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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

### Dedication

This thesis is dedicated with love and joy to my daughter  ${\tt Nicky}$ 

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.

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### 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). 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. 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

minimise the impact of symptoms of chronic conditions on children by

•adapting the environment

•helping children to cope with the environment

optimise children's feelings of 'being healthy'

increase feelings of well-being

increase participation in early childhood education - being included

increase developmental outcomes

increase individual educational attainment

increase personal contribution = increased sense of well being

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 The effects of exclusion may have childhood education. 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.