How Do Practitioners Create Inclusive Environments For Children With Chronic Health Conditions? An Exploratory Case Study

Thesis

How to cite:


For guidance on citations see FAQs.

© 2014 The Author

Version: Version of Record

Link(s) to article on publisher’s website:
http://etheses.whiterose.ac.uk/6174/1/Jackie%20Musgrave%20-%20Final%20Thesis%20incl%20Access%20Form%20for%20submission.pdf

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online’s data policy on reuse of materials please consult the policies page.
How do practitioners create inclusive environments in day care settings for children under the age of five years with chronic health conditions? An exploratory case study

Jackie Musgrave

Thesis submitted in part for the award of Doctor of Education

March 2014
Dedication

This thesis is dedicated with love and joy to my daughter Nicky who died in 2006, aged 18

When you are joyous, look deep into your heart and you shall find it is only that which has given you sorrow that is giving you joy. When you are sorrowful, look again in your heart, and you shall see that in truth you are weeping for that which has been your delight (Gibran, 1923)
Acknowledgements

This thesis could not have been completed without the help of many people. I wish to thank my family for their unfailing support over the last few years. Jenny and Laura, my precious daughters, thank you for your patience and encouragement. My Mum, Sheila, who could not be more proud and my dear, recently departed Dad, Patrick – thank you both for everything. To Paul, my husband, I am so grateful to you for your unfailing support, encouragement, love and help. You have lived the doctoral journey with me every single day and have never complained about the time I have spent in the study. I am indebted to you.

My grateful thanks to people at the School of Education who have been an inspiration, in particular Cathy Nutbrown and Jools Page. I would especially like to thank my supervisor, Rachael Levy, for her wisdom and support. I have valued our supervisor/student relationship and can honestly say that I cannot think of how it could have been improved.

I am grateful to friends who have supported me in various ways and have not complained when I have had to change plans to accommodate studying. Helen Perkins has been a valued critical friend and it is partly because of Helen that I became a doctoral student.

I am eternally indebted to the students who have taught me so much and it is their wisdom and knowledge that has informed the research question for this study.
I have been touched by the willingness of the participants in this study, to everybody who gave me their time so generously. I am especially grateful to ‘DJ’ the child who I observed for this study. He will always have a place in my heart.
Abstract

The concept of inclusion within the English education system is often taken for granted. There are a number of factors that can impact on inclusive practice and this demands careful exploration. Chronic health conditions (CHCs), such as anaphylaxis, asthma, diabetes, epilepsy and eczema, pose particular challenges to inclusion for practitioners who teach, educate and care for children under the age of five years in day care settings. These conditions can have a significant effect on children’s health, especially in the minority world. However, there is a paucity of research about how the symptoms affect children’s early education.

This mixed-methods study collected quantitative data by sending a postal survey to 60 settings in order to find out how many children are affected by these conditions in day care settings. Four of the surveyed settings went on to participate in the qualitative aspect of the study. Qualitative data were also collected from parents of children with CHCs and the study included observations of a child in his early childhood setting over the course of a year.

The findings revealed that 11% of children attending the settings in this study had been diagnosed with one or more CHCs and that CHCs had a profound effect on children and their parents. Parents reported that knowledge of the specific conditions is important for practitioners to have in order to create inclusive relationships with them. Practitioners in this study demonstrated a collaborative approach to leadership when creating inclusive environments. However, the findings revealed
tensions for practitioners regarding the inclusion of all children in the curriculum. The findings suggest that achieving inclusion may therefore be problematic for some children. However, the communication skills, knowledge of CHCs and willingness of practitioners were vital to the inclusion of children with CHCs in their early education.
Contents

Dedication

Acknowledgements

Abstract

Chapter 1: Introduction ........................................ 1
  Overview .................................................................. 1
  The research and field questions .......................... 10
  My positionality .................................................. 11
  Overview of chapters ......................................... 12

Chapter 2: Literature Review ........................... 15
  Introduction to the literature .............................. 15
  Children learn best when they are healthy .......... 16
  The welfare requirements of the EYFS ............... 19
  Personal, social and emotional development ....... 20
  Including and supporting every child: current understandings of inclusion .......................... 23
  Inclusion of children with chronic health conditions in education and society ...................... 26
  High quality early learning: staff qualifications, training, support and skills ....................... 30
  Playing and exploring in Early Childhood Education ........... 33
  Creating an enabling environment ....................... 38
  Positive relationships and the key person ............ 39
  Partnership working with practitioners and/or carers ...... 41
  Conclusion ......................................................... 45

Chapter 3: Methodology and Methods ................. 47
  Introduction ........................................................ 47
  Becoming an ethical researcher: reflexivity and positionality ................................................. 47
  From the perspective of a nurse ............................ 48
  From the perspective of a teacher ......................... 51
  From the perspective of a mother ......................... 53
Chapter 5: Overview of the findings from the data ... 103
  Introduction ...........................................103
  Quantitative data: Findings reporting incidence and type of CHC ...........................................103
  Qualitative data: Structure of the research story ......106
  Epilepsy: a hidden condition? ............................110
  Conclusion ............................................111

Chapter 6: The effects of chronic health conditions on children and families ........... 112
  Introduction ...........................................112
  1. Effects of chronic health conditions on children and families ...........................................113
     1.1 Effects on children’s and parents’ sleep...........113
     1.2 Children’s understanding of their conditions......117
     1.3 Children noticing when they have been given different food............................................120
     1.4 The effects of medication and interventions.......127
     1.5 Children’s experiences of pain and discomfort.....129
     1.6 Children being unwell and absence from the setting.136
  2. Effects on the family of living with a child with chronic health condition(s) ...............139
     2.1 Family routines and activities......................140
     2.2 Parental concerns................................142
     2.3 Parents and childcare arrangements.................144
     Conclusion ............................................149

Chapter 7: The importance of communication .............. 151
  Introduction ...........................................151
  1. Communication between parents and practitioners ....152
  2. Communication between practitioners and staff ....158
  3. Communication with other professionals ..............161

Chapter 8: Considerations for inclusive practice .... 165
  Introduction ...........................................165
  1. Adapting the environment in the setting ..............166
  2. Adapting the curriculum: activities ..................168
  3. Adapting the curriculum: outdoor play ..............171
  4. Creating safe places for food ........................173
  Conclusion ............................................178
Chapter 9: Responsibilities and qualities of practitioners

Introduction ................................................................. 179
1. Qualifications, knowledge and training ................... 180
2. Administration of medication and medical interventions 185
3. Responsibilities ......................................................... 188
4. Qualities and dispositions of practitioners ............... 190
Conclusion ................................................................. 192

Chapter 10: Discussion of findings ............................ 194

Introduction ................................................................. 194
Examining inclusion and considerations for children with CHCs ............................................. 195
The role of practitioners in creating an inclusive environment ......................................................... 199
The key person ................................................................. 203
Practitioners’ emotional resources ................................................. 204
The importance of practitioners working in partnership with parents ......................................................... 205
Implications for practice ......................................................... 208
Observations of children: a tool for creating an inclusive environment ........................................ 208
Routines for children with CHCs ........................................ 209
Conclusion and considerations for policy ....................... 210

Chapter 11: Concluding reflections ............................ 213

From the perspective of a nurse ........................................ 213
From the perspective of a teacher .................................... 214
From the perspective of a mother .................................... 215
From the perspective of a researcher ................................. 216
From the perspective of an emerging academic ............... 221

References ................................................................. 223

Glossary of Terms ........................................................ 238
Figures

Figure 1.1: Inter-relationship of chronic health conditions on health, inclusion, wellbeing and learning 2

Figure 2.1: Bronfenbrenner’s ecological systems theory 18

Figure 2.3: Child engaging in messy play with shaving foam 35

Figure 2.4: Image of person with eczema – photograph obtained from Wikipedia 35

Figure 3.1: ‘Joshua’ and me in 1982 49

Figure 3.2: Summary of the design of the case study 70

Figure 4.1: Process of analysis of the data – taken from Glesne and Peshkin (1992) 96

Figure 4.2: Example of a tree diagram 98

Figure 6.1: Visual map summarising the effects of CHCs on children 112

Figure 6.2: Effects on the family 140

Figure 7.1: The importance of communication 151

Figure 7.2: Modes of communication between parents and practitioners 153

Figure 8.1: Considerations for inclusive practice 166

Figure 9.1: Responsibilities and qualities of practitioners 180
Tables

Table 1.2: A summary of the chronic health conditions explored in the study ............................................... 5

Table 3.1: Summary of practitioner participants interviewed in study ......................................................... 75

Table 3.2: Parent participants ........................................ 76

Table 3.3: DJ’s observations timetable .......................... 83

Table 4.1: Summary of the main points of observations of DJ ................................................................. 100

Table 5.1: Summary of data from survey – November 2011 ................................................................. 104

Table 5.2: Summary of the children, their CHCs and contribution of their parents to the study ................. 107

Table 5.3: Overview of themes ................................. 108

Table 9.1: Qualifications of respondents to survey .......... 181

Appendices

Appendix 1: Ethical approval ................................. 242

Appendix 2: Covering letter to settings in the case . 243

Appendix 3: Questionnaire for Practitioners .......... 245

Appendix 4: Semi-structured interview schedule for practitioners ............................................................ 250

Appendix 5: Information letter for parents .......... 251

Appendix 6: Semi-structured interview questions: parents ................................................................. 252
Chapter 1: Introduction

Overview

The Early Years Foundation Stage (DfE, 2012) (EYFS) is the Statutory Curriculum Framework in England for providers of Early Childhood Education and Care (ECEC) from birth to five years of age. An overarching principle of the EYFS is “to provide equality of opportunity and anti-discriminatory practice, ensuring that every child is included and supported” (p.2). Definitions of what is meant by inclusion are discussed in Chapter 2. However, the aim of this study resonates with Nutbrown and Clough’s (2006) definition that “inclusion may be seen as the drive towards maximal participation in and minimal exclusion from early years settings, from school and from society” (p.3). This study explored how practitioners in early years settings implemented and adapted the EYFS in order to minimise exclusion and maximise participation for children aged five and below with chronic health conditions. Therefore, this definition is consistent with the intention of this study, which is to contribute towards a theory of inclusive practice for children with chronic health conditions.

A chronic condition is one that is of long duration (Oxford Concise Medical Dictionary). Furthermore, chronic conditions are incurable and the symptoms of these conditions can interfere with daily life (Brown, Krieg and Belluck, 1995). The impact of chronic conditions on children’s activities is an on-going consideration because they may be restricted from joining in some activities for considerable periods of time. This is especially the case for young children accessing
their early education. The ways that chronic conditions can impact on children’s inclusion in their early education is the focus of this study. **There is a need to examine the significance of these chronic health conditions on children, because the effects on children can be under-estimated or possibly over-looked.** The effect of symptoms of these conditions may be minimised if there is an understanding of the signs, symptoms, treatment and triggers that characterise each condition. Such understanding is vital for practitioners to bear in mind when considering ways to make the curriculum inclusive for children with chronic health conditions. However, it is also important to be aware that, even if there is careful management of the effects and symptoms, there can still be a significant impact upon children’s health, meaning they may experience suboptimal health. As a consequence, children may experience poor wellbeing, which can impact on their learning. Figure 1.1 summarises the inter relationship between health, inclusion, wellbeing and learning.

**Figure 1.1: Inter-relationship of chronic health conditions on health, inclusion, wellbeing and learning**
The considerations that need to be borne in mind in order to make the curriculum inclusive for children with chronic health conditions are an additional layer of complexity. This is an important point for early years practitioners because this can mean that children in day care settings may be excluded from some aspects of early childhood education. The effects of exclusion may have an impact on children’s wellbeing. This is a term that can have a range of definitions, however, definitions of wellbeing frequently link health as a factor that can influence an individual’s sense of wellbeing. The Oxford English Dictionary defines wellbeing as “the state of being comfortable, healthy or happy”. Statham and Chase (2010) define wellbeing as “generally understood as the quality of peoples’ lives... it is understood both in relation to objective measures, such as... health status” (p.2). Laevers and Heylen (2003) measure children’s level of wellbeing by assessing their involvement in activities. Therefore, it can be argued that children’s wellbeing can be improved by minimising the effect of chronic health conditions on them, as well as by adapting activities to make them inclusive, thus maximising participation in early years education.

The chronic health conditions that are included in this study are very different conditions from each other and have different signs and symptoms. However, anaphylaxis, asthma and eczema are regarded as allergic (or atopic) conditions and it is not unusual for children to have a combination of two, or all of these conditions. Furthermore, anaphylaxis and allergy are descriptions of conditions that are often used interchangeably. Health conditions are diagnosed by the presence of signs and symptoms.
The Oxford Concise Medical Dictionary (2010) offers the following definitions:

- **Sign**: an indication of a particular disorder that is detected by a physician while examining a patient but is not apparent to the patient
- **Symptom**: an indication of a disease or disorder noticed by the patient
- **Trigger**: a substance that can exacerbate symptoms of chronic health conditions: for example, dust can exacerbate the symptoms of asthma.

Please note: For the remainder of this thesis, unless otherwise indicated, the use of the words child, children, parent, and parents refer to a child (children) under the age of five with chronic health condition(s) or their parent(s). Similarly, the use of the term practitioner(s) refers to those professionals caring for such children. In addition, to avoid repetition, the term ‘chronic health conditions’ will be abbreviated to CHCs.

Table 1.2 summarises important information about the conditions in this study. It includes information highlighting substances that can ‘trigger’ the symptoms of CHCs, as well as a summary of the possible impact on inclusion.