including: dealing with disabled children who have challenging behaviour in terms of multidisciplinary assessment tools, support teams and availability of procedures to manage multi-agency work (Figure 3). The British Department of Health (DH 2007) suggests that all staff within service provision need to understand the causes of challenging behaviour. This is reinforced in the White Paper ‘Valuing People: A New Strategy for Learning Disability for the 21st Century’(DH 2001 b).

Collins (2008) highlights that the transitions agenda is a prominent issue throughout the White Paper “Valuing People: A New Strategy for Learning Disability for the 21st Century”(DH 2001 b). Additionally, the “Aiming High for Disabled Children: Better Support for Families” policy (HM Treasury, DfES 2007) emphasises that a smooth transition for disabled children to adulthood results in decreasing insecurity, increasing awareness of available opportunities, and overcoming barriers, as well as giving an opportunity to parents with disabled children to express their perspective on

the services they receive. The provision of the transition service across the department satisfactorily meets the criteria as judged by the audit tool.

In addition, in order to optimise the potential of disabled young people, the Disabled Child Standard, National Service Framework (DH 2004) makes strong recommendations for improving service provision for disabled children and their families, as well as meeting their wishes and aspirations. The “Aiming High for Disabled Children: Better Support for Families” policy (HM Treasury, DfES 2007) provides a benchmark for family forums as an opportunity to gain awareness of the perspective of parents with disabled children related to service provision. The current pilot audit revealed that the family forum has still not been fully established across the children’s outpatient department. There is, however, good evidence of feedback from families.

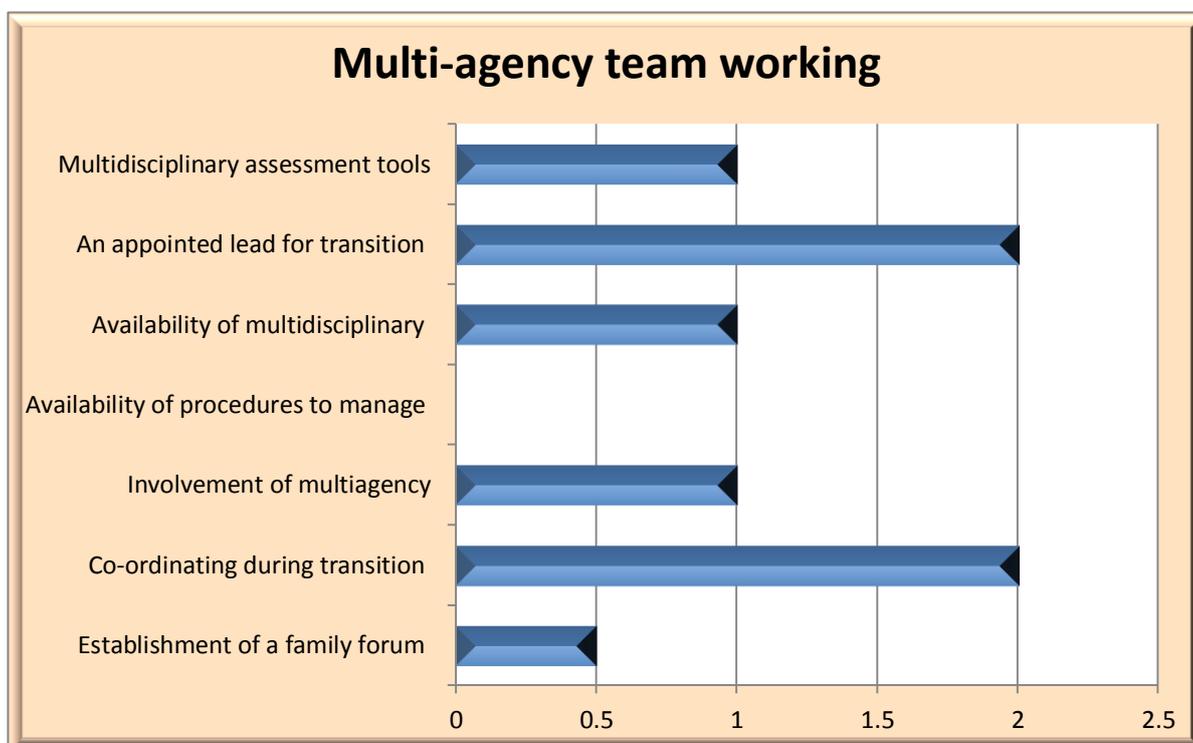


Figure 3. Evidence scores for multi-agency team work

Appendices

4. Information (score range 0–10)

This part of the audit seeks information about care delivery to disabled children and their families within the children’s wards of the NHS Foundation Trust

The White Paper “Valuing People: A New Strategy for Learning Disability for the 21st Century” (DH 2001b) emphasises the importance of giving culturally and age appropriate information to disabled children and their families in a sensitive, timely and skillful manner as a part of high quality care standards. Additionally, “Together from the Start-Practical Guidance” (DfES,DH 2003) states that parents have a right to access comprehensive, accurate and relevant information about their children and their service provision. The provision of culturally appropriate information in multimedia formats for families and their children with disabilities falls short of best practice guidelines across the department (Figure 4).

The “Better Care: Better Lives” policy (DH 2008) suggested that the process of transition should be age and developmentally appropriate, planned early and frequently reviewed. The transition pack and the information given to families within the outpatient department satisfactorily met the standards. There is good evidence of a transition plan package between paediatric and adult services within this area.

The issue of fully instructed family carers was generally non compliant to the Carers Act 2007 and the White Paper “Valuing People: A New Strategy for Learning Disability for the 21st Century” (DH 2001b). The White Paper (Department of Health 2009) which highlighted the importance of supporting and meeting carers’ needs and providing training resources for them (Collins 2008). However, a booklet for the carers service was available within the outpatient department.

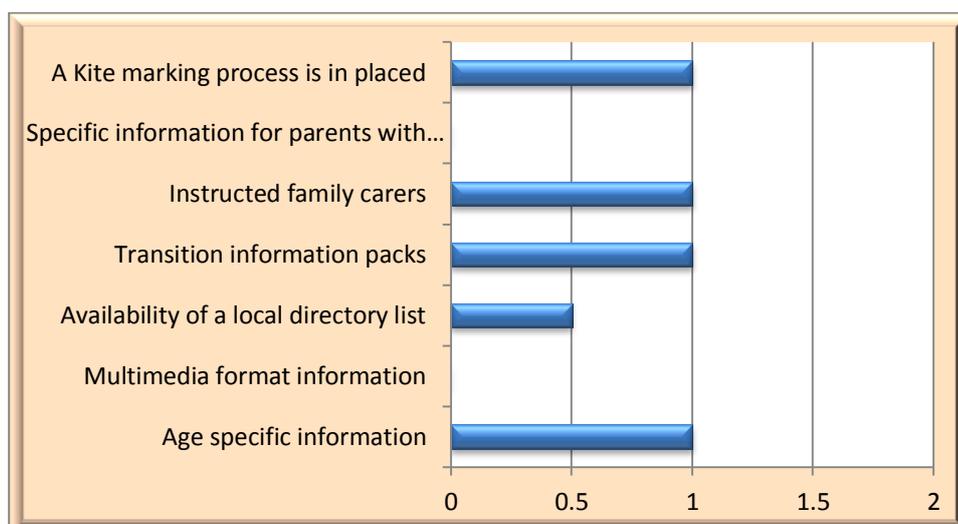


Figure 4. Evidence scores for information

5. Support Services (score range 0–10)

This aspect of the audit examines the availability of support services for children with disabilities and their families.

The highest concern within this section of the pilot audit was related to the lack of access to free parking (figure 5). Clarke (2006) reported that lack of disability services such as parking is a barrier for families to access mainstream facilities and might socially exclude disabled children and their families. Additionally, access to a blue parking badge for families of children with disabilities as a facility is addressed by “Together from the Start - Practical Guidance” (DfES, DH 2003) .

The standard 8 within the “Getting the Right Start Framework” (DH 2003) highly recommends that disabled children and young people should receive coordinated, high quality family-centred care based on their assessed needs. The availability of family support services appears not to be fully embedded within practice in the outpatient department. However, there are good examples of an information booklet related to family support services available throughout the Trust.

The “Aiming High for Disabled Children: Better Support for Families” policy (HM Treasury, DfES 2007) proposes short breaks to give families respite from caring and give them a normal life (Langer et al. 2010), help improve relationships between parents (Stalker & Robinson 1994), decrease parents’ stress (Cowen & Reed 2002a), and provide new experiences of relationships, environments, and social activities for disabled children (Benson & Dewey 2008; Robertson et al. 2010a). Short breaks may also help to prevent hospital readmission and therefore provide financial benefits for the NHS (Social Care Institute of Excellence 2008). The current pilot audit revealed that this standard needs to be raised further as at present the coordination of respite services is inadequate.

The sections related to the hospital liaising with and contributing to the Primary Care Trust early support programme was not applicable for this department.

Appendices

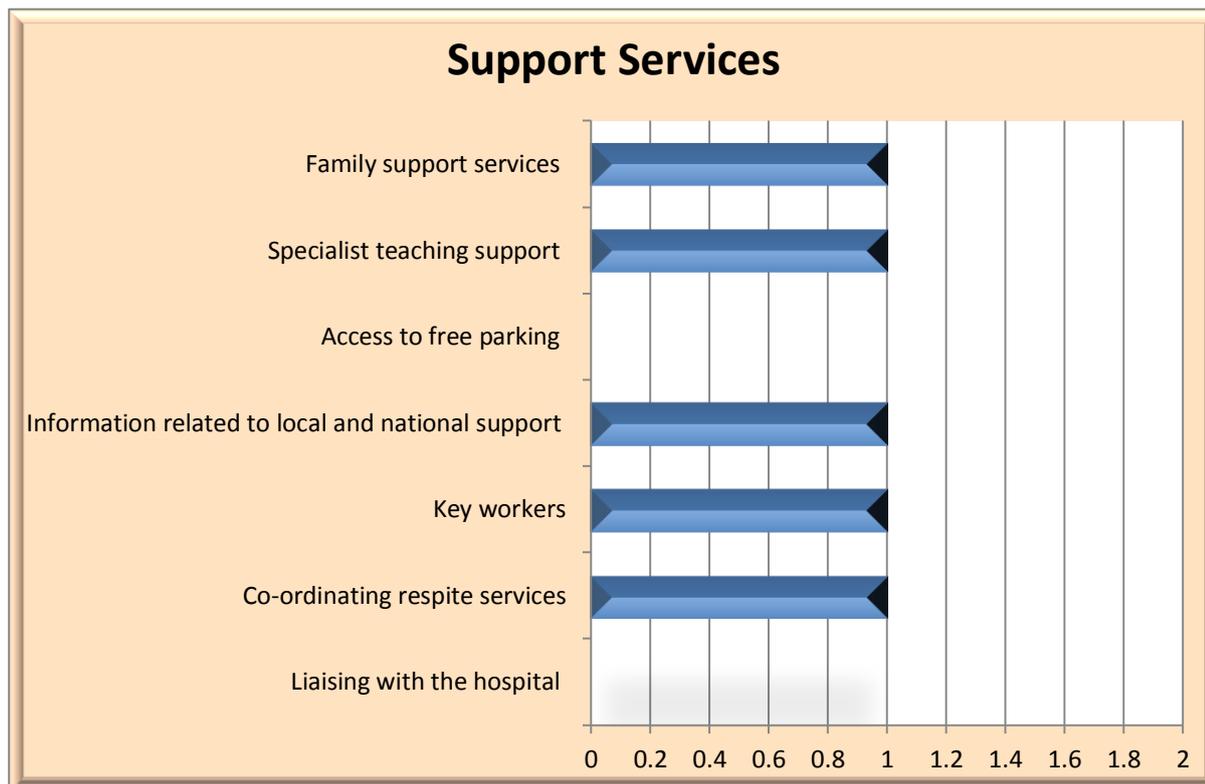


Figure 5. Evidence scores for support services

6. Decision Making (score range 0–10)

This element of the audit concentrated on the extent to which children with disabilities and their families are involved with decision making related to their treatment and care.

A person-centred approach for people with learning disabilities is at the heart of the White Paper “Valuing People: A New Strategy for Learning Disability for the 21st Century”(DH 2001b) which highlights that people with learning disabilities should be completely and actively involved in all decisions which impact on their lives. Additionally, the “Aiming High for Disabled Children: Better Support for Families” policy (HM Treasury, DfES 2007) argues that the shaping of services by disabled children, young people and their parents improves the outcomes of care and meeting their needs. This current pilot audit revealed that the involvement of children with disabilities and their families in decision-making is generally at a low level of development (Figure 6). The person-centered philosophy addressed by the White Paper “Valuing People: A New Strategy for Learning Disability for the 21st Century” (DH 2001b) and “Together From the Start-Practical Guidance for professionals working with disabled children” (DfES, DH 2003) suggests that professionals should be working in partnership with families and disabled children and involving them in any decision-making process that impacts on their provision of support. The views of children with

disabilities were taken into account during every decision-making process throughout the department; thus, this segment met the required standards.

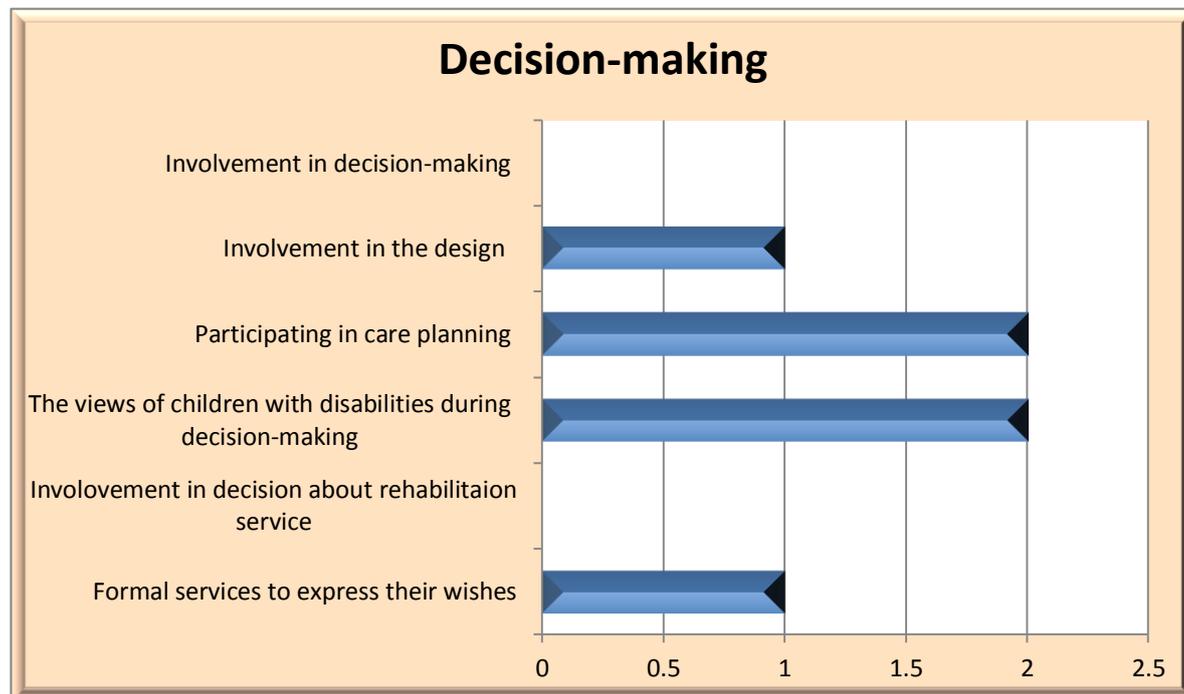


Figure 6. Evidence scores for decision making

7. Assessments (score range 0–10)

This part of the audit seeks to investigate how multidisciplinary teams collaborate to utilize and record the common assessment framework. Accessibility to mental health services for disabled children is not investigated in the audit tool.

Multidisciplinary assessment and multidisciplinary common report fail to meet the minimum standards stipulated within the “Disabled Child Standard, National Service Framework” (DH, 2004), and the “Best Value Review Report” which suggest that children and young people with a disability and their families should be involved throughout the assessment and planning of care (Peterborough City Council 2005). The Guideline “Carer’s Assessment” is available via the NHS choices Website. However, the common record for all professional better to be considered by the Trust which could help to enhance care delivery to disabled children.

A major concern of the White Paper “Every Child Matters: Change for Children” (2006) relates to improving working together and information sharing which lead to improved outcomes for children and their families (DH 2004a). Therefore, this White Paper proposed the Common Assessment Form (CAF) to reduce the number and duration of different assessment processes, enhance the quality and consistency of referrals between agencies, and promote the appropriate sharing of information. The audited

Appendices

department generally demonstrated good compliance with the Common Assessment Form, collaboration between all the professionals during the assessment process, and accessibility to mental health services (Figure 7).

Walsh (1998) believes that multidisciplinary record-keeping can lead to an improvement in the quality of documentation and interdisciplinary communication. The issue of common records across the Trust falls short of best practice guidelines.

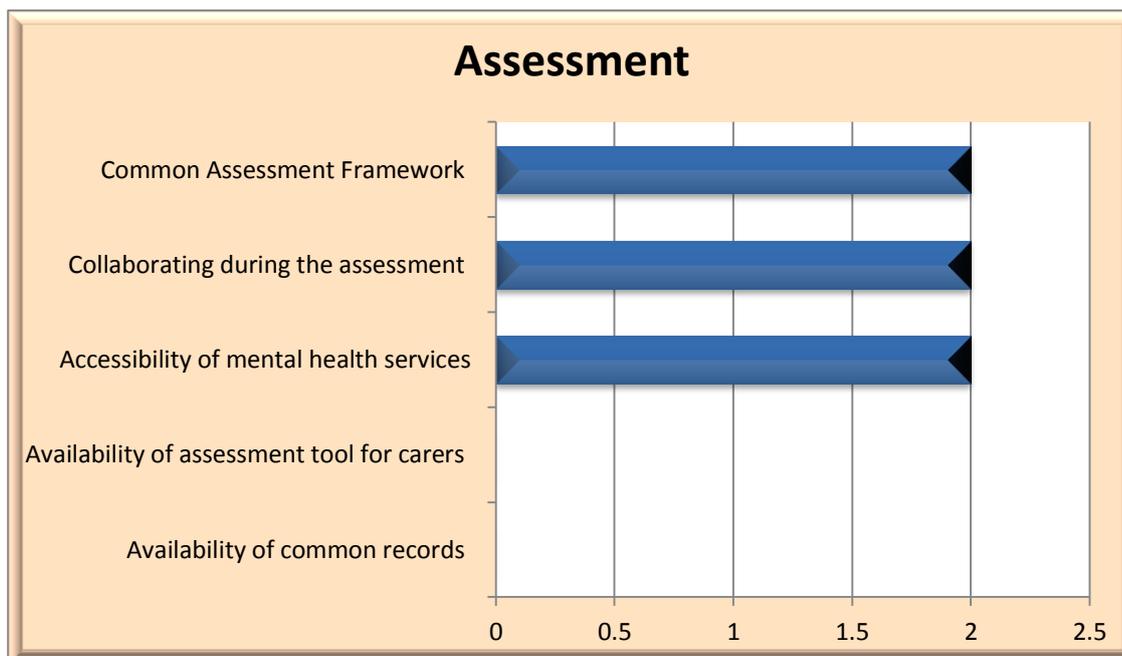


Figure 7. Evidence scores for Assessments

8. Equipment (score range 0–10)

This component of the audit seeks to ascertain whether children with disabilities can access appropriate equipment and how the equipment was accessed.

The “Aiming High for Disabled Children: Better Support for Families” policy (HM Treasury, DfES 2007) focuses on the assessment and provision of equipment and wheelchair services for disabled children which might help to improve the efficiency of service provision and decrease waiting times. Within this audit, the lack of access to special equipment and provision of equipment before discharge across the children’s outpatient department were clearly tangible. The audit shows that only one wheelchair is available for disabled children throughout the Trust (figure 8).

There are some encouraging examples of good practice related to appropriate, safe and age-specific equipment for children with disabilities, and the assessment for technology, equipment or wheelchair support.

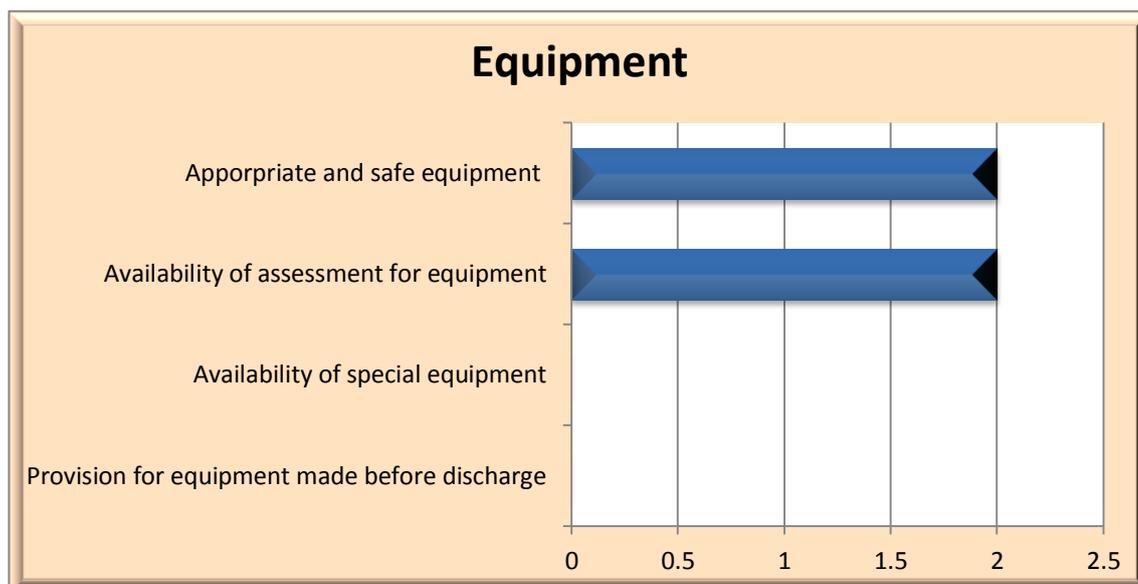


Figure 8. Evidence scores for equipment

9. Bereavement (score range 0–10)

This part of the audit examined bereavement support for families of disabled children. The “Better Care: Better Lives” best practice Guidance (DH 2008) places well-managed and well-supported end-of-life care as a key component of palliative care services. The areas of psychological, spiritual and bereavement support to disabled children and their families meet the required standards across the children’s outpatient department. A booklet related to bereavement care services was accessible throughout the Trust. Conversely, maintaining contact with families following bereavement requires further attention (Figure 9). Contact with families is a part of delivering a high standard of care to disabled children and their families.

NB: The “Care of bereaved children and young people” and “the effect on families of children in the end of life care plan” segments were not applicable for the department participating in the pilot audit.

Appendices

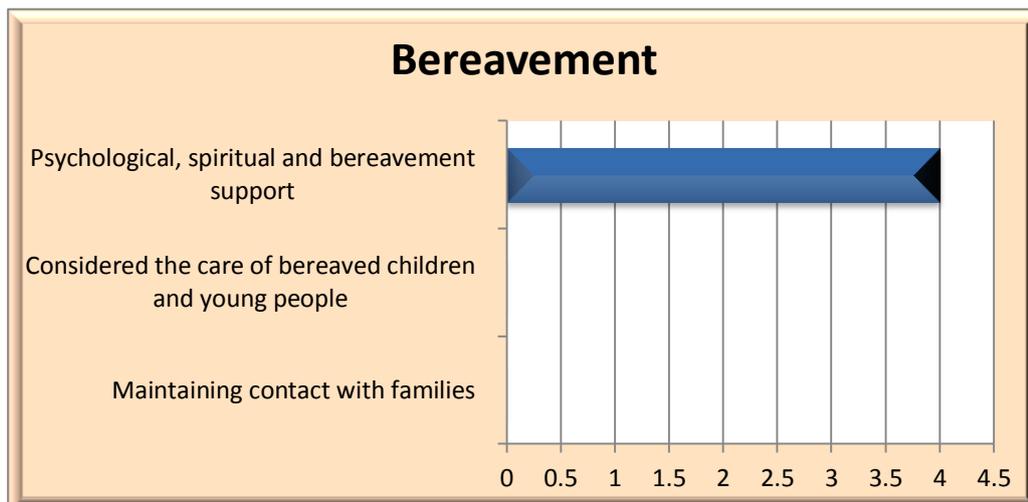


Figure 9. Evidence scores for bereavement

Limitations

According to Crossan et al. (2004) and Irvine and Irvine (1991) the main point of an audit is identifying the need for changes. The biggest challenge pertaining to this pilot audit was that the auditor was not able to complete the audit cycle which is emphasised by (Sealey 1999), although the auditor prepared and submitted a report with detailed data analysis to the Trust. The Trust senior clinicians will be able to address the problems identified as part of their long term plans for improving facilities for disabled children and those with complex health needs.

Conclusion

A pilot audit was undertaken within a children's outpatient department prior to a full audit of compliance to disability benchmarks of care.

The pilot audit has shown that the audit tool is sensitive enough to gather data on disabled provision in children's wards. The audit sections on communication, training, equipment and bereavement are generally poor and fail to meet minimum standards (Figure 10). Some fields, such as multi-agency support services, decision-making and assessments require improvement. The children's outpatient department generally performed well. In order to meet the needs of disabled children and their families whilst in hospital, improving the areas found to be lacking or poor in the pilot audit is recommended. As this audit was only based on the Audit Compliance Assessment Instrument which takes evidence from staff, further studies on the perspectives of children with disabilities and their families need to be planned in the future. The results of the full audit of compliance to childhood disabilities policy will be presented in a subsequent paper.

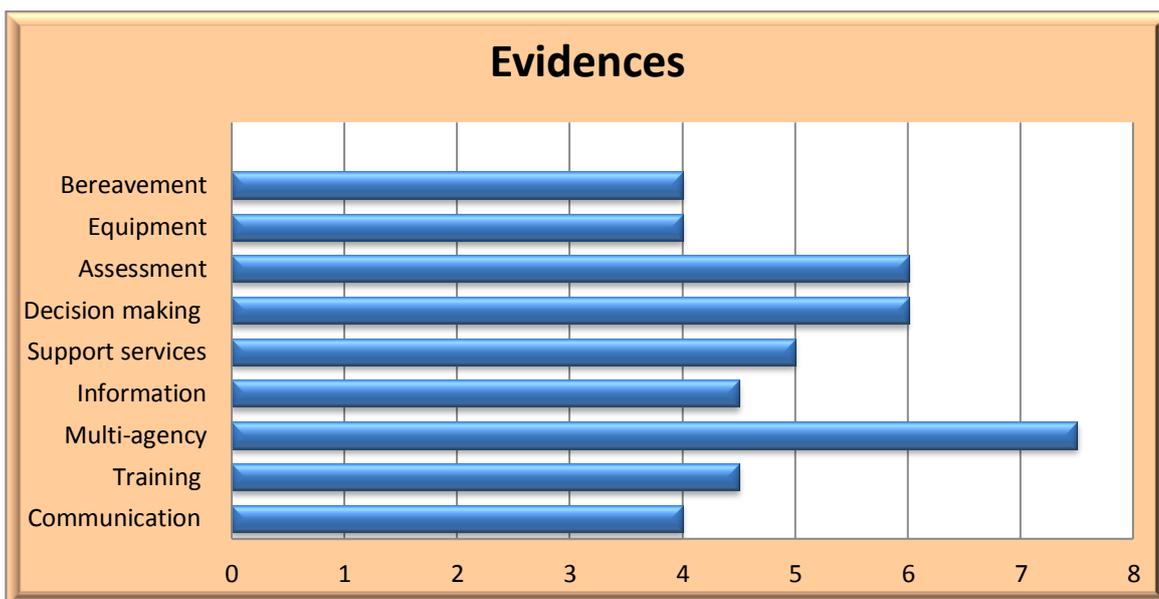


Figure 10. Comparison of the total scores among different sections (possible score range 0–10)

Adopted from: Ilkhani et al. (2012)

Appendices

Appendix 3.9: Care Quality Commission Essential Standards of Quality and Safety – Compliance Assessment Form

Care Quality Commission Prompts	Assessment of Compliance				Benchmark Criteria	Score	Field Notes
	Competent	Minor Concern	Moderate Concern	Major Concern			
Communication:					<ul style="list-style-type: none"> • Dialogue pertinent to children with disabilities is tangible across all parts of the service provision. Score 2 • Evidence of developing and using appropriate communication system where children with disabilities have little or no verbal communication. Score 2 • Members of staff directly communicate with non-verbal children with disabilities using a variety of methods including sensory equipment/facility. Score 2 • Children with learning and other disabilities from minority ethnic communities have access to advocacy support. Score 2 • Staff have access to Makaton and other similar communication training. Score 2 		
Training:					<ul style="list-style-type: none"> • New staff receive information pertinent to children with disabilities during induction. Score 2 • Joint multi-agency training initiative between health, education and social services staff has been implemented. Score 1 • Specific technology pertinent to the care of children with disabilities is available. Score 2 • Specific instruction in the care of children with disabilities is available in the undergraduate curriculum. Score 2 		

Care Quality Commission Prompts	Assessment of Compliance				Benchmark Criteria	Score	Field Notes
	Competent	Minor Concern	Moderate Concern	Major Concern			
					<ul style="list-style-type: none"> Staff training relating to communication, interpersonal skills and behavioural management for working with children with disabilities is available through in-house training and annual updating. Score 2 There is a regular review of staff training needs relating to the care of children with disabilities. Score 1 		
Multi-agency teamwork:					<ul style="list-style-type: none"> Evidence of multi-disciplinary assessment tools for children with disabilities. Score 2 A lead has been appointed for transition. Score 2 Multi-disciplinary support team with experience of dealing with challenging behaviour available where appropriate. Score 1 The service has procedures to manage children with disabilities whose behaviour presents challenges. Score 1 Multi-agency involvement in the children with disabilities transition to adult services strategy. Score 1 Evidence of coordination between the relevant agencies to transition children with disabilities to adult services with a formal healthcare plan. Score 2 A family forum has been established (community setting). Score 1 		
Information:					<ul style="list-style-type: none"> Age-specific and focused information is available for children with disabilities and their families (including siblings). Score 2 Multimedia format information is available to families and 		

Appendices

Care Quality Commission Prompts	Assessment of Compliance				Benchmark Criteria	Score	Field Notes
	Competent	Minor Concern	Moderate Concern	Major Concern			
					<p>children with disabilities. Score 2</p> <ul style="list-style-type: none"> • There is a clear local directory listing relevant specialist and mainstream services for families with children with disabilities. Score 1 • Transition information packs have been developed for specific groups of children with disabilities. Score 1 • Family carers are fully instructed in the provision of care. Score 1 • Specific information given to the parents of children with disabilities is culturally appropriate and available or can be obtained (within 24 hours) in different languages. Score 1 • A Kite marking process is in place to ensure good quality, consistent, and up-to-date information is given to children with disabilities and their families. Score 2 		
Support services:					<ul style="list-style-type: none"> • Family support services for children and young people with a disability and their families are available. Score 2 • Specialist teaching support is available to children with disabilities. Score 1 • Families of children who have a disability have access to free parking. Score 2 • Families of children with disabilities are given information about local and national support groups. Score 1 • Key workers contribute to children with disabilities parent support groups. Score 1 • Coordinated services for helping families to access respite care are available. Score 1 • The hospital liaises with and contributes to Primary Care 		

Care Quality Commission Prompts	Assessment of Compliance				Benchmark Criteria	Score	Field Notes
	Competent	Minor Concern	Moderate Concern	Major Concern			
					Trust (this term will change soon) early support programme (ESP). Score 2		
Decision-making:					<ul style="list-style-type: none"> • Children with disabilities and their families are involved in decisions about service planning, commissioning, innovation and unit design. Score 2 • Families of children with disabilities are involved in the design and delivery of any care packages. Score 1 • Children with disabilities and their families participate in care planning and treatment decision-making interventions. Score 2 • The views of children with disabilities are taken into account during all decision-making processes. Score 2 • Children with disabilities and their families access and are involved in decisions about rehabilitation services. Score 1 • Formal services exist for children with disabilities and their families to express their wishes, choices and aspirations to the organisation. Score 2 		

Appendices

Care Quality Commission Prompts	Assessment of Compliance				Benchmark Criteria	Score	Field Notes
	Competent	Minor Concern	Moderate Concern	Major Concern			
Key workers:					<ul style="list-style-type: none"> • Children with disabilities are allocated a key worker during hospital admission and this is documented. Score 2 • The key worker is identified to the family during the admission assessment. Score 2 • The parents/carers are fully informed of the role of the key worker. Score 2 • The role of the key workers is fully understood by all members of the multi-disciplinary team. Score 2 • The key workers have the necessary training competencies and experiences to work with children with disabilities and their families. Score 2 		
Assessments:					<ul style="list-style-type: none"> • The clinical area utilises the Common Assessment Framework. Score 2 • All professionals work in collaboration during the assessment process. Score 2 • Children with disabilities and their families can access child and adolescent mental health services. Score 2 • Special assessment tools are available for carers. Score 2 • A common format/multi-disciplinary records are used when the child or young person is admitted to hospital. Score 2 		
Equipment:					<ul style="list-style-type: none"> • Equipment used for children with disabilities is appropriate, safe, and age specific. Score 4 • Children with disabilities undergo assessment for technology/equipment/wheelchair support (hospital or community). Score 2 • Special equipment or assistive technology for children with disabilities is available. Score 2 		

Care Quality Commission Prompts	Assessment of Compliance				Benchmark Criteria	Score	Field Notes
	Competent	Minor Concern	Moderate Concern	Major Concern			
					<ul style="list-style-type: none"> The provision of equipment is made before the children with disabilities are discharged. Score 2 		
Palliative care:					<ul style="list-style-type: none"> Care delivered by staff skilled in children’s palliative care management. Score 2 Further support is available to families with children with disabilities who require palliative care. Score 2 Good links are established with local children’s hospices. Score 2 There is a formal plan of care (Advanced Care Plans) designed with all relevant agencies for children with disabilities and their families who require palliative care. Score 2 The environment of care is conducive to the dying child. Score 2 		
Bereavement:					<ul style="list-style-type: none"> Psychological, spiritual and bereavement support for families, siblings and carers is available during end of life care. Score 4 The care of bereaved C&YP and the effect on families of children with disabilities is considered in the end of life care plan. Score 4 Staff (hospital or community) maintain contact with families after the death of a child. Score 2 		

Appendices

Appendix 4.1: Effective Communication Thematic Chart

Key Issue	Sub-Component	NGT		Content Analysis	Audit
		RNs	HCSWs		
Effective Communication 1	Promoting communication 1.1	<ul style="list-style-type: none"> • Building up trust with child and family (S1) • Building a rapport or relationship (S3) • Interacting with each individual child (S2) • Reassuring parents (S11) • A smile (S6) • Delivering human touches (S14) • Promoting communication (S15) 	<ul style="list-style-type: none"> • Being able to talk about personal interests and individual lives (S4) • Forming relationships with the families (S30) • Introducing the child to other patients and seeing them enjoy their company (S20) • Being there to listen (S5) • Seeing them smile and laugh (S4) • Giving a hug to the child (S11) • Using special communication skills such as Makaton (S17) • Good communication 	<ul style="list-style-type: none"> • Within syllabus M2/U2: 'communication strategies and negotiating skills for advocacy' • Within syllabus M4/U3: 'building a relationship' • Syllabus M1/U3: as strategies for effective communication • As a primary attribute (85.7%) • Description from M1/U2: 'Essential communication and assessment skills' • Syllabus M1/U2: 'communication skills for partnership with families' 	<ul style="list-style-type: none"> • Advocacy support (mean=1.10/2) • Dialogue across the service (mean=1.40/2)

Key Issue	Sub-Component	NGT		Content Analysis	Audit
		RNs	HCSWs		
			(S1)	<ul style="list-style-type: none"> Frequency of communication terms (7 times/5M) 	
Effective communication 1	Communication Barriers 1.2	<ul style="list-style-type: none"> Communication barriers (S4) Colleagues not understanding the child's individual needs (S2) Talking over the child while on medical rounds (S26) More teaching on Makaton and signing (S34) Communication with IP team (S16) 	<ul style="list-style-type: none"> Difficulties in building rapport (S44) Not English-speaking/translating problems (S7) Disrespect shown to the child by others (S33) Patient e.g. teenager not wanting to speak to parent (S46) Lonely child with no visitors (S18) Parental dispute with care management (S15) Difficult aggressive parents (S6) Difficult 	<ul style="list-style-type: none"> Preverbal communication as a deficiency within modules (14.2%) Classified communication within the modules (0.00%) No mention of communication disorder (0.00%) 	<ul style="list-style-type: none"> Communication benchmark criteria (score=5.89/10) Not using a variety of methods for communication (mean=0.72/2) Makaton training (mean=1.27/2)

Appendices

Key Issue	Sub-Component	NGT		Content Analysis	Audit
		RNs	HCSWs		
			challenging rude visitors (S35)		

Appendix 4.2: Provision of Training Thematic Chart

Key Issue	Sub-Component	NGT		Content Analysis	Audit
		RNs	HCSWs		
Training 1	Improving Skill 1.1	<ul style="list-style-type: none"> Teaching skills and improving independence (S7) 	<ul style="list-style-type: none"> No training to use special equipment (S34) Care restrictions applied to the HCSWs (S4) 	<ul style="list-style-type: none"> Within module content: M1/U2: Developing essential communication and assessment skills Frequency of skill terms 15/5 Modules As a deficiency in modules: Developing knowledge and skills about caring for children with long term health needs (14.2%) As a deficiency in modules: Counselling skills (28.5%) Within syllabus content: Developing nursing assessment skills (M4/U4) Communication skills in complex care 	Training benchmark criteria (score=3.65/10)

Appendices

Key Issue	Sub-Component	NGT		Content Analysis	Audit
		RNs	HCSWs		
				(M2/U2) <ul style="list-style-type: none"> As aim: Develop skills to assess, plan, implement and evaluate care of children with disability in different care setting (M1/U2) Develop skills to act as an advocate to empower children and their families within the care setting 	
Training 1	Improving knowledge 1.2	<ul style="list-style-type: none"> I learn something new (S9) More teaching on Makaton and signing (S34) 	N/A	<ul style="list-style-type: none"> Within syllabus content: Continuing of education (M3/U3) As aim: Develop an understanding and knowledge of key concepts related to care of children with special health needs (M3/U3) Develop and apply biological/psycho/social base knowledge for caring for children with disabilities within 	N/A

Key Issue	Sub-Component	NGT		Content Analysis	Audit
		RNs	HCSWs		
				different setting (M1/U2) <ul style="list-style-type: none"> • Develop the knowledge to act as an advocate to empower children and their families within the care setting (M2/U2) • As brief description: Develop fundamental knowledge related to pathophysiological and psycho-social aspects of the chronically ill children with special healthcare • needs (M1/U2) • As a deficiency within modules: • Knowledge about the nature, frequency and causes of disability (28.5%) • Frequency terms within the modules: • Knowledge 7/5 Modules 	
Training 1	Not specified 1.3	<ul style="list-style-type: none"> • Privilege to learn from families (S22) 	N/A	N/A	<ul style="list-style-type: none"> • Staff communication training

Appendices

Key Issue	Sub-Component	NGT		Content Analysis	Audit
		RNs	HCSWs		
		<ul style="list-style-type: none"> Finding out more about day to day living (S8) Complexity of drugs regimes (S18) 			<p>(mean=1.27/2)</p> <ul style="list-style-type: none"> The necessary training for key workers (mean=0.80/2) The availability of staff training in some area (mean=0.41/2) Multi-agency training (mean=0.50/2) Annual up-dating staff training (mean=0.54/2)

Appendix 4.3: Provision of Equipment Chart

Key issue	Sub-component	NGT		Content Analysis	Audit
		RNs	HCSWs		
Equipment 1	Discharge plan 1.1	N/A	Slow unnecessary proceeding (e.g. getting funding for wheelchair) (S34)	N/A	Make the provision of equipment before the children with disabilities are discharged (mean=0.66/2)
	Special Equipment 1.2	Availability of appropriate equipment (S8)	Lack of equipment and resources (S1)	As deficiency within modules: Care needs of technology-dependent children and young people (14.2%)	<ul style="list-style-type: none"> • Availability of special equipment or assistive technology for children with disabilities (mean=0.88/2) • Availability of appropriate, safe, and age specific equipment for children with disabilities (mean=2.90/4)

Appendices

Key issue	Sub-component	NGT		Content Analysis	Audit
		RNs	HCSWs		
	Not specified 1.3	Promises from management for facilities which are not fulfilled (S28)	No training to use special equipment e.g. hoists (S20)	N/A	<ul style="list-style-type: none"> • Availability of individual assessment for the provision of technology/equipment/wheelchair support (mean=1.20) • Equipment benchmark criteria (score=5.64/10)

Appendix 4.4: Unfavourable Environment Chart

Key Issue	NGT		Content Analysis	Audit
	RNs	HCSWs		
Unfavourable environment	<ul style="list-style-type: none"> • Non-wheelchair friendly care environment (S21) • Helping them to adapt to new environment (S17) • Lack of privacy and space (S1) • No disabled changing area • Lack of space (S32) • Family expense in having a child in hospital e.g. car parking (S14) 	<ul style="list-style-type: none"> • Lack of privacy for the child (S14) • Too little space (S27) • Not having a multi-sensory room (S22) • No outdoor play area (S32) 	N/A	<ul style="list-style-type: none"> • Making arrangements for environment to provide palliative care (mean=1.33/2) • Access to free parking (mean=1.18)

Appendix 6.1 Executive Summary

Introduction

A number of studies indicate that disabled people and their families are dissatisfied with the care they receive during hospital admission (Iacono & Davis 2003; Liptak et al. 2006). Gaps in care provision revealed via this service evaluation included among others a lack of dedicated care equipment and a failure of the curricula to address the importance of enhancing the physical care environment through the provision of for example external play areas. This service evaluation was completed in the summer of 2013 in response to negative correspondence from parents of children with disabilities to a local primary care trust regarding the standards of inpatient care their children received from the local children's unit within a large District General Hospital. This service evaluation provides some practical recommendations for improving the quality of services for disabled children and their families during hospital admission.

The evaluation was conducted with the aim of exploring the inpatient care of disabled children in a children's unit within a district general hospital. The service evaluation was conducted in three discrete components (Figure 1), namely:

1. Focus group meetings with nursing staff, using the Nominal Group Technique (NGT)
2. An in-depth content analysis of contemporary nursing curricula
3. An audit of compliance to national policy best practice for disabled children and young people and those with complex health needs

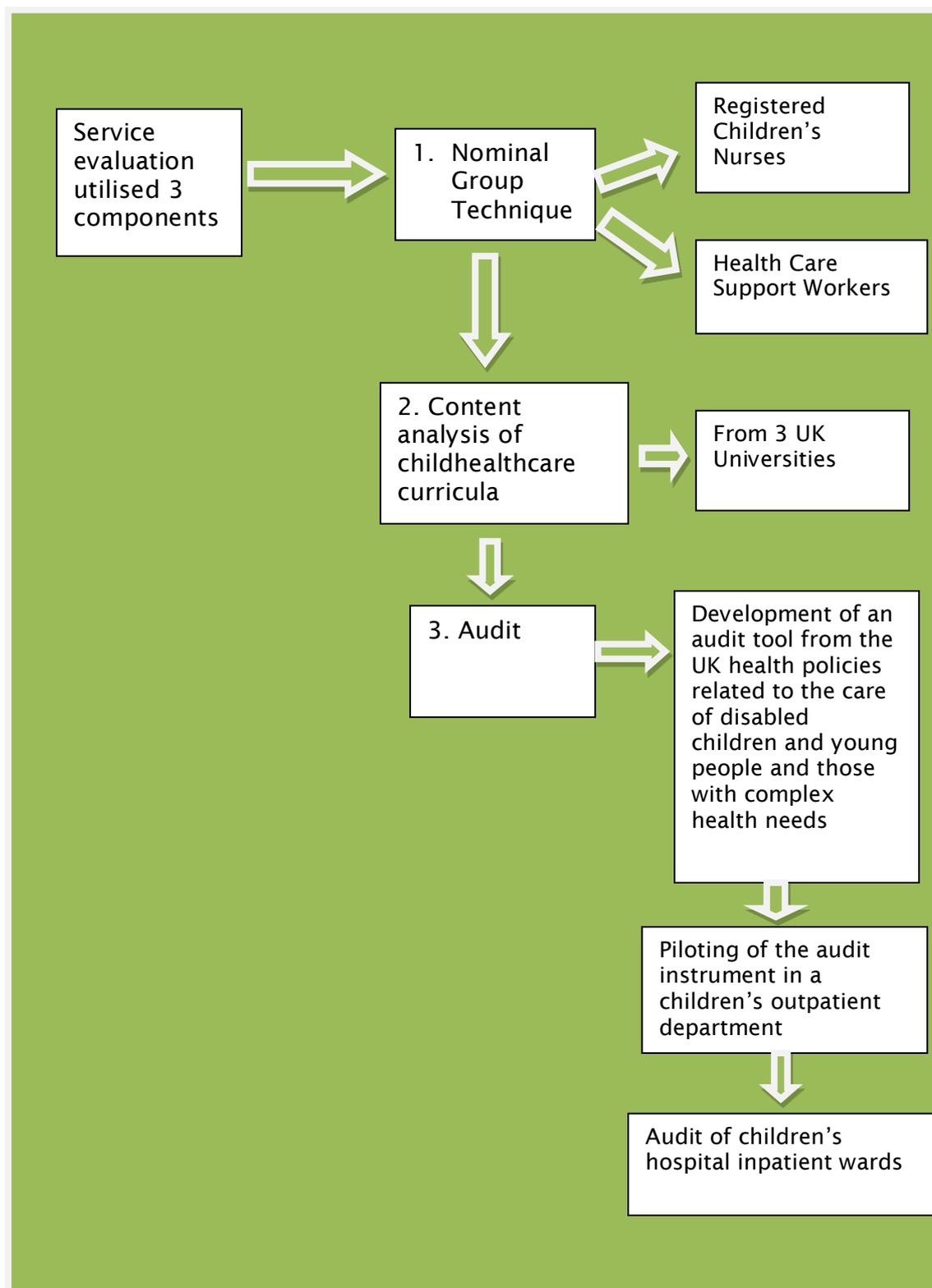


Figure 1: The service evaluation design

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Component 1

The first component of the service evaluation was a focus group activity, using the Nominal Group Technique (NGT).

Objective

To identify the rewards and challenges of caring for disabled children and young people and those with complex health needs

Participants

Registered children's nurses (n=8)

Health Care Support Workers (n=6)

Setting

The venue was the child health seminar room at a general hospital

Methods

Focus group meetings using the nominal group technique

Main Outcome Measures

Description and analysis of items relating to the challenges and rewards of caring for disabled children and their families during hospital admission

Results

There were 5 identified categories of reward cited, the most important of which were 'good communication' and 'teaching skills and improving independence'.

There were five identified categories of challenges cited, the most important being 'limited number of nursing staff available to provide care for disabled children',

Conclusions

This component of the service evaluation demonstrated that nurses and HCSWs share common concerns about the care of children with disabilities during hospitalisation.

The results show that in both groups, more items were generated for challenges than rewards, which may suggest that nursing staff experience more challenges during care delivery than rewards. The NGT shows that all the items identified by nurses and HCSWs relate to the psychological rewards of delivering care to disabled children.

From the viewpoint of nurses and HCSWs in this service evaluation, interaction is both a reward and a challenge. However, 'communication barriers with the child' was one of the five most prioritised challenges for both groups.

The greatest concern among nurses and HCSWs who contributed to this NGT related to the amount of time required to deliver care to disabled children. The next-greatest was the limited number of nursing staff available to provide care for this population.

Component 2

The second component of the current service evaluation was an in-depth content analysis of contemporary nursing curricula.

Objective

This component of the service evaluation sought to gain insight into the provision of contemporary undergraduate nursing curricula in UK universities, and how disabilities and special health needs relating to children and young people are covered within them.

Sampling Strategy

A convenience sample of two universities from England and one university from Northern Ireland were selected for the content analysis of undergraduate nursing curricula.

Method

This content analysis followed the eight-category coding set out by Carley (1993).

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Results

All of the modules examined by the current content analysis showed both strengths and weaknesses. One of the strengths was effective communication, with a content coverage area of 85.7%.

The current study does not cover all groups of disabilities. Additionally, the medical model is still influential on the nursing curricula under examination. The content analysis also showed that nursing textbooks are the most common source of information used. Furthermore, didactic methods (lectures, seminars or tutorials) are still the major approaches to teaching disability-related subjects.

Conclusions

This content analysis revealed that many areas relating to disabled children and young people and those with complex health needs were not fully covered by the curricula of the three selected universities.

Component 3

An audit was carried out as part of the service evaluation, relating to the care and welfare of disabled children and young people and their families who use the children's wards at an NHS Foundation Trust.

Objective

- To assess the care and welfare of children with disabilities and their families
- To evaluate whether the current care delivered to disabled children and young people meets the optimal standard of care
- To identify improvements that could be made in care delivery to disabled children and their families
- To provide recommendations for improving the quality of care delivery to children with disabilities

Participants

The audit was arranged by approaching the senior children's nurse and members of the inter-professional team (n=14) involved with care delivery to

disabled children throughout the children's wards within the NHS Foundation Trust under evaluation.

Method

The audit tool was developed as part of the Association of Chief Children's Nurses' (ACCN) generic healthcare audit tool. The Compliance Assessment Instrument for this discrete audit tool was comprised of 11 individual segments, reflecting all aspects of policies relating to care delivery to disabled children and their families. After piloting of the audit instrument, the baseline benchmarking exercise was completed over two days (3-4 July 2012).

Results

This audit shows that the areas which require improvement include: training, delivery of information, multi-agency teamwork, assessment and support services. Some fields, such as equipment, palliative care, communication and key workers, raised moderate concerns which need to be considered with a view to improvement.

Conclusions

The audit component of this service evaluation has shown that there are major deficiencies in areas of care delivery to disabled children and their families.

Overall Discussion

Four themes were identified by this service evaluation which has a significant impact on care of disabled children and their families: effective communication, provision of training, provision of equipment and unfavourable environment.

The service evaluation revealed that lack of effective communication skills among nursing staff depends more on training in the workplace than deficiency in their undergraduate education.

The current service evaluation has shown that there are deficiencies in the areas of 'developing students' knowledge and skills about caring for children with long term health needs', 'positive attitude towards disabled children' and 'needs of disabled children' in children's nursing education.

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The service evaluation also revealed that induction training is an important point at which to deliver information to nursing staff caring for disabled children.

'Lack and access of special equipment' and 'lack of training in customising equipment for disabled children' were two points that emerged from the evaluation. It has also been shown that another deficiency within nursing education relates to 'special equipment and resources used by disabled children'.

'Not having a multi-sensory room' and 'outdoor play area' were identified as physical environment barriers by the evaluation. 'Lack of privacy', 'insufficient space in wards' and 'unavailability of access to free parking' were also recognised as physical environment barriers.

Summative Conclusions

This service evaluation has highlighted a number of barriers and deficiencies in providing a high quality of care to disabled children and their families in a local NHS Foundation Trust.

Recommendations

- To consider an adequate nurse-patient ratio in order that nurse managers can better meet the needs of disabled children and their families
- To identify the most effective training methods for improving the knowledge and clinical skills relating to the care of disabled children
- To provide more training in the workplace by experienced staff who are well aware of disabled children's needs
- To identify AAC resources and ways of accessing these
- To establish a nurse lead or link, who is an expert in this field, to plan and coordinate the care of disabled children with the aim of meeting their needs
- To provide guidance for staff on supporting disabled children and their families

- To provide more training, support and skills for staff in using the special equipment and devices required to care for disabled children
- To consider a family forum for this population
- To identify environmental barriers to accessing health services and make the necessary changes
- To ensure greater involvement and commitment to meeting the needs of disabled children and their families on the part of policy-makers and hospital managers

Permission Letter

Appendix 6.2 Permission Letter for Publication

Dear Mahnaz,

Re your published paper in WPHS entitled "Are the children's and young people's units disabled friendly? A preliminary inquiry".

As deputy editor of the faculty e journal, Working Papers in the Health Sciences, I hereby give you permission to distribute and print this paper.

Kind regards

Alan Gasper

Dr Edward Alan Gasper

Professor of Nursing

Faculty of Health Sciences

Editor in Chief "Issues in Comprehensive Pediatric Nursing"

(<http://informahealthcare.com/loi/cpn>)

Deputy Editor of "Working Papers in the Health Sciences"

(<http://www.southampton.ac.uk/wphs>)



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